

THE EXPERIENCE OF RURAL CHILDREN  
WHOSE DAILY LIVES ARE LIMITED BY ASTHMA

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In Partial Fulfillment  
of the Requirements for the Degree  
Doctor of Philosophy

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by  
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The undersigned, appointed by the Dean of the Graduate School, have examined the dissertation entitled

THE EXPERIENCE OF RURAL CHILDREN  
WHOSE DAILY LIVES ARE LIMITED BY ASTHMA

Presented by Benjamin David Francisco

A candidate for the degree of Doctor of Philosophy

And, hereby certify that in their opinion it is worthy of acceptance.

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## DEDICATION

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THE EXPERIENCE OF RURAL CHILDREN  
WHOSE DAILY LIVES ARE LIMITED BY ASTHMA

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ABSTRACT

Asthma is the most common cause of disability in childhood, affecting more than one million U.S. children. The purpose of this cross-sectional study was to describe children's experience of disabling asthma. After obtaining informed consent from the parent and assent from the child, 8 rural children aged 7 to 10 had 3 interviews in their homes over a period of 2 to 3 weeks. Data were analyzed using Porter's descriptive phenomenological method. Features of the personal-social context of the experience included: discovering that asthma changes what I can do, becoming the one who knows my asthma, knowing how other people respond to my asthma, and coming to know more about asthma. Phenomena capturing the children's overall intentions included: making the best of things, noticing when my asthma is getting worse, making my breathing better, asking to be treated like a normal person, getting someone to help me, showing others my asthma, learning about asthma, and thinking about having asthma the rest of my life. Children described aspects of disability and manifestations of asthma that have not been adequately appreciated by health care professionals. Findings pointed to opportunities to improve care at home, at school, and in clinical settings. These 8 young children expressed clear intentions that are a basis for future research and efforts to reduce the public health burden of asthma.

## CHAPTER ONE

### INTRODUCTION

#### A Phenomenological Perspective on the Research Question

This study was designed to describe the experience of rural school-age children who have disabling asthma. The first research aim is to describe children's intentions related to asthma. A second aim is to examine the varied contexts of their experiences at home, at school, in their community, and in the places where they receive health care services. A third aim is to compare and contrast the phenomena of children's experience of disabling asthma with pertinent theoretical frameworks, concepts, and constructs found in the research literature and current clinical practice.

Chapter One includes three sections. The purpose of the study is explained. Next, the research problem is discussed in the context of current approaches to childhood asthma and the public health burden of asthma. Finally, the rationale for using descriptive phenomenology in this study of childhood asthma is presented. In this section methodological goals and the framework of the study are described in detail. Finally, the research questions are presented.

#### The Purpose of the Study

The purpose of this phenomenological study was to describe the experiences of rural school children with disabling asthma. Large numbers of rural children are absent from school, are unable to fully participate in curricular and extracurricular activities, or suffer major disruptions in their school routines due to asthma. Functional disability due to asthma is rarely a result of intractable disease. Rather, disability arises from known and

unknown factors related to the child, the home environment, the school, the community, and the health-care system. Most known factors associated with asthma morbidity are modifiable. Children's health status improves with correction of contributing factors. Whereas thousands of articles have been published describing asthma-related factors in the settings listed above, very few scholars have investigated asthma from the perspective of children. In preparation for this study, I found no published investigations of the experience of disabling asthma among children in general or rural children in particular. This description of phenomena associated with children's experience of asthma has contributed new knowledge and informed efforts to reduce asthma disability.

### The Research Problem

A brief discussion of asthma is presented first to provide an orientation to the research problem. Next a synopsis of the research problem is provided. An overview and analysis of the literature is presented to describe historical trends of published work. Validity of the concept of self-management in relation to children who have asthma is questioned. Next a detailed statement of the research problem is presented. Finally, the significance of the research problem is presented in relation to the wellbeing of children, the public's health, and the practices of health professionals.

### *An Overview of Asthma*

#### *Asthma Defined*

Asthma is a chronic inflammatory disorder of the airways. Airway changes at the cellular level occur as a result of altered immune function and exposure to activating factors, such as viruses, allergens, and irritants. These changes include a patchy stripping away of the airway epithelium, thickening of the basement membrane due to collagen

deposition, epithelial edema, increased mast cell activity, and infiltration of inflammatory cells and mediators into the airways. Airway inflammation manifests as bronchial narrowing and airflow obstruction. Mechanisms of airway narrowing include acute bronchoconstriction, airway swelling, excess airway mucus, and in some cases, airway remodeling. Airway inflammation predisposes to airway hyperresponsiveness, airflow reduction, respiratory symptoms, and chronic illness. A genetic predisposition for IgE-mediated responses to common airborne substances is strongly associated with the risk of developing asthma. However, even in the apparent absence of inherited traits for allergy individuals can develop asthma symptoms. Environmental exposure to certain noxious inhaled substances can also lead to asthma (National Heart, Lung, and Blood Institute [NHLBI], 1997).

#### *Origin and Development of Expert Clinical Guidelines for Asthma*

Remarkable progress in the understanding and treatment of asthma has taken place over the last three decades. In response to rapid changes in pharmacotherapy and clinical practice, the NHLBI first convened an expert panel in 1991 (NHLBI, 1991). The group was charged with responsibility to review the available evidence and to provide clinical guidelines for the management of childhood and adult asthma. Careful review of more than 5,000 articles culminated in publication of the first national asthma guidelines. A second expert panel convened five years later and published revised guidelines in 1997, the “National Asthma Education and Prevention Program (NAEPP) Expert Panel Report 2 (EPR-2): Guidelines for the Diagnosis and Management of Asthma” (NHLBI, 1997). Most recently the third NAEPP expert panel recommendations were published in

the form of the “Guidelines for the Diagnosis and Management of Asthma—Update on Selected Topics 2002” (NHLBI, 2002).

### *Classification of Asthma*

The EPR-2 recommended use of a four-level classification system for the diagnosis and treatment of asthma: (a) mild intermittent asthma, (b) mild persistent asthma, (c) moderate persistent asthma, and (d) severe persistent asthma. According to EPR-2 guidelines, initial classification of asthma in children under age six is based on the symptom frequency and pattern. Clinical findings of wheezing, prolonged expiratory time, and chest x-ray changes, including hyperinflation and increased peribronchial markings are supportive of the diagnosis, but they do not contribute directly to the classification of asthma. Children six years of age and older are usually able to perform complete spirometry or at least a maximal forced expiration maneuver for peak expiratory flow rate determination. These objective measures of lung function contribute to the classification and treatment of asthma in children six years of age and older. However, symptom frequency and pattern remain the primary means of assessing asthma severity and guiding therapies in children six years of age and older (NHLBI, 2002).

### *An Introduction to the Research Problem*

There is a widening gap between what is technologically possible in the treatment of asthma and what is actually being achieved in the care of children. Advances in clinical approaches for diagnosis and treatment have not produced the expected amelioration of asthma among children in the U.S. population (Beasley, 2002). This fact is evidenced by two decades of prevalence data indicating a worsening national asthma burden (Mannino et al., 2002) and dramatic increases in the number of school children

with disabling asthma (Newacheck & Halfon, 2000). There is no clear explanation for the trend of increasing asthma disability among children; however, a commonly cited reason for poor health outcomes is lack of adherence to medical treatment plans (Hogan & Wilson, 2003). This explanation arises from the perspective of clinicians, with emphasis on what the child and family should do to comply with medical plans for disease management, rather than on how a clinician should support a child as she or he comes to understand and respond to the illness.

Further investigation of children's perceptions and behaviors in relation to asthma is warranted, given the critical role children must play in their own care. By age 11 children's reports to clinicians correlate better with objective measures of asthma status than do parental reports (Guyatt, Juniper, Griffith, Feeny, & Ferrie, 1997). Current clinical approaches to the control of asthma clearly require a large amount of self-care by children. However, awareness in the scientific community that children should be supported in their efforts to care for themselves has evolved very slowly. A chronological overview of the asthma literature provides evidence of the existence of inadequate conceptualizations of childhood asthma. These erroneous views have likely hindered the care of children. An overview of the literature will also demonstrate the emergence of self-management as a researcher-derived construct that has greatly influenced current expert guidelines and clinical approaches to children with asthma.

A critical review of the validity of self-management as a construct is warranted, given its widespread acceptance and use. Scholars and clinical experts advocate self-management education to improve children's ability to engage in therapeutic behaviors and to reduce asthma-related illness. Many interventions have been developed based on

self-management (Guevara, Wolf, Grum, & Clark, 2003). Researchers have sought to demonstrate associations between self-management factors and asthma outcomes among children (Miles, Angela, Sawyer, & Kennedy, 1995b; Taggart, Zuckerman, Lucas, Acty-Lindsey, & Bellanti, 1987; Taylor, Rea, McNaughton, Smith, et al., 1991a). However, little attention has been given to the construct validity of self-management. Worsening asthma disability suggests that current approaches and assumptions should be questioned. Research has not led to an adequate understanding of how effective behavioral interventions can be developed (Clark, 2002).

### *Conceptual Foci and Trends in the Literature*

#### *Introduction and Methodological Context*

The proposed study will use a method for nursing research developed by Porter (1998a) that was derived from the phenomenology of Edmund Husserl. An important tenet of Husserl's phenomenology is the primacy of evidence over conceptualizations about human experience. "It is the spirit of science to count nothing as really scientific which cannot be fully justified by the evidence" (Husserl, 1929/1975, p. 6). Therefore, application of Husserl's philosophy requires critical examination of contemporary concepts and constructs. "In other words, science demands proof by reference to the things and facts themselves, and that these are given in actual experience and intuition" (Husserl, 1975) p. 6. Husserl proposed that the process of generating new knowledge about human experience requires suspension of judgment about all pre-existing concepts until a careful examination of the experience is completed (Husserl, 1975). Therefore, evaluation of construct validity and critical analysis of influential scientific concepts are of central importance in Porter's (1998) method. Pre-existing and potentially biasing

ideas related to the experience of interest must be identified and intentionally set aside by the researcher. The following overview of conceptual trends in the asthma literature reflects my application of these methodological principles.

*Psychological Concepts and constructs Pertaining to Asthma and Children*

Particular trends were readily apparent in the literature over the last four decades. When a search for asthma and psychology and children was submitted in Ovid™ for Medline™, CINAHL™, and PsychInfo™, distinct thematic shifts were apparent. In the decade from 1964-1973 asthma as a psychosomatic disease predominated the literature (Apley, 1973). Psychological and psychiatric profiling of the person with asthma (Aaron, 1967; Cernelc, Skuber, & Kos, 1968; Gross, Hirt, & Seeman, 1968; Stubblefield, 1966), behavior modification approaches (Creer & Yoches, 1971), and residential treatment (Mascia, 1970) were characteristic of the literature. Interest was emerging in breathing techniques and the use of exercise as therapy (Strick, 1969).

By the decade of 1974-1983 growing interest in psychological aspects of asthma was evident in the scientific literature. The number of articles nearly doubled. A division in the literature was apparent between scholars pursuing a psychosomatic model of disease and those who focused on children's disease management skills. Psychosomatic themes included pathological mothering (Meijer, 1980; Minuchin et al., 1974) and children's dependency behaviors (Khampalikit, 1983). Belief in a psychosomatic basis for asthma was linked to experimentation with direct behavioral techniques for treating asthma. Examples included studies of relaxation therapy (Erskine-Milliss & Schonell, 1981; Kotses, Glaus, Bricel, Edwards, & Crawford, 1978), hypnosis and biofeedback (Dikel & Olness, 1980; Scherr & Crawford, 1978), and de-conditioning of responses

aimed at stopping bronchospasm (Danker, Miklich, Pratt, & Creer, 1975; Khan & DL, 1977; Kotses et al., 1978)

During this era when direct behavioral methods aimed to alter the pathophysiology of asthma were failing, a pragmatic focus on what children could do to better manage their illness gained a foothold (King, 1980). Intervention in the form of practical training was proposed to teach children to use inhalation equipment correctly (Renne & Creer, 1976). Subsequently, the general idea of asthma self-management training for children was introduced (Creer & Burns, 1979). Creer and Burns proposed an alternative approach to asthma in childhood.

By teaching a child and his or her family ways that the youngster can learn to manage asthma means that the disease will become less of a disruptive influence within the home, that costs of the affliction can be contained, and that the youngster can remain within the mainstream of both his or her family and community. (p. 270)

Literature from the decade of 1984-1993 revealed continued efforts to understand the relationship between emotion and asthma (Chiari, Foschino-Barbaro, Nuzzo, Pecci, & Rossi, 1987). A study of stress among children with asthma identified social and psychological strain imposed by the disease among school children (Walsh & Ryan-Wenger, 1992). Work with biofeedback continued without significant breakthroughs (Harver, Segreto, & Kotses, 1992; Kotses et al., 1991). Researchers continued searching unsuccessfully for causative links between parental and familial psychological functioning and childhood asthma (Hermanns, Florin, Dietrich, Rieger, & Hahlweg, 1989; Weinstein, 1987). A small study suggested a relationship between child depression

and intra-familial conflict in poor management of asthma with fatal outcomes (Strunk & Mrazek, 1986). The concept of empowerment in the care of children with asthma was introduced as a component of self management. (Lewis, Mary A. & Lewis, 1990).

The decade from 1994-2003 was notable for the rapid advancement of asthma self-management as a pivotal concept addressing two primary goals of the person with asthma: (a) meeting the objectives of treating and controlling the disease and (b) improving the quality of one's life (Clark, Evans, Zimmerman, Levison, & Mellins, 1994). Interest in quality of life emerged as a means of addressing the chronic and sometimes disabling nature of childhood asthma (Bender, 1996; Sterling, 2001; Williams et al., 2000). Study of factors related to adherence among children with asthma was also evident in this decade (Burkhart, Dunbar-Jacob, Fireman, & Rohay, 2002). Interest in children's experience of asthma first appeared in the literature with publication of several studies in which children were interviewed directly (Horner, 1998; Ireland, 1997; Yoos, 1994). A systematic review of evidenced-based research was published that confirmed the efficacy of some educational interventions for children with asthma (Wolf, Guevara, Grum, Clark, & Cates, 2003).

#### *Expert Clinical Guidelines and the Importance Ascribed to Self-care*

In the last two decades national asthma guidelines evolved, placing increasing emphasis on facilitating asthma self-care. Early asthma guidelines focused only on the clinician's role in the diagnosis and treatment of the disease (NHLBI, 1991). EPR-2 guidelines were organized in a multidimensional strategy known as the four components approach (NHLBI, 1997). The four components were (a) measures of assessment and monitoring, (b) control of factors contributing to asthma severity, (c) pharmacologic

therapy, and (d) education for a partnership in asthma care. Each component was described as critical to the control of an individual's asthma. Each required a high degree of participation by the child and caregivers (NHLBI, 1997). The large extent to which expert clinical guidelines required self-care by children largely reflected technological limitations in the diagnosis and treatment of asthma. Optimal outcomes required optimal self-care behaviors.

To encourage a high degree of self-care, authors of expert guidelines advocated development of an ongoing partnership between health care providers and patients (NHLBI, 1997). Evidence has supported this recommendation. A greater degree of cooperation and planning between the health care provider and the child and family was associated with improved control and reduced morbidity (Gavin, Wamboldt, Sorokin, Levy, & Wamboldt, 1999; Volovitz, Nussinovitch, Finkelstein, Harel, & Varsano, 2001). The need for improved relationships and communication between health care providers and those with asthma also has been supported by identification of individual factors that influence asthma expression and the level of disease control (Bender, Milgrom, & Apter, 2003; McQuaid, Kopel, Klein, & Fritz, 2003). Some researchers have argued that a further shift away from traditional clinical approaches must occur if health professionals are to enable larger numbers of people to achieve control over asthma (Adams, Weiss, & Fuhlbrigge, 2003; Clark & Partridge, 2002; Paterson & Britten, 2000). The need for more effective partnerships has been particularly evident for those individuals who are experiencing difficult or disabling asthma (Clark, Gong, & Kaciroti, 2001; Payne & Balfour-Lynn, 2001).

### *Critical Analysis of the Concept of Children's Self-Management of Asthma*

Whereas the need for greater involvement of individuals in the planning and evaluation of their health care is evident, current use of the concept of asthma self-management as it relates to children is problematic. The origins of asthma self-management used in association with children reveal a number of problems. The first discussion that I found in the medical literature was by Creer and Burns (1979). Their brief preliminary article described development of an approach for helping children learn to manage their illness more effectively (Creer & Burns, 1979b). A decade later Creer (1988) published a more detailed description of an asthma self-management educational program for children and parents. The program reportedly evolved over a 40-year period at a residential treatment facility for children with asthma. Creer (1988) stated that “the program rests heavily on social learning theory, particularly two major tenets: 1) the concept of reciprocal determinism and 2) the learning/performance dichotomy” (p. 335). Researchers attributed children's clinical progress to improved performance of self-management skills. No information regarding the validity of the construct of self-management was provided. Problematic aspects of the use of the construct in these reports included the unusual setting in which the concept was developed (a residential asthma treatment facility), a strong theoretical bias, and lack of reported observational data to validate the concept.

At about the same time, Clark et al. (1980) also described use of the concept of asthma self-management in development of an educational program addressing children's asthma. Whereas the researchers presented their approach as one based on a study of self-

management behaviors, there were in fact no reported direct observations of children in their natural settings. Instead, data were obtained through interviews with both children and adults in hospital clinics. Data from adults appeared to be highly favored in the research protocol, reported findings, and development of a self-management index. Data pertaining to children were actually limited to answers obtained in a single interview lasting about 40 minutes during which 100 children ages 7-13 answered closed and open-ended questions.

Construction of the interview questionnaire was based on theoretical and clinical perspectives of the researchers. "In this first phase of defining self-management, we enumerated only important management practices from the clinical perspective of health-care providers" (Clark et al., p. 282). The researchers reported using some open-ended questions in the preliminary interview. "These yielded extensive anecdotal information and answers not anticipated by our closed-end questions" (Clark et al., p. 281). Responses to open-ended questions from the first interviews were "categorized and closed" (Clark et al., p. 281) for the development of a second set of interview questions. Elimination of open-ended questions was a procedural step intended "to reduce interviewing time" (Clark et al., p. 281). Only adults were interviewed a second time. Only half of interviews with children were utilized in subsequent development of a self-management construct. No explanation was offered to explain the process by which half of the data were excluded.

By induction 12 categories of behaviors were identified in interview transcripts that researchers believed were associated with self-management. "In this phase we relied on face validity of categories as conceptually coherent and mutually exclusive" (Clark et

al., 1980, p. 283). Derived categories of self-management behaviors were identified from interviews alone. Later researchers illustrated their findings with examples drawn from adult rather than child responses in 9 of 12 instances (Clark et al). If children were asked to validate the proposed categories and specific behaviors that researchers identified as components of self-management, that effort was not reported.

Clark et al. (1980) also reported developing a self-management index from the 52 items included in the adult questionnaire. “We elected not to develop an index of children's management behavior from questionnaire data, since we felt that a child's ability to answer questions on self-management varied considerably both with age and experience. This was not regarded as a drawback to data used in descriptions of family self management practices, since the responses from caretakers and children were combined to provide a qualitative description of positive family actions and their obstacles” (Clark et al, p. 284). The authors’ suggestion that children are not capable of adequately describing their own behavior and experience of asthma stands in contradiction to the construct they sought to describe – self-management. Use of caretaker views as reliable proxies for children’s views has not been supported by the literature (Guyatt, 1997; Lewis, 1977; Odigwe, 2004).

Other aspects of this study by Clark et al. (1980) warrant critical review. They listed four citations as foundational to the development of a self-management construct. “We gained significant insight regarding asthma management from preliminary work by Green, Maiman, Becker, and Parcel” (Clark et al., p. 282). None of the four cited sources utilized observational studies to determine how children viewed or lived with asthma. This research was conducted more than 25 years ago when few effective asthma

medications were available (Martin, Landau, & Phelan, 1982). Despite dramatic changes in the treatment of asthma in the next two decades, I found no evidence in the literature that the construct of asthma self-management among children was re-examined. At the time of the study by Clark et al. (1980) management of asthma was characterized by the inadequacy of available therapies, episodic treatment of bronchospasm, and serious physical and psychological side-effects of poorly controlled disease (Rachelefsky et al., 1986). In addition, the operational definition of asthma used for selection of child participants was limited to wheezing. This choice suggests that participants represented only a clinical subset of children who have asthma (Kelly et al., 1996).

Despite the absence of validating observational data in preliminary studies by Creer and Burns (1979) and Clark et al. (1980), the intuitive appeal of self-management to scholars and clinicians was evident, as the concept was widely utilized in the literature over the next three decades. At least 228 articles have been published pertaining to asthma and children and self-management since 1977. I found no studies in which scholars had established construct validity based on observations and interviews with children in their natural settings. In the first decade from 1977-1986 general enthusiasm for asthma self-management education was reflected in numerous preliminary reports of apparent efficacy of educational approaches that claimed to promote self-management (Fireman, Friday, Gira, Vierthaler, & Michaels, 1981; Hindi-Alexander & Cropp, 1981). However, Mullen and Mullen (1983) sounded an early cautionary note when they concluded that asthma self-management education was complex, difficult to communicate, incongruent with clinical incentives, and inherently of no great advantage over conventional approaches.

Nonetheless, development of at least four formal asthma self-management courses signaled general acceptance of the approach: (a) Air Wise (McNabb, Wilson-Pressano, Hughes, & Scamagas, 1985), (b) Asthma Care Training (Lewis et al., 1987), (c) Open Airways (Indinnimeo et al., 1987), and (d) Living with Asthma (Creer et al., 1988). Whereas each of these courses offered new venues to support children with asthma and their families, logistical problems in implementing and evaluating self-management educational programs were formidable (Lewis & Lewis, 1987).

Along with the first report of efforts to formalize self-management as a construct, component concepts emerged in the literature over the next decade. Health beliefs and self-efficacy were advanced as important factors in children's self-management of asthma (Clark et al., 1988). Researchers evaluated the impact of knowledge gain and change in locus of control after asthma self-management education (Taggart et al., 1987). Factors contributing to children's sense of competency in self-management were explored (Miles, Sawyer, & Kennedy, 1995). A tool for measuring children's self-management competency was developed and tested among 380 children 5 to 11 years of age (Taylor et al., 1991).

Additional asthma self-management programs were developed in the 1990's (Detwiler, Boston, & Verhulst, 1994; Taggart et al., 1991; Villone, 1995; Yoos et al., 1997). Shortened versions of some programs were found to be as effective as more lengthy versions (Ronchetti et al., 1997). Follow-up sessions were shown to improve asthma self-management over time (Gebert et al., 1998). Numerous multimedia programs involving printed materials, video (Holzheimer, Mohay, & Masters, 1998), and computer software (Bartholomew et al., 2000) were developed to overcome logistical barriers to

delivering self-management education. Self-management interventions were developed and tested in a variety of new settings including the home (Demi, Brown, & Jones, 1998), asthma camps (Robinson, 1999), community settings (Galea et al., 2001; Page et al., 1999), and schools (Bruzzese, Markman, Appel, & Webber, 2001). In 1998 the largest multi-center research program for childhood asthma in history, Children's Asthma Management Program Research Group (CAMP), announced that "three major tenets of self-management were highlighted in the CAMP patient education program: anticipate problems before they arise, determine the appropriate responses, and rehearse and practice behaviors that are effective solutions" (CAMP, 1998, p. 572). Asthma self-management was recognized as a critical component of care (Robinson, 1999; Velsor-Friedrich & Srof, 2000).

However, evaluation of self-management interventions has continued to be problematic. Confounding factors include lack of a clear definition of what constitutes self-management (Myers, 2002), a multitude of interventions claimed to improve self-management (Burkhart, Dunbar-Jacob, Fireman, & Rohay, 2002), the complexity of most interventions (Guendelman, Meade, Benson, Chen, & Samuels, 2002), and the wide variety of outcome measures used to evaluate interventions (Velsor-Friedrich & Srof, 2000). Particular assumptions about asthma self-management, such the importance of peak flow monitoring, have been seriously questioned (Kamps & Brand, 2001). An attempt to develop asthma self-management scales demonstrated serious logical inconsistencies. Researchers reported construction and validation testing of four childhood asthma self-management scales. However, only one scale addressed child-specific factors (Bursch, Schwankovsky, Gilbert, & Zeiger, 1999). Three of the scales

actually addressed parental factors. The only scale intended to measure self-management pertained to child self-efficacy. This conceptual blurring of the role of children and the role of caregivers reflects back on the flawed origins of the concept of asthma self-management in the literature.

Failure to clearly distinguish child behaviors from caregiver behaviors related to asthma self-management has continued to cloud scholarly discussions. Recently, qualitative methods were employed to identify helpful behaviors of adults caring for children with asthma (Chiang, Huang, & Lu, 2003). Chiang et al. described three broad categories of behaviors important in adult management of children's asthma including preventing, assessing, and managing asthma. Qualitative analysis of interviews with 16 parents, who were deemed successful by researchers in the management of children's asthma, was used to propose construct validity for 21 self-management behaviors (2003). However, use of the term self-management to describe behaviors enacted by adults on behalf of children with asthma is conceptually flawed. Other scholars have distinguished such behaviors as dependent care actions (Orem, 1995).

Evidence also suggests that other researchers have developed self-management and related constructs without adequate knowledge of the experience of children with asthma. Recent efforts to develop a scale to assess children's asthma beliefs illustrates researchers' use of constructs without adequate attention to validity (Velsor-Friedrich, Pigott, Srof, & Froman, 2004). "The Asthma Belief Survey has sound reliability and validity evidence to support its use to measure a child's asthma self-management self-efficacy" (Velsor-Friedrich et al., 2004). Velsor-Friedrich et al. proposed that children's answers to survey questions measured the construct of self-efficacy pertaining to the

construct of asthma self-management. In the literature I did not find evidence that construct validity was established for either asthma self-efficacy or asthma self-management among children. Development of a survey by Velsor-Friedrich et al. to measure these two constructs exemplifies the problem of researchers studying their own concepts rather than the actual experiences of children who have asthma.

In summary, efforts to promote asthma self-management over the last three decades have evolved with very little direct knowledge about how children actually view and experience their illness. While many educational programs have demonstrated efficacy in reducing the burden of disease in clinical trials (Cicutto, 2003; Guevara, Wolf, Grum, & Clark, 2003), no widespread approach has emerged to date that is effective, practical, and sustainable. Reasons for failure to achieve hoped-for reductions in the burden of asthma through self-management approaches (Scarfone, Zorc, & Capraro, 2001) are likely related at least in part to the longstanding oversights and conceptual flaws described above. Descriptive, observational studies are needed to ascertain and incorporate children's perspectives related to asthma.

In the last decade, a few researchers have looked at the actual experiences of adolescents and children who have asthma, with promising results (Pradel, Hartzema, & Bush, 2001). Findings from these studies challenge conventional clinical and scholarly views of self-management. In-depth interviews with 49 adolescents with asthma revealed a need to carefully examine individual reasons for non-compliance and to address personal barriers individuals face in their efforts to care for themselves. (Buston & Wood, 2000). In an unconventional research methodology, Rich, Lamola, Gordon, & Chalfen (2000) analyzed video journals kept by adolescents to chronicle their experiences related

to asthma. The study revealed many factors shaping the illness experience that were not detected by conventional clinical approaches, such as the history-taking procedure. Researchers concluded that teens' experiences of asthma were not adequately represented by clinicians' assumptions about self-management (Rich, Patashnick, & Chalfen, 2002a).

These findings raise important questions. Is self-management an adequate construct around which health care services for children with asthma should be designed? Are there better conceptual frameworks for understanding children's needs and behaviors? Would knowledge of children's actual experiences better prepare health care professionals for building partnerships with children to improve asthma outcomes? An investigation of children's experience of disabling asthma is warranted to try to answer these questions. Porter (1998a) has demonstrated that a nursing research approach based on Husserl's (1913/1962) phenomenology is well suited to describe health-related experiences and to examine the validity of related constructs (Porter, 1994, 2003; Porter, Ganong, & Armer, 2000; Porter, 1995b, 2000).

#### *Detailed Statement of the Research Problem*

There is a wide gap between what is technologically possible and what has actually been accomplished in efforts to reduce the burden of childhood asthma. Both the prevalence of asthma and the rate of disabling asthma among school children have grown, despite the availability of more effective asthma treatments over the last 3 decades. Explanations for these paradoxical trends might exist within the day-to-day experiences of children and their families who are living with disabling asthma (Payne & Balfour-Lynn, 2001). However, I found no data that describe such phenomena.

Current use of self-management by scholars and clinicians to conceptualize asthma self-care is problematic because it might not adequately represent children's experience of asthma. For example, self-management as a construct does not address choices children make between living life normally and acting to avoid adverse effects of asthma (Meng & McConnell, 2002). A large amount of skilled self-care by children is currently required to avoid adverse health effects of asthma. Many children appear to be unable to sustain protective behaviors (Scarfone et al., 2001). Disability due to asthma among children is widespread (Newacheck & Halfon, 2000). Recommended self-care actions impose demands on children and can interfere with day-to-day life (Ireland, 1997). Little is known about this and other aspects of the experience of disabling asthma. New knowledge stands to be gained from a study of the experience.

Clinicians must rely heavily upon the active involvement of children for correct diagnosis and appropriate treatment of asthma (Guyatt et al., 1997). Good clinical outcomes are related to effective communication and existence of a trusting relationship that is ongoing over a period of months and years (Riekert et al., 2003). However, researchers have found that clinicians exhibited poor communication patterns when caring for children with asthma (Wissow et al., 1998). Guidance that describes how clinicians should build and maintain partnerships with children and their families has been missing from expert clinical guidelines. This deficiency is likely related to a lack of research and knowledge pertaining to the specific needs and challenges faced by children. Clinician behaviors would be expected to have special bearing on the child with disabling asthma, who is experiencing an unusually high burden of disease (Bender, B. G., 2002; Dolan et al., 2004; Halterman et al., 2003).

Qualitative research is warranted to describe phenomena associated with children's experience of disabling asthma and the context of their experience. Such research holds potential for providing a scientific basis for more effective partnerships to improve health care services to children with asthma. A descriptive phenomenological study was proposed to identify children's intentions related to asthma. These data were needed to help close the gap between what is technologically possible and the high level of asthma disability currently experienced by many children (Newacheck & Halfon, 2000).

A detailed review of relevant prior work related to the study will be further described in Chapter Two through a systematic appraisal of (a) scientific literature pertaining to human and environmental factors in settings where children live and receive care, (b) known aspects of children's experience of asthma, (c) and consideration of the influences of technology and culture on childhood asthma. It will be shown that a disproportionately small number of studies have used appropriate methods and designs to investigate children's perspectives related to asthma. Whereas more than 14,000 peer-reviewed articles pertaining to childhood asthma have been published, I found only 6 in which scholars used unstructured interviews to ascertain children's beliefs, intentions and behaviors. I did not find any qualitative study in which researchers investigated children's experience of asthma in natural settings.

My review of the literature suggests that children's voices have not been heard. In particular there is little knowledge about the experience of disabling asthma among rural school children. A descriptive phenomenological investigation was appropriate for studying this important aspect of childhood asthma because the method focuses on

participants' experience rather than current constructs. Knowledge gained from this research approach is likely to benefit both professional and lay efforts to support children who have asthma (Abdulwadud, Abramson, Forbes, & Walters, 2001; Zimbro, 2000) and to strengthen scientific constructs related to disabling asthma among children.

### *Significance of the Research Problem*

#### *Impact on the Public's Health*

Asthma is a major public health problem that imposes an enormous burden on individuals and society. It is a disease of burgeoning significance. According to the National Health Interview Survey (NHIS), National Center for Health Statistics (NCHS), Center for Disease Control and Prevention, from 1980-1996 the prevalence of asthma increased by 73.6% (Mannino et al., 2002). The NHIS is a probability sample that prior to 1997 included a measure of asthma prevalence based on the percentage of individuals who reported that they experienced asthma symptoms in the previous 12-month period. In 1997 the NHIS definition of asthma prevalence was redefined as two distinct rates, lifetime prevalence and 12-month attack prevalence (NCHS, 2003).

Lifetime asthma prevalence includes anyone who has been told by a physician at any point in their lifetime that they have asthma. In 1997 9.7% of respondents reported lifetime asthma suggesting that an estimated 26.7 million people in the United States have asthma. Approximately 4.1% of all respondents reported an asthma attack in the last 12 months (Mannino et al., 2002). In 2001 the NHIS further elaborated the definition of asthma prevalence to include current asthma prevalence, defined as the number of individuals who have been previously diagnosed with asthma by a physician and who have asthma at the time of the interview. In 2001 approximately 7.3% of respondents, an

estimated 20.3 million Americans, had current asthma, while 10.9% of adults reported a lifetime diagnosis of asthma.

In 1998, the National Heart, Lung and Blood Institute (NHLBI) estimated that the annual costs of asthma were \$11.3 billion per year. This estimate includes \$7.5 billion in direct medical expenses and \$3.8 billion in indirect expenses, such as lost workdays for adults with asthma and lifetime earnings lost due to mortality from asthma. However, the far-reaching significance of asthma extends beyond both its financial impact and the very large number of people directly affected by the disease. A national cross-sectional survey of 1000 adults from the general public revealed that 77% of participants had either experienced asthma personally (12.5%), through a family member with asthma (35.1%), or through a friend or co-worker (29.4%) (Schulman, 1999).

These data point to the relevance of efforts to better understand asthma and to promote widespread public awareness of this disease as a human experience. Initiatives to inform the public and increase social support for those with asthma should be based on the actual challenges facing individuals. This knowledge is distinct from an understanding of the epidemiology and pathophysiology of asthma. Currently, little is known about the actual day-to-day experiences of persons as they live with asthma.

The importance of asthma as a national public health crisis was reflected in the Healthy People 2010 goals of the U.S. Department of Health & Human Services (DHSS, 2001). Eight objectives were included for asthma, including rate reductions in deaths, hospitalizations, emergency department visits, days of activity restriction, and school and work days lost. In addition, Healthy People 2010 called for an increase in the number of persons participating in formal patient education programs, in the number of persons

receiving asthma care according to expert clinical guidelines, and in the number and adequacy of state surveillance systems (DHSS, 2001).

Healthy People 2010 (DHSS, 2001) objectives respond to serious problems and gaps in asthma care. Only 6.4% of persons with asthma received formal patient education in 1998. Healthy People 2010 objectives targeted an increase to 30%. Among more than 2500 patients and parents of children with asthma surveyed, 98% reported a moderate to strong need for better asthma education (Schulman, 1999). From 1994-1996 19.5% of persons with asthma reported physical activity limitations due to their disease. Healthy People 2010 objectives targeted a decrease in the percentage of people who experience activity limitations to 10%. More than 10 million school days are lost annually due to asthma. Healthy People 2010 objectives called for a decrease in school absenteeism (DHSS, 2001).

*Racial disparity in asthma morbidity.* Asthma prevalence, morbidity, health care use, disability (Akinbami, LaFleur, & Schoendorf, 2002) and mortality differ markedly by race (NCHS, 2003). In 2001 lifetime asthma prevalence by race was 11.6% for Whites, 12.1% for Blacks, and 9.2% for Hispanics. Current asthma prevalence was 7.5% for Whites, 8.3% for Blacks, and 5.8% for Hispanics. Asthma attack prevalence was disparate with prevalence at 4.4% for Whites, 5.4% for Blacks, and 3.4% for Hispanics. These statistics are amplified by health care use and mortality data. Asthma emergency department visit rates for Blacks in 2000 were more than twice as high as for whites. Hospitalization rates and asthma deaths for Blacks were more than three times higher than for Whites. Comparable data for Hispanics was lacking in 2000 (NCHS, 2003).

Reasons for racial disparities in asthma morbidity are not well understood. The problem did not appear to be related to failure of clinicians to establish the diagnosis. Akinbami, Lara J., Rhodes, and Lara (2005) found that the odds ratio of receiving the diagnosis of asthma among wheezing children was higher among minority children than among Whites. However, there were important underlying differences in allergen exposure and sensitization among American children. Black and Mexican American children were found to be about twice as likely to be sensitized to cockroach antigen. (Stevenson et al., 2001) These children also had much greater exposure to dust mites and the fungus *Alternaria alternata*, which has been linked to increased risk of asthma deaths. Other researchers have found that among children with similar insurance and sociodemographic backgrounds, Black and Hispanic children are far less likely than White children to use preventive medications for asthma (Lieu et al., 2002) “This suggests that non-financial barriers – such as differences in health beliefs and concepts of disease, fears about steroids, or communication barriers (including language) between doctors and patients – may play an important role in suboptimal medication use” (Lieu et al., p. 859).

*Urban and rural asthma.* Urban and rural variables are important in the etiology and epidemiology of asthma. People among ethnic minority populations living in urban areas were reported to experience the highest asthma burden (Clark et al., 1999). Among children, asthma prevalence and severity were worse among the poor living in inner city settings (Sudhir & Prasad, 2003). However, poverty was strongly associated with increased asthma morbidity (Halfon & Newacheck, 1993) independent of residence. Both

rural and urban poor were difficult to reach populations for disease management efforts (Bender et al., 2003).

Over the last three decades emphasis on urban rather than rural asthma has led to disproportionate levels of research and funding. A search of the scientific literature using Ovid™ accessing the Medline™, CINAHL™, and PsycInfo™ databases yielded 1751 abstracts for “asthma and urban” compared to 753 for “asthma and rural”. When the word “children” was added to these two search strings a total of 884 abstracts were identified for “asthma and urban and children”, compared to 325 for “asthma and rural and children”. Recent funding reflected a similar emphasis with three large asthma grants targeting urban rather than rural populations, including the Robert Wood Johnson Foundation Allies Against Asthma, the Centers for Disease Control & Prevention Controlling Asthma in American Cities, and the Merck™ Children’s Asthma Network.

#### *Impact on the Health of Children*

Prevalence of asthma in childhood differs from that in adulthood. Asthma prevalence is higher with a lifetime asthma prevalence of 12.6%. In 2001 current asthma was reported among 8.7% or approximately 6.3 million children in the United States (NCHS, 2003). Asthma is 30% more common among males than females between the ages of 0 to 17 years with 10% of males having current asthma. This prevalence contrasts asthma in adulthood when females have a 30% greater incidence than males. There is a disproportionate burden of asthma on children, evidenced by a 50% greater asthma attack prevalence among children aged 0 to 17 compared to adults (NCHS, 2003). In 2001 the NHIS asthma attack rate for children was 57/1000 with 4.2 million U.S. children

experiencing an asthma attack in the preceding 12 months. Increased asthma attack rates carry serious implications for quality of life, morbidity, health care utilization, and cost.

Childhood asthma contributes to use of a disproportionately large number of health care services. In 2000 there were 4.6 million outpatient visits for children with asthma 0 to 17 years of age. This visit rate was more than twice that of adults with asthma. Children had 728,000 emergency department visits for asthma at twice the rate of adults with asthma. Children had 214,000 hospital admissions for asthma for children, a rate two and a half times the rate among adults with asthma. In contrast, there were only 223 asthma deaths among children 0 to 17, a rate that was only one seventh of the adult mortality rate (NCHS, 2003).

Asthma has become the single most common cause of childhood disability (Msall et al., 2003). In this context disability is defined as a long-term condition that reduces a child's ability to participate in ordinary activities (Newacheck & Halfon, 2000). The prevalence of disabling asthma in childhood has increased dramatically by 232% over the last three decades, while the prevalence of disability due to all other childhood conditions increased by only 113% according to Newacheck and Halfon (2000). The reasons for the disproportionate increase in asthma disability are not clear. A reported 73.6% increase in asthma prevalence from 1980 to 1999 (Mannino et al., 2002) does not explain the magnitude of increase in disabling asthma. Disabling asthma affects approximately 1.4% (more than one million) U.S. children (Newacheck & Halafon, 2000).

The epidemiology of childhood asthma is distinct in rural communities (Braun-Fahrlander et al., 2002). A number of risk factors related to rural residence were identified. Rural children were less likely than urban children to see an asthma specialist

(Yawn, Mainous, Love, & Hueston, 2001). Rural children were less likely than urban children to receive care at school from a nurse who is familiar with asthma (Huss et al., 2001). Data suggest geographic disparity in Missouri related to childhood asthma. Emergency room visit rates in 2003 for Missouri children living in many rural counties (Figure 1) demonstrated excessive asthma morbidity (Missouri Information for Community Assessment, 2003). The mean rate of disabling asthma among rural school children in Missouri in 2005 was 2.1% (Francisco & Konig, 2005) compared to the national rate of 1.4% (Newacheck & Halfon, 2000). Figure 2 shows the distribution of more than 3200 rural children with disabling asthma across Missouri counties. These data indicate a compelling need for research to explore the problem.

*Rationale for Undertaking a Qualitative Study of Children's Experience of Asthma*

Whereas a variety of research approaches, both quantitative and qualitative, might contribute to a better understanding of childhood asthma, the focus of this proposed study calls for a method for describing asthma from the perspective of children. Quantitative methods in general are not designed to address complex research questions related to human experience (Omery, 1983). In Chapter Two an analysis of the body of published work related to childhood asthma will illustrate the preponderance of quantitative methodologies and biomedical themes in prior studies. In my opinion these studies have contributed little to an understanding of how children perceive and respond to having asthma. Foundational values of qualitative research methods are consistent with my intent to investigate children's experience of disabling asthma. Qualitative research values and aims to understand human experience. "Lived experience is the basic empirical datum, as gleaned from the participant's description free of comparison to objective realities or

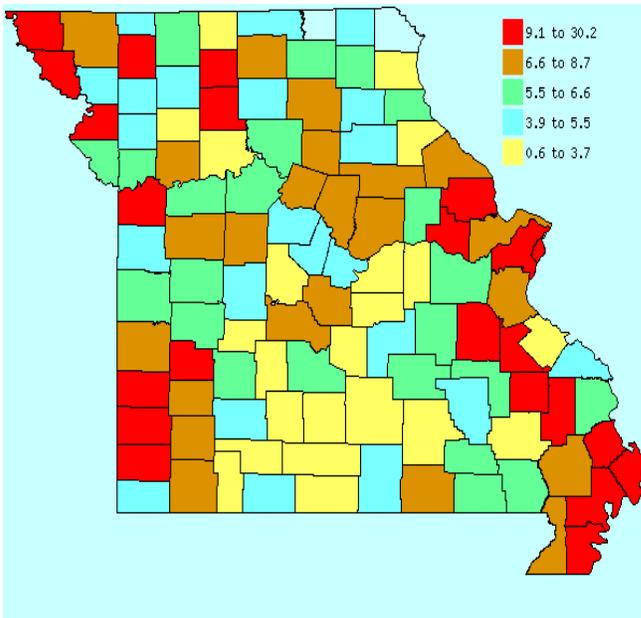
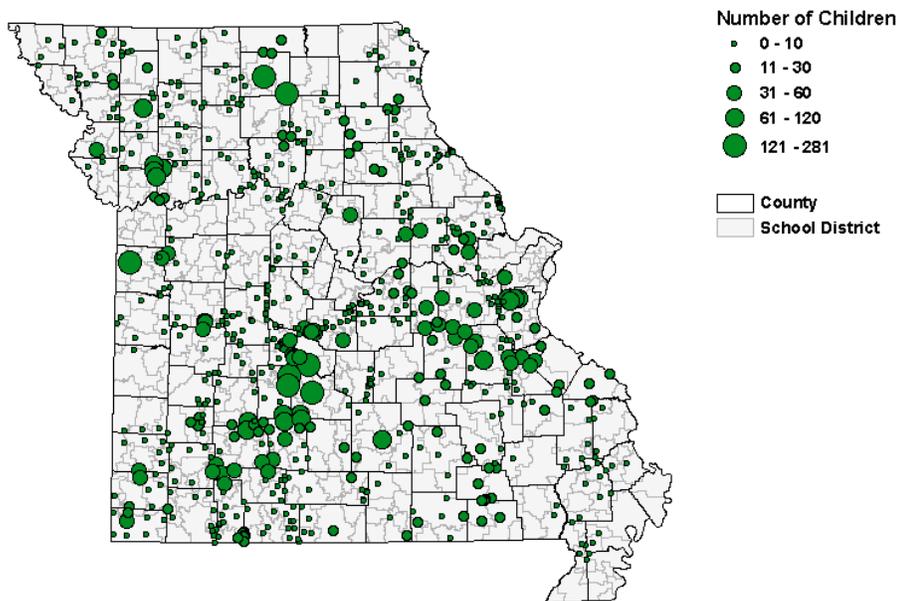


Figure 1. 2003 Missouri emergency room visit rates for asthma among children less than 15 years of age. County rate quintiles illustrate high morbidity in many rural locations.

Numbers of Rural School Children in Missouri with Disabling Asthma  
by School ZIP Code, May 2005



Source: Francisco, B. and König, P., 2005. School Nurse Survey of Disabling Asthma in Missouri, Unpublished Data, University of Missouri, Columbia.

Figure 2. Missouri schools with excessive rates of disabling asthma

predefined norms. The person's co-participation in generating knowledge of lived experience is respected, and no more fundamental reference than what is disclosed by the person is sought" (Cody & Mitchell, 2002, p. 6). Dahlberg and Drew (1997) specifically advocated a "life-world research paradigm" (p. 303) as an appropriate conceptual basis for qualitative investigations concerned with holistic nursing practice.

A number of qualitative research methodologies were available to me. I considered and eliminated several alternative methods, because each was inconsistent with my goal of describing the experience of children who have disabling asthma. Ethnography is a qualitative methodology concerned with cultural patterns (Leininger, 1985). Ethnography is used to observe, describe, and analyze meaning that is shared among people by living with them in their environment. That method was not suitable because my intent is not to describe cultural patterns. I did not intend to live within the cultural setting of participants. Grounded theory method aims to generate theory about social situations or psychological realities (Strauss & Corbin, 1990). I rejected this method because I did not intend to generate a theory to explain children's experience of asthma. Development of theory was not consistent with the goal of describing the experience and life-world of children with asthma while setting aside constructs.

As a philosophy phenomenology inspired an array of doctrines relating to human experience that arose against "uncritical simplification" (Spiegelberg, 1960, p. 658) that had become typical of the sciences. "Phenomenology was not founded: it grew. Its fountainhead was Edmund Husserl" (Spiegelberg, 1975, p.3). Husserl articulated an eidetic (descriptive) approach to understanding human experience (Husserl, 1929/1975). Modern phenomenological research includes two distinct schools gave rise to differing

research methods (Cohen & Omery, 1994). Hermeneutic phenomenology is an interpretive method that focuses on the meaning of being (Heidegger, 1962). After a detailed comparison of Husserl's (1929/1975) descriptive phenomenology and Heidegger's (1962) hermeneutic phenomenology, I rejected hermeneutics for this study because I did not want to interpret the meaning of being a child with disabling asthma.

Instead, I identified a qualitative research method that supports descriptive inquiry. Selection of a particular method for the study was based on the conclusion that Husserlian phenomenology, as elucidated by Porter (1998a) is a good fit for the research questions to be addressed by this study and the need to examine the construct validity of leading theories and concepts pertaining to children's experience of asthma. Strengths of Porter's (1998a) methodology include its scientific basis, perceived fairness to participants, and the opportunity to give voice to a group of people who have not been adequately heard (Porter, 1998b). Whereas a method will be used to guide this study, Omery (1983) and Porter (1998a) have pointed out that Husserl's writings are a critical source of inspiration to the researcher who would use a phenomenological approach. The conduct of descriptive phenomenological research requires knowledge of the philosophical underpinnings of the particular method (Porter, 1998). I will present a brief summary of Husserl's phenomenology, as I have come to know it, to describe how I have been inspired to conduct this study.

### *Background and Overview of Husserl's Phenomenology*

#### *Historical Context*

Edmund Husserl was born in Prossnitz in the Bohemian province of Moravia in 1859, the same year that Darwin's "Origin of the Species" was published. He studied

astronomy, mathematics, physics, psychology, and philosophy (Husserl, 1929/1975). Husserl held three professorships in his lifetime, devoting his work first to mathematics, then to development of the phenomenological method, and finally to elaboration of the philosophical doctrine of the transcendental Ego. Husserl was born of Jewish heritage. This fact proved of great consequence during his later years, with the rise of the Third Reich. Husserl's letters, manuscripts, and library were craftily hidden by his supporters after the Nazis stripped him of a professorship in 1933 and sought to destroy all remnants of his work. Most of his manuscripts were secretly transported out of Germany and saved in Louvain, Belgium. At the time of his death in 1938, Husserl's writings consisted of more than 40,000 pages of manuscripts in stenographic form. This collection has been the principal source for subsequent translations and scholarly reviews of Husserl's work (Koestenbaum, 1975).

Among the influential writings of Edmund Husserl, two primary sources have been important in the development of this research proposal. *Ideas – General Introduction to Pure Phenomenology* was published in 1913 and translated into English by Gibson in 1962. This was an early, exhaustive, description of the philosophical foundations of Husserl's phenomenology. A later, more succinct work *The Paris Lectures* was published as an English translation with introductory essay by Koestenbaum in 1975. This later book contains two lectures entitled "Introduction to Transcendental Phenomenology" that Husserl delivered at the Sorbonne in 1929 at the invitation of the French Academy. Koestenbaum described the lectures as "an introduction to the mature thought of Edmund Husserl and in the author's own words" (Koestenbaum, 1975, p. LXXVII). Several concepts found in these primary sources will

be presented as background information for methodological applications of Husserl's phenomenology.

*Husserl's Critique of Contemporary Science and Scholasticism*

Husserl was concerned about the origins of knowledge and the basis for intellectual certainty or "apodictic" (Husserl, 1929/1975, p. 6) awareness. He believed that science had drifted away from its philosophical moorings, moving away from certainty in pursuit of support for presuppositions arising from reasoning about phenomena rather than direct, unbiased observation. Husserl associated this intellectual departure with failure of the sciences of his time to generate knowledge that was clearly based on evidence. "Nonetheless, and despite the brilliant development experienced by the sciences over the last three centuries, they find themselves today seriously limited by the obscurity of their foundations" (Husserl, 1929/1975, p. 5). Husserl found support for his views in the work of Rene Descartes, who had previously sought to reform the sciences.

Husserl regarded Descartes as the father of phenomenology (Husserl, 1929/1975, p. 3), yet he took issue with a number of Cartesian concepts. Husserl sharply criticized an "unarticulated prejudice" (Husserl, p. 9) of scholasticism in Descartes' reasoning. Husserl rejected the contemporary and popular practice of scholarly articulation of dogma. He attributed the errors of scholasticism to a preoccupation with the derivation of theorems and abstractions that had proven important in the origins of mathematical and physical sciences. "We must above all avoid prejudices, hardly noticed by us, which derive from our emphasis on the mathematically oriented natural sciences" (Husserl, 9).

Despite his training as a mathematician, Husserl (1929/1975) cautioned against deductive reasoning in the study and analysis of human experience.

In relation to this we must under no circumstances take for granted that, with our apodictic and pure ego, we have salvaged a small corner of the world as the single and indubitable fact about the world which can be utilized by the philosophizing ego. It is not true that all that now remains to be done is to infer the rest of the world through correct deductive procedures according to principles that are innate to the ego. (p. 9)

He also articulated concern that superficial observation and logical reasoning would obscure the actual nature of human experience.

Husserl advocated a rigorous approach that demands setting aside all knowledge of human experience not based on actual evidence. “Phenomenological procedure possesses no antecedent realities or conceptions of reality, but instead, from the very beginning, creates its concepts through original acts -- which in turn are fixed in original concepts” (Husserl, 1929/1975, p. 37). He advocated a framework for coming to know another’s experience in an intelligible, scientific way by distinguishing a naïvely objective view of human experience from a phenomenological understanding. Husserl cautioned against the shortcomings of a “naïve objectivism” (p. 5) whereby scientists or scholars study human experience without direct observation and dialogue. Husserl described this as the natural or naïve view of experience and considered it pre-scientific. He held that the rote description of observed behavior cannot reveal the true nature of human experience, because human consciousness holds and acts upon both sense data and idealized concepts.

Husserl (1929/1975) stated:

Daily and practical existence is naïve; it is the immersion in an already given world and consists of experiencing, thinking, valuing, acting. All those intentional acts of experience through which objects simply exist are carried out anonymously; the experiencer knows nothing of them. (p. 36)

Husserl suggested that the incidental nature of daily living obscures intentions that underlie consciousness. On face value, an observer sees only the natural, incidental aspects of life in what Husserl termed the naïve view of experience. Husserl believed that science, particularly psychology, had lapsed into this naïve, natural view of the world. “The basic concepts which, in science, determine the meaning of its sphere of objects, of its theories, and which are common to all the sciences, originate in a naïve manner” (Husserl, p. 36)

Husserl (1929/1975) articulated an approach that would move science away from a naïve view toward what he described as a phenomenological understanding.

Every attempt to move from sciences that have become historically established onto a better foundation – to arrive at meanings and acts by means of a better self-understanding - is merely one item of self examination on the part of the scientist. But there is only one type of radical self-examination, and that is the phenomenological one. (p. 37)

Husserl stated that he sought “an absolutely secure starting point and rules of procedure, when, in actual fact, I lack any support from the existing disciplines” (p. 4). He advocated an approach that would provide experiential evidence that would constitute and clarify scientific ideas pertaining to human experience. “Consequently, phenomenology must

arrive from within itself at those conceptual systems which determine the fundamental meaning of scientific constructions” (p. 37).

*Science, Human Experience, and Evidence*

Husserl (1929/1975) argued that human consciousness and experience were the proper subject matter for science.

To say, in my natural existence, “I am, I think, I live,” means that I am one human being among others in the world, that I am related to nature through my physical body, and that in this body my cognitions, perceptions, memories, judgments, etc. are incorporated as psycho-physical facts. Conceived in this way, I, we, humans, and animals are subject-matter for the objective sciences, that is, for biology, anthropology, and zoology, and also for psychology. (p. 10)

The premise that human experience can be known through evidence is central to Husserl’s phenomenology. He meticulously considered how the study of consciousness should be conducted as a scientific activity. “It is the spirit of science to count nothing as really scientific which cannot be fully justified by the evidence. In other words, science demands proof by reference to the things and facts themselves, and that these are given in actual experience and intuition” (p. 6).

Husserl (1929/1975) also clarified what he believed to be required if the sciences were to be rational and evidence-based. “First, anyone who seriously considers becoming a philosopher must once in his life withdrawal into himself and then, from within attempt to destroy and rebuild all previous learning” (p. 4). “We will keep this much: experiential evidence that is to serve as radical foundation for knowledge needs, above all, a critique of its validity and range. It cannot be accepted as apodictic [certain] without question and

qualification” (p. 7). “In other words, we must not make assertions about that which we do not ourselves see” (p. 9).

Husserl (1929/1975) developed a phenomenological philosophy that prescribed setting aside preconceived ideas about an experience prior to its investigation. He advocated the preliminary step of identifying and describing concepts or constructs associated with, but not derived directly from, the experience of interest. Next, he recommended suspending judgement about the validity of these ideas. The archaic term “epoche” is used often in Husserl’s writings in reference to this intellectual commitment to suspend judgment in favor of examining the evidence. “This ubiquitous detachment from any point of view regarding the objective world we term the phenomenological epoche” (p. 8). Bracketing was used as a procedural term to describe the epoche. Husserl also used the phrase “phenomenological reduction” (p. 10) to designate the intellectual process of consciously suspending judgment in regards to concepts and constructs pertaining to experience until evidence, derived intersubjectively, can be examined and analyzed.

#### *Reality, Objectivity, Transcendental Subjectivity, Solipsism, and Intersubjectivity*

Husserl (1929/1975) acknowledged the problem that one's experience of the world does not always represent reality when he said:

Our experience of the world is continuous, incessant, and unquestionable. But is it true that this experiential evidence, even though taken for granted, it is really apodictic and primary to all other evidence? We will have to deny both. Is it not the case that occasionally something manifests itself as a sensory illusion? (p. 6)

While questioning the validity of perceived reality, Husserl maintained that human experience is preeminent and knowable.

The independent epoche [suspension of judgment] with regard to the nature of the world as it appears and is real to me - that is, “real” to the previous and natural point of view - discloses the greatest and most magnificent of all facts: I and my life remain -- in my sense of reality -- untouched by whichever way we decide the issue of whether the world is or is not. (p. 9)

Husserl advocated transcendental subjectivity as an appropriate scientific means of understanding others (Husserl, 1929/1975). Use of the term transcendental addressed specifically the need to set aside an observer’s natural and naïve view of experience. The term transcendental in this context is distinguished from incidental, daily experiences that are common-place and embedded in the routines of living. While incidental occurrences are readily observed, these do not fully describe lived experience. Husserl suggested that people view and describe their lives transcendently, not as a compilation of incidentals, but reflectively as life is lived over time. Husserl recognized and addressed this aspect of consciousness in great detail and with rigor.

Husserl (1929/1975) held that it is possible for the phenomenological observer to attend to evidence of experience by transcending personal points of view, natural perspectives, and common preconceptions. However, the danger of granting credibility to descriptions of experience that claim to be transcendent was evident to him. He recognized that phenomenological analysis might become immersed in solipsism: a self-indulgent preoccupation with an observer's self-awareness. Solipsism holds that reality is defined by the ego – that self is the source of everything. This critical threat to

phenomenology, that the observer's reality would overshadow the evidence, evoked his deep concern. "And yet it is as if we were on the brink of a precipice, where the ability to step calmly and surely decides between philosophic life and philosophic death" (p. 8).

Husserl's (1929/1975) phenomenology evoked intersubjectivity as the antidote for solipsism and a means by which evidence relating to human experience would become known.

But I experience the world not as my private world, but as an intersubjective world, one that is given to all human beings and which contains objects accessible to all. In it others exist as others, as well as for each other, as being there for anyone. (p. 34).

For Husserl intersubjectivity also solved a more fundamental problem.

As a natural human being, can I seriously ask, and ask in a transcendental sense, questions such as "How can I go beyond the island that is my consciousness? How can that which appears in my consciousness as an experience of evidence acquire objective significance?" (p. 32)

### *Consciousness, Intentionality, and Phenomenological Analysis*

Husserl (1929/1975) identified the obvious difficulties of describing something as dynamic as consciousness. He described consciousness as fluid and wavelike "with its antithetical occurrences of fulfillment and disappointment" (p. 22).

Our research is not hindered by the fact that its province is the realm of subjective flux and that it would be madness to proceed in terms of a method of concept- and judgment-formation that is appropriate to the objective and exact sciences. (p. 20)

The nature of consciousness was a central theme in Husserl's work. He proposed "a descriptive tripartite formula," "ego cogito cogitatum," (Koestenbaum, 1975, p. XXX) for understanding consciousness. The formula can be translated "I" "act" "object". The phrase sounds obscure, much as would a mathematical formula employing "x" and "y" as place-holders for unknown values. By substituting familiar words for "act" and "object," it is easy to illustrate the basic idea behind Husserl's formula. "I see trees." "I fear death." "I admire loyalty." In each of these examples the conscious ego acts toward an (ideal or real) object. Husserl contended that the tripartite formula demonstrates a critical truth – that intentionality structures consciousness.

Husserl (1929/1975) emphasized that the nature of human experience is intentional. That is people constitute their realities as they act toward objects in the world around them. His assertion that intentionality is the structure of consciousness was framed by two critical ideas. Husserl held that "Everything in the world, all spatio-temporal being, exists for me because I experience it, because I perceive it, remember it, think of it in any way, judge it, value it, desire it, etc." (p. 8).

If I place myself above that entire life and if I abstain from any commitment about reality, specifically one which accepts the world as existing, and if I view that life exclusively as consciousness of the world, then I reveal myself as the pure ego with its stream of cogitations [reflections]. (p. 8)

In these statements Husserl advanced two central concepts of his phenomenology. First, he advanced the understanding that human experience is held in consciousness as awareness of the world. Secondly, he argued that human consciousness can be willfully

assigned to ascertain and reflect on experience. Therefore to be conscious means it is possible to be self-aware and capable of comprehending the experience of others.

Through phenomenological analysis Husserl (1929/1975) viewed the discovery of knowledge as an ongoing and endless process that must return to the original experience. He encouraged the use of original language when describing human experience to avoid introducing concepts not derived from the data.

When phenomenology examines objects of consciousness -- regardless of what kind, whether real or ideal -- it deals with these exclusively as objects of the immediate consciousness. The description -- which attempts to grasp the concrete and rich phenomena of the cogitations -- must constantly glance back from the side of the object to the side of consciousness and pursue the general existing connections. (p. 16)

Husserl (1929/1975) used a solid geometrical form, the hexahedron (cube), as an object lesson to explain that there are many views of the same object. He argued that there is a unitary nature to the various descriptions reflecting changing views of the cube. This unity is based on the fact that all descriptions are directed toward the same object. Likewise, in describing a person's consciousness of experience, various views are linked because these represent aspects or different views of the same thing. Through the example of the cube, Husserl also distinguished between the real and the irreal (ideal).

The object of perception, considered phenomenologically, does not appear as a real thing either in perception or in the streaming perspectives that are unified through synthesis, or any other manifold of experience. Two appearances which, because the synthesis of present themselves to me as appearances of the same

thing are nonetheless really separate, and because of this separation they possess no datum in common; at the most they have only related and similar traits. (p. 17)

Husserl (1929/1975) suggested that human perception likewise occurs as “variegated” (p. 17) impressions of phenomena.

The same [cube] may thus appear to me in a variety of recollections, expectations, or distinct or vacuous conceptions as intentionally the same... This identity always resides in consciousness proper and is apprehended through synthesis. It follows that the stream of consciousness is permeated by the fact that consciousness relates itself to objects. (p. 18)

Finally, the example of a cube served only to illustrate a more far-reaching definition of object of consciousness in which object means both that which has a tangible, sensory basis in reality and as well as intangible things like fear, hope, or wellness. Husserl held that stream of consciousness is characterized by its association with objects, both tangible and intangible.

Husserl (1929/1975) also advanced the concept of the horizons of consciousness as a critical aspect of intentionality that is characteristic of human experience.

“Potentiality in existence is just as important as actuality, and potentiality is not empty possibility.” “It is a potentiality for possible experiences referring to the same intentional object, experiences which the ego can actualize” (p.18). “Perception occurs and sketches a horizon of expectations, which is a horizon of intentionality. The horizon anticipates the future as it might be perceived, that is to say, it points to coming series of perceptions” (p. 18).

For Husserl (1929/1975) a verbatim description of another's experience was not the purpose of phenomenological analysis. The purpose was to understand the demarcation between what is actually happening and what is potential in a person's experience. "Intentional analysis is the disclosure of the actualities and potentialities in which objects constitute themselves as perceptual units" (p. 19). Husserl emphasized the unique goal of phenomenology in ascertaining the actualities and possibilities of horizons in human experience.

The important distinction is that we must not -- as is the case with the objective factual sciences -- concern ourselves with pure experience and give a realistic analysis of the datum of experience, but follow the lines of intentional synthesis, as these are indicated in terms of their intentionality and horizons. In this manner we must exhibit and disclose the horizons themselves. (p. 20)

Husserl (1929/1975) proposed that consciousness is "governed by a highly pronounced class structure" (p. 20) including perceptions and memories. "Naturally, the research develops on different levels" (p. 20). He also held that intentions are structured by classes.

This late insight prescribes to phenomenological analysis and description an altogether new methodology. It is a methodology which goes into action whenever objects and meanings, questions about being, questions about possibilities, questions of origin, and questions of right are to be considered seriously. (p. 19)

Husserl equated intentionality with meaning in human experience.

“Phenomenology always explains meanings, that is, intentionality, by producing these sense-fulfilling syntheses” (p. 19).

Husserl (1929/1975) held that confirmation is an ongoing process of disclosing evidence about consciousness and experience. “An object exists for me; that is to say, it has reality for me in consciousness. But this reality is reality for me only as long as I believe that I can confirm it” (p. 23). Husserl’s concept of confirmation was based on descriptions derived intersubjectively through “progressive confirmation” (p. 23). In response to a letter from an American philosopher who asked about the problem of error in phenomenology, Husserl replied “phenomenology exists, as real work in living development” (Spiegelberg, 1981, p. 184). Therefore, methods using Husserl’s phenomenology would be expected to incorporate multiple interviews over time to encourage a participant to clarify and confirm (or modify) a researcher’s descriptions. “Also, the evidence itself must be subjected to critical verification, and that on the basis, of course, of further available evidence” (Husserl, 1929/1975, p. 6).

In conclusion, Husserl’s (1929/1975) phenomenology has relevance for efforts to understand how people experience chronic disease. We have inadequate knowledge of the motivational factors behind critical choices people make in relation to their health. Efforts to reduce the prevalence and impact of disabling asthma could be informed by a better understanding of children’s experience and intentions. Husserl’s philosophy provided a foundation for understanding and describing experience. His concern about the validity of scientific constructs and his acute sense of the primacy of evidence resonate with current emphasis on evidence-based clinical practice. Whereas Husserl’s

work laid a solid philosophical basis for a scientific approach to the study of human experience, it remained for others to articulate methods that could guide novice researchers. In the following section I will describe the development of the nursing research method, based on Husserl's phenomenology, that I propose to use in this study.

*Description of a Nursing Research Method Based on Husserl's Phenomenology*

Over a ten year period, Porter (1998a) developed a descriptive research methodology that is based on Husserl's philosophy. As a nurse researcher Porter used this approach to investigate the experience of living alone for older widows (Porter, 1998). I came to appreciate the clarity and power of Porter's application of Husserl's (1913/1962) phenomenology in a qualitative research method. A compelling aspect of Porter's method was the practice of incorporating participants' language into the description of the experience. It was evident to me that this approach conveyed participants' perspectives effectively. I was also drawn by the concept of "philosophical reverence" (Porter, 1998a, p. 19). Holding deep respect for the experience of participants was noted by Spiegelberg (1960) to distinguish phenomenology as a method. This attitude is appropriate in a study of children, whose experience often has not been valued or included in scientific work.

I found Porter's (1998a) method to be a good fit for the philosophical underpinnings and purpose of this study. Porter provided clear explanations for her research method; however she joined with Omery (1983), Kohak (1975), and others to caution against linear methodologies and rigid procedural approaches to descriptive phenomenology. Porter (1998a) pointed back to Husserl's warning that no there was no easy formula to be discerned from the underlying philosophy. "There is no 'royal road' in

phenomenology” (Husserl, 1913/1962, p. 259). Instead, Omery (1983) and Porter (1998a) pointed to philosophical inspiration as the guiding force. However, a clear set of activities are needed to guide phenomenological research along paths that are consistent with Husserl’s philosophy.

Porter’s (1998a) nursing research method incorporated specific aspects of Husserl’s phenomenology that have been articulated and influenced by others. Porter (1998a) recognized the contributions of several key scholars and researchers. An overview of these influences is relevant to a description of the method. Porter (1998a) acknowledged the important contribution of Omery (1983) who explained phenomenology, described Spiegelberg’s (1975) phenomenological method, and compared psychological adaptations of phenomenology. Porter (1998a) also cited Spiegelberg’s (1994) scholarship, particularly a detailed historical account and philosophic analysis of the phenomenologic movement as influential. Spiegelberg (1975) considered in depth what “doing phenomenology” (p. XIII) might require. Spiegelberg took the position that there are “multiple road ways into phenomenology” (p. 13) rather than a single, linear approach to the method.

Porter (1998a) also drew from the work of Kohak (1978) in developing methodological activities. Kohak (1978) considered Husserl’s phenomenology more a scientific perspective than a specific method. “In a science, the method, in the sense of tools, techniques, and procedures, is wholly contingent on the task at hand” (Kohak, 1978, p. 133). Finally, Porter (1998a) acknowledged the contributions of Spiegelberg (1994) and Schutz and Luckmann (1973) in relation to Husserl’s unpublished writings about the life-world. The life-world describes a person’s view from within an experience.

This perspective provides important insights. “We can also contrast the world of scientific thought with the life-world of natural experience” (Schutz and Luckmann, p. 21). A summary of Porter's (1998a) method as it was used for this study follows.

#### *Explore the Diversity of One's Consciousness*

Because consciousness is the tool used to conduct phenomenological research, a critical first step is to examine how one thinks about the experience to be investigated (Porter, 1998a). The natural or naïve view must be recognized and explored (Husserl, 1929/1975). Self-examination makes it possible to move from a natural or casual consideration of person's experience to a formal framework that is consistent with the purpose of the study and the questions to be asked (Porter, 1998a). The framework identifies types of data that are of interest and potential sources of data. “The research questions are framed within a phenomenologic perspective to focus on the experience, its context, and intentionality, or what persons are trying to do with their experience” (Porter, 1998a, p. 20).

#### *Reflect on Experiences*

Reflection makes it possible to consider what is already believed or held in consciousness about an experience to be studied. Porter (1998a) suggested that a doubtful attitude should be adopted concerning conventional concepts related to the experience.

Every attempt to move from sciences that have become historically established onto a better foundation – to arrive at meanings and acts by means of a better self-understanding - is merely one item of self examination on the part of the scientist. But there is only one type of radical self examination, and that is the phenomenological one.” (Husserl, 1929/1975, p. 37)

If the researcher concludes that current scientific constructs and current evidence do not adequately describe and explain the experience of interest, then a phenomenological study is justified (Porter, 1995).

#### *Bracket, or Perform the Phenomenological Reduction*

To bracket is to formally state and set aside preconceptions, beliefs, and opinions about the experience of interest that would prevent a researcher from seeing and hearing participants without bias. Husserl (1929/1975) used the phrase “phenomenological reduction” (p. 10) to designate the intellectual process of consciously suspending judgment in regards to concepts and constructs pertaining to experience until evidence, derived intersubjectively, would be examined and analyzed. The phenomenological reduction is intended to both acknowledge and remove schema that would otherwise influence the collection of data that describe the phenomena of interest. The purpose of the bracket is to clear the slate and to make it possible to see and describe the experience as it appears in consciousness (Porter, 1998a).

#### *Explore and Participate in the Life-World*

Descriptive phenomenology focuses on participants as they live their lives in their own familiar settings. The study of the life-world was advocated by Husserl in his later work as he realized that the ordinary person’s day-to-day context differed greatly from the context of the natural sciences (Spiegelberg, 1975). Both experience and its context are foci of interest (Porter, 1998a). Life-world is a descriptive term used by Husserl to denote the particular features that lead back to the experience of interest (Spiegelberg, 1975). “One of its basic features is that it has a center in the experiencing subject (in contrast to the uncentered objective world of science)...” (Spiegelberg, 1975, p. 260).

The life-world has spatial and temporal features. Relevance of features relates to distance from the center. “The life-world is polarized around these centers and displays such spatial characteristics as closeness or farness...” (Spiegelberg, 1975, p. 261).

The structure of the life-world was described as stratifications by Schutz and Luckman (1973) and composed of zones or regions by Spiegelberg (1975). Time, location, objects, concerns, and social relationships are aspects of the life-world. Concerns might be political, economic, cultural, or religious. Spiegelberg (1975) warned that attempts to completely inventory or articulate all aspects of the life-world exhaustively would be “doomed to defeat” (p. 262).

#### *Intuit the Phenomenon through Descriptive Analysis*

The important distinction is that we must not -- as is the case with the objective factual sciences -- concern ourselves with pure experience and give a realistic analysis of the datum of experience, but follow the lines of intentional synthesis, as these are indicated in terms of their intentionality and horizons (Husserl, 1929/1975, p. 20).

Porter (1998a) described this process as the researcher using consciousness to “intuit the principle shared by the facts” (Porter, p. 21) to come to understand the structures of experience. “The life of consciousness is neither a mere aggregate of data, nor a heap of psychic atoms, or a whole composed of elements unified by gestalt-like qualities” (Husserl, 1929/1975, p. 19).

Data that describe what persons are trying to do in their experience point to the existence of underlying intentions. “Furthermore, all perceptual analysis takes place in the transition from real events to the intentional horizons suggested by them” (Husserl,

1929/1975, p. 19). Porter (1998a) described this process as movement back and forth between conceptual levels, not strictly inductive or deductive. “Intentional analysis is the disclosure of the actualities and potentialities in which objects constitute themselves as perceptual units” (Husserl, p. 19).

Porter’s (1998a) method employs a taxonomy of specific intentions that can be grouped together as component phenomena when similarities are shared. Groups of related component phenomena comprise the larger phenomena. Phenomena describe the essence of experience (Husserl, 1913/1962). Porter (1998a) suggested that this taxonomy of intentions, component phenomena, and phenomena are comprehended and described over time and in context. In Porter’s (1995) method the life-world or context was also described by a taxonomy of elements, descriptors, and features. “Taxonomies... are physical representations of the relationships among components” (Porter, 1998a, p. 23). Experience and context change over time. Therefore, taxonomies of experience and descriptions of a life-world are never completed or finalized (Husserl, 1929/1975; Porter, 1998a).

#### *Engage in Intersubjective Dialogue about the Phenomenon*

Dialogue between researcher and participant and researcher and other scientists is an expected step in the research dialectic (Porter, 1998a). Porter's (1998a) method draws from Husserl's “first” and “second formations” (Husserl, 1913/1962, p. 387). The first formation involves the processes described above that make it possible to intuit the structures of experience and the features of the context (Porter, 1995a). The second formation considers the range of experiences known among persons, considers “counter cases” (Husserl, 1913/1962, p. 388), and incorporates what is learned through dialogue

with participants and scholars into the description of the phenomena and life-world features.

#### *Attempt to Fill Out the Phenomenon*

“Finally, the Husserlian phenomenologic approach enables the researcher’s attempt to fill out the phenomenon as a nexus of experiential structures and bracketed constructs and theories” (Porter, 1998a, p. 23). Filling out is an ongoing process with continuing circulation of ideas through dialogue about the bracketed knowledge and empirical findings from the study of lived experience. “The sciences and the world of experience are reaffirmed... as constitutive correlates” (Husserl, 1929/1975, p. 30). Further phenomenologic study clarifies and extends understanding of the experience and life-world (Porter, 1998a).

#### *Determine the Uses for the Intuited Phenomenon*

Porter (1998a) stated:

This approach to the study of an experience, which the researcher initiates by critically analyzing the empirical validity of relevant constructs, is finished, in part, as the researcher recommends specific enhancements of construct validity or applications of theory grounded in the structures of experience. (p. 23)

Enhancements of the original knowledge base, current scientific constructs, working theories, and health care approaches might be applicable. In the context of health care, science is strengthened and improved upon when a researcher brings back a sharper image of an experience as it is lived by those persons who are the focus of services.

#### The Framework of the Study

In descriptive phenomenological research the framework is a rationale for data collection and analysis that guides the investigation (Porter, 1998a). In this study I investigated the experience of disabling asthma among rural children. Structures of the experience and features of the life-world were described. Aspects of the life-world explored were those features of the child's familiar world that are close to the experience of disabling asthma (Spiegelberg, 1975). This framework guided the study:

1. It was expected that phenomenon of rural children's experience of disabling asthma would be revealed from an analysis of the child's relevant beliefs, perceptions, intentions, and behaviors expressed by the child or observed by the researcher during face-to-face time in the family home.
2. Relevant beliefs of children were those viewed as related to (a) asthma as a disease, (b) medications, treatments, and routines associated with asthma, (c) the effects of having asthma on their life, (d) the effects of their having asthma on the lives of their family and friends, and (e) the roles of other people involved with them in the experience of having asthma.
3. Relevant perceptions of children were those viewed as having to do with (a) changes in their body due to asthma, (b) the effects of medications, (c) how others perceive them because of asthma, (d) the effects of having asthma on their relationships
4. Data sources considered relevant to children's behavior included (a) actions directly observed by the researcher, (b) behaviors described by the child to the researcher, and (c) behaviors the child has considered enacting in relation to the experience of asthma

5. Data sources considered relevant to children's intentions included (a) children's descriptions of what they were trying to do in relation to having asthma, (b) researcher insights based on observation and conversation with children.
6. The home where the rural child lives was considered the best place for conducting the study.
7. Focused study of the life-world of children experiencing asthma was an important part of this research. Data related to the context of the experience of disabling asthma were viewed as features of the children's natural world that are close to the experience of disabling asthma. These features were spatial, temporal, and contextual correlates that are relevant to the experience.
8. Data relevant to the home setting were understood as being readily available through observation and interaction with the child.
9. Data relevant to clinical care were viewed as being available through observation and dialogue with the child.
10. Data pertinent to the school setting were obtained through dialogue with the child.
11. Data related to the community setting were obtained through dialogue with the child.
12. The researcher's communications with the child and the child's reactions to data analysis were considered sources of data as well (Drew, 1989).
13. Answers provided by caregivers to the Children's Health Survey for Asthma were considered relevant to the demographic characteristics of the family.

#### Research Questions

The primary research question was: What is the lived experience of disabling asthma among rural schoolchildren? The subsidiary research questions were:

1. What phenomena structure the experience of disabling asthma among schoolchildren ages 7 to 12 years who live in rural settings?
2. What are the features of the context of children's experience of disabling asthma?
3. What similarities and differences exist between the structures of the experience of disabling asthma for school-age children and those concepts, constructs, and theories that guide clinical practice and research?

Each child is unique. Aspects of the experience of disabling asthma and the life-world were viewed as distinct for individual children. However, commonalities among rural children were also viewed as possible. A better description of these structures and features was my purpose and I pursued this to provide insight into the increasing problem of disability among school age-children with asthma. Current concepts and constructs used in the scientific literature are not based on empirical descriptions of children's experiences of disabling asthma. This study was done to yield an empirical basis for strengthening scientific constructs and informing efforts to improve health care services.

Graue and Walsh (1998) articulated another compelling reason for this study:

Why study children? Our answer: To find it out. And to keep finding it out, because if we do not find it out, someone will make it up. In fact, someone probably has already made it up, and what they make up affects children's lives; it affects how children are viewed, and what decisions are made about them.

Finding it out challenges dominant images. Making it up maintains them. (p. xvi)

## CHAPTER TWO

### REVIEW OF THE LITERATURE

#### Organizational Framework of the Bracket

Consideration of prior research, current concepts, relevant theories, and personal perspectives was a critical step in the method I have chosen for this study (Porter, 1998a; Schutz & Luckmann, 1973). Careful review and discussion of these data were necessary for the formation of a bracket concerning the experience of disabling asthma among rural school children. Development of the bracket allowed me to set aside conceptualizations that might hinder the goal of describing children's experience in their own words and from their own point-of-view. Consistent with Husserl's (1913/1962) phenomenology, a framework that I characterize as a natural view of the child's world was used to organize the literature review. A natural view of the child's world considers relevant features of children's daily experience.

The sciences that would interpret and explain human action and thought must begin with a description of the foundational structures of what is prescientific, the reality which seems self-evident to men remaining within the natural attitude.

This reality is the everyday life-world. (Schutz & Luckmann, 1973, p. 3)

I found a natural view to be appropriate for structuring the literature review because much prior scientific work has focused on environmental and human factors in settings where children with asthma live and receive care. A survey of the literature through the lens of natural settings also served to organize the bracket of prior knowledge into a schema that relates directly to children. This framework supports study of the child's

experience and life-world by avoiding complex abstractions that do not relate to children's perspectives. Graue and Walsh (1998) stated:

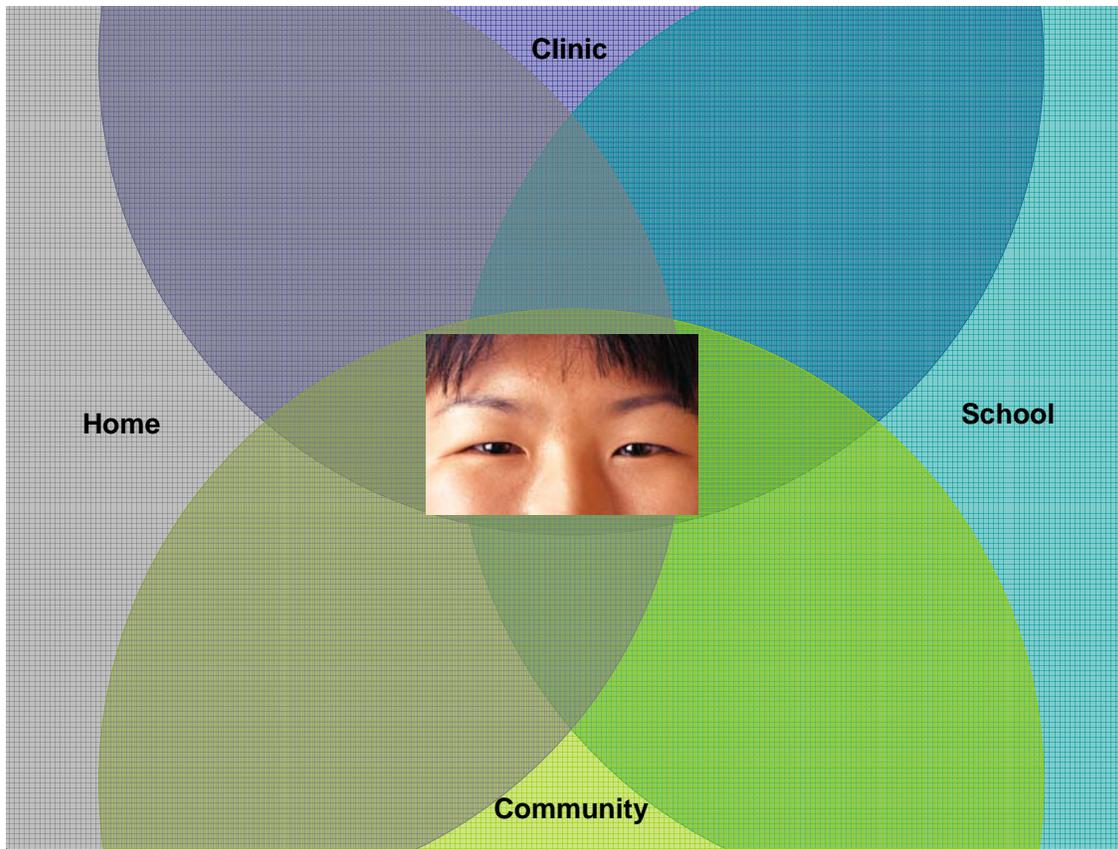
We propose that researchers think of children as living in specific settings, with specific experiences and life situations. We suggest that researchers spend less time attempting to develop grand theories and more time learning to portray the richness of children's lives across the many contexts in which children find themselves. (p. 5)

#### *Natural Settings as an Organizing Framework*

Before documenting the literature review I will further explain my organizing framework and search methods. The schema of natural settings will facilitate discussion of data that pertain specifically to the context of children's experience of disabling asthma. I first identified a body of knowledge related to each of four natural settings: home, school, health care, and community (Figure 3). A logical division is apparent within this literature, suggesting that prior scientific work related to the four settings be grouped into two categories a) the physical environment and b) the human environment. This division reflects the nature of asthma as an illness with a highly variable course that is readily altered by environmental and human factors (NHLBI, 1997).

#### *Technology as a Dominant Influence on Children's Experience*

Much, but not all, of the relevant scientific literature pertaining to the context of disabling asthma among school children can be reviewed by consideration of the natural settings. Some influences likely shape children's experience of asthma across multiple settings. However, Spiegelberg (1975) cautioned that any attempt to articulate all aspects of the life-world would be futile. He advised that some influences, such as political,



*Figure 3.* Illustration of four important settings where rural school-age children experience disabling asthma through environmental and human factors

economic, cultural, or religious concerns, might have compelling relevance to a given experience. My review of the literature suggested three important influences illustrated by Figure 4. I found that technology and culture were pervasive concerns related to children's experience of disabling asthma that could be readily analyzed. However, the influence of the media, while conceptually important (Rich, Lamola, Amory, & Schneider, 2000), did not lend itself to analysis within the scope and procedural limitations of this literature review. The inadequacy of current technology emerged from

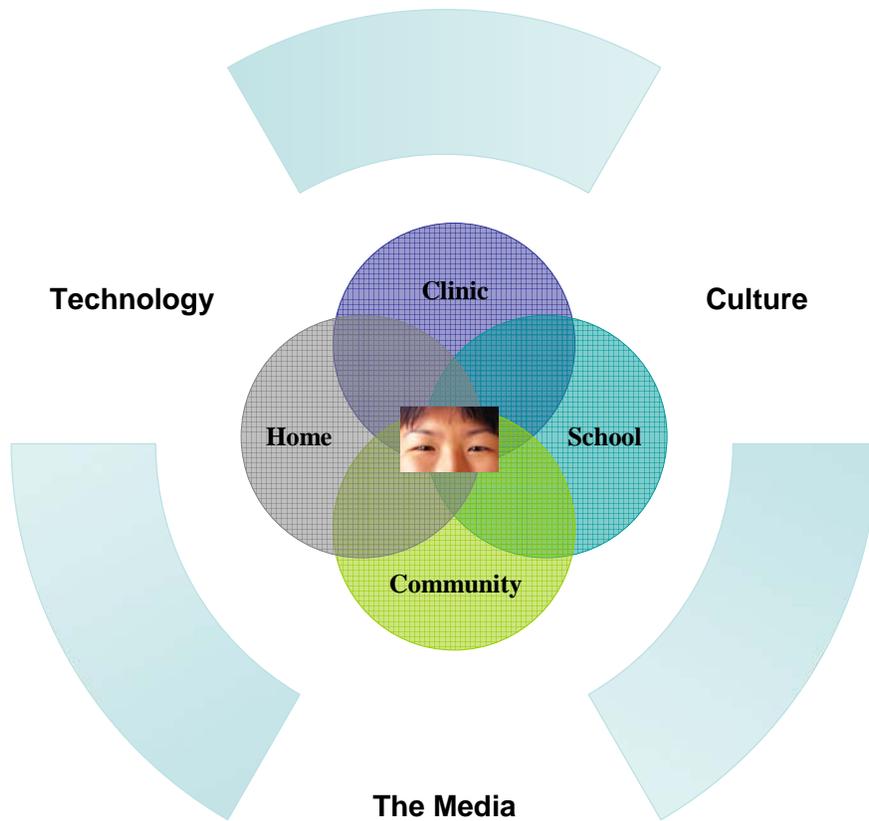


Figure 4. Pervasive influences affecting school-age children’s experience of disabling asthma across the settings where they receive care and live with the illness day-by-day

this literature review as a particularly important factor in children’s experience of disabling asthma. This finding merits further explanation.

Consideration of technology is extremely relevant to an inquiry into the experience of asthma among school-age children. A broad definition of technology was used to guide the review of related literature. Technology is “a capability given by the practical application of knowledge” (Merriam-Webster On-line Dictionary, 2005).

Whereas medical technology plays a major role in children’s experience of asthma, other

types of technology are also important, including complementary and alternative medicine (CAM), dietary interventions, physical training, and cultural and familial practices aimed at reducing illness. The most compelling argument for including a review of literature pertaining to technology and asthma is that the large amount of self-care required of children who have asthma today ultimately arises from technological shortcomings (Bender, 2000). A detailed review of asthma technology later in this chapter is intended to expose some of these limitations and to explore possible connections with the experience of asthma disability among children.

Technological problems surrounding pediatric asthma are not limited to the shortcomings of basic and clinical science to provide answers to nagging questions and more effective diagnostic and therapeutic tools. Current knowledge has not been effectively translated for the control of asthma. Clinical practice has not adequately embraced emerging evidence and new treatment approaches (Sawyer & Fardy, 2003). Numerous barriers have been identified in relation to current asthma approaches (Houston, Cunningham, Metcalfe, & Newton, 2000). Many of these problems are related to ascertaining how people can be motivated to embrace, enact, and sustain behaviors known to bring about better asthma outcomes. Poor adherence to treatment regimens has been cited as the single greatest barrier to improved asthma care (Hogan & Wilson, 2003). However, poor adherence is only one dimension of the problem.

The current state of technology has a profound effect on children's experience of asthma. In the absence of an absolute cure, asthma control requires of the school age child a high level of personal responsibility and initiative that goes far beyond the simple act of adhering to a treatment regimen. Currently, achievement of improved health

outcomes depends largely on intentions and actions of the person who has asthma (Bender, 2002). This is true for the school age child as well (Guyatt et al., 1997). A review of the literature is warranted to elucidate likely effects of technology on children's experience. I believe that future technological innovations should be based on a better understanding of children's experiences, rather than upon manufacturers' interests alone. I assumed that a study of the experience of disabling asthma among school children was likely to reveal some technological shortcomings of current therapies and to suggest some solutions.

#### *Overview of a Personal Bracket for this Study*

In addition to the literature review, Chapter Two contains a personal bracket. My personal bracket includes consideration of (a) theories that have influenced my understanding of childhood asthma, (b) the implications of expert asthma guidelines (NHLBI, 1997), and (c) other influences that should be acknowledged to explain my orientation to this study. Porter's method (1998a) provides an opportunity to reexamine the validity of constructs, theories, and practices after initial phenomenological analysis of the experience of interest. Careful development of a personal bracket relevant to the experience of interest will facilitate this methodological step. This section will include an appraisal of expert asthma guidelines for the purpose of identifying expectations for self-care by children. This discussion reflects my belief that findings from this study will be largely viewed in that context by clinicians. I believe that the expert asthma guidelines present a special translational challenge for applying the findings of this study. I have also included a brief overview of personal influences that was acknowledged and set aside as I prepared to describe rural children's experience of disabling asthma. This step

was consistent with the method chosen for the study (Porter, 1998a). The discussion of my personal bracket allows others to know more about my background and to further evaluate of the validity of my findings.

## Organizing the Review of the Literature - Logistical Challenges and Procedural Issues

### *Overview of the Approach to the Literature*

In preparation for this study of childhood asthma, I had to handle very large data sets in the form of thousands of published articles. I believe this aspect of the study merits some detailed discussion, as it relates to a growing research problem -- the analysis of relevant prior findings and knowledge. I first ascertained the range, content, and structure of the existing body of relevant knowledge. This was complex and time-consuming. Next, in support of the proposed research method, I carefully examined previous research to determine if school age children had disclosed meaningful information about themselves and their experience through semi-structured interviews. Six in-depth studies pertaining to asthma met these criteria, and they are described in this chapter.

Development of an organizing framework for the literature review was a major challenge. However, this step was necessary before I could meaningfully identify, screen, sort, and scrutinize selected work from among the extremely large number of published articles and books pertaining to childhood asthma. A search for *asthma* in Ovid™ using the Medline™, CINAHL™, and PsycInfo™ databases yielded approximately 50,000 peer-reviewed articles between the years 1964 and 2004. The vast majority of these articles addressed the biochemical basis of asthma or emerging pharmacotherapy, revealing that asthma research has been dominated by technological and biochemical

aspects of the disease. The top five subheadings accounted for 61% of the total number of published articles and included: (a) drug therapy (26%), (b) physiopathology (12%), (c) immunology (8%), (d) etiology (8%), and (e) diagnosis (7%). In contrast, four subheadings clearly related to this study accounted for only 6% of total articles (a) prevention and control (3%), (b) psychology (2%), (c) nursing (<1%), and (d) rehabilitation (<1%).

A chronological appraisal of the literature suggested a growing interest in factors related to the environment and the care of people affected by asthma. A search using the databases listed above for the strings *asthma and environment* and *asthma and care* confirmed a sharp upward trend over the last four decades. During this period the percentage of articles pertaining to environmental components of asthma increased by five-fold from 1964-1973 to 1994-2003. Total output by decade jumped from 53 to 876. An even more dramatic increase was apparent in the percentage of articles about the care of those who have asthma. A more than 30-fold increase occurred from 0.4% of asthma articles in 1964-1973 to 13.1% in 1994-2003. Over 3700 articles pertaining to the care of people who have asthma were published over those four decades.

When the literature search was narrowed to *asthma and children* more than 14,000 abstracts were returned. This database was still much too large for systematic review and analysis. I had to develop a rationale for conducting several focused searches that would yield a manageable number of relevant citations. Initially, I found this logistical problem to be nearly insurmountable, but out of this quandary came an acute awareness of the need for an organizational framework to guide the literature review. To

understand the relevant experiences of school-age children who have asthma, I needed to examine two sources of information: context and content (Porter, 1998a).

### *Contextual Sources*

The first type of information relevant to this study was contextual. Many abstracts described studies about factors expected to shape a child's experience of asthma. I marked these abstracts for inclusion in the review if there was a reasonable expectation that data would help to explain why children might experience asthma in particular ways. Context was examined systematically based on the framework of the natural world in which a child lives and experiences asthma. I considered four specific settings where children live, interact with others, and encounter the effects of asthma. As previously mentioned I then considered technology and culture as pervasive influences shaping children's experiences across settings.

I will briefly explain my rationale for using a setting-specific search strategy to review the literature. Children live their lives under the care of others in distinct settings. Different settings might contain dissimilar factors relevant to children's experience of asthma. Home, school, clinical, and the community settings contains important human and physical factors that might impact a child's experience of asthma (Lara et al., 2002). For example, within the home, physical conditions contribute to the control or exacerbation of asthma. The level of cigarette smoke, pet dander, mold and mildew, dust mites, and cockroaches in the home environment affect a child's asthma severity. Likewise, a number of human factors such as general parenting practices, psychological traits of caregivers, and parent-child communication patterns mediate the child's experience of asthma.

In this manner I viewed each of the common settings of child's daily life as possibly exerting similar physical and human influence over the disease experience. I developed a search methodology to probe the literature by setting. A search of *asthma and children and school* returned 1269 abstracts. A search of *asthma and children and home* returned 720 unique abstracts. I merged these two collections to identify duplicates with a resulting set of 1800 unique abstracts. This file was exported from a bibliographic database as a rich text formatted (RTF) file consisting of 749 pages of abstracts (over 1.5 million bytes of data). This document was too large to view efficiently or to import into a qualitative database for coding and analysis. I divided the document into 5 smaller files of about 150 pages each. Next, I reviewed each set of abstracts. Many articles were replication studies of the International Study of Asthma and Allergy in Childhood (ISAAC) and were deemed as irrelevant to this study. ISAAC is an epidemiological initiative reporting the incidence and prevalence of asthma and allergy in populations of children around the world. About two-thirds of the abstracts related to home and school were found to be relevant to the context of children's experience of asthma. This was the largest subset of abstracts reviewed for this study. The sheer size of this knowledge domain underlines its importance in the current research literature. More than 500 pages of abstracts were imported into a database for inclusion in the review.

#### *Content Sources – What Children Relate Directly About Their Experience*

The second type of source for knowledge relevant to this study is that pertaining to the particular content of children's experience of disabling asthma. To search the literature for articles likely to address content, five search strings were submitted to Ovid™, again using the same three databases. Key word selection arose from concepts

central to a phenomenological framework in which children's experiences are held to be understood by their particular perceptions, beliefs, actions, and intentions. A search using *asthma and children and experience* produced 361 abstracts. A search using *asthma and children and perception* yielded 121 abstracts. A third search using *asthma and children and behavior* produced 421 abstracts. A fourth search using *asthma and children and beliefs* produced 77 abstracts. A final search using *asthma and children and intentions* produced 2 abstracts. Neither of these last two articles actually related to children's intentions relative to the experience of asthma. This finding supported the need for this study and other studies to describe the intentions of children who have asthma.

After I merged these four libraries of abstracts deemed likely to describe the content of the children's experience of asthma, there were 554 abstracts. This search methodology was viewed as sensitive but not specific for the topics of interest. For example a search of *asthma and children and beliefs* returned articles about the beliefs of health-care workers and parents held regarding children who have asthma, in addition to the desired focus of children's beliefs about asthma. Therefore, the search strategy cast a broad net for knowledge about children's experience of asthma. As would be expected, the search results included articles considered pertinent to context rather than the content, as in cases where beliefs of parents and health-care workers were the primary topic.

#### *Analysis of Asthma Research Trends in Dissertation Abstracts International*

An additional challenge of the literature review was the task of examining the work of peers who had completed research related to asthma at the masters or doctoral level. In the last four decades more than 1100 dissertations were written. I expected to find a somewhat different distribution of topics in this body of work compared to the

distribution of medical subheadings of published asthma literature. Behind this assumption was the notion that compared to published research, graduate research studies are more theoretically based and are more likely to yield new research approaches. I categorized this set of 988 abstracts as follows: (a) molecular research, (b) patient or family research, and (c) health system research.

Quantitative dissertations far outnumbered qualitative dissertations. Most qualitative studies involved research designs aiming to establish correlations between a construct selected by the researcher and either asthma in general or selected disease factors. Few studies adequately identified the characteristics of the population under study, for example, by differentiating mild, moderate, and severe asthma within the design. Children were the focus of research in 18.4% of asthma dissertations. However, no researcher used a descriptive phenomenological approach to describe the experience of disabling asthma among school-age children. Few researchers directly interviewed school-age children.

After reading and coding 988 abstracts related to asthma found in the Dissertation Abstracts International data set, I found the following distribution by subject category: (a) molecular research (43.4%), (b) patient or family research (42.7%), and (c) health systems research (13.9%). Molecular research included (a) biochemical and biophysical effects (27.4%), (b) environmental factors (9.4%), and (c) cellular physiology (6.6%). Foci of patient and family research were (a) children (18.4%), (b) adults (14.9%), and parent-child or family factors (9.4%). Health system research concentrated on (a) data mining (5.4%), (b) provider factors (4.6%), (c) educational interventions (2.4%), and (d) instrument validation (1.5%).

## A Bracket on the Home and Children's Experience of Asthma

### *Physical Attributes of the Home*

Numerous scholars have found that poor indoor air quality and exposure to inhalant antigens in the home associated with allergic sensitization were strongly correlated with increased asthma prevalence and morbidity. Exposure to environmental tobacco smoke was found to be associated with a marked increase risk of persistent wheeze among children (Somerville, Rona, & Chinn, 1988). Use of wood-burning stoves for home heating has been found to be associated with a 4.8-fold increase risk for asthma among 704 children aged 7 to 16 years (Kuhr et al., 1991). The specific antigens associated with allergic sensitization vary by geographic region, housing type, altitude, and climate. Dust mites and cockroach are important antigens in urban environments, whereas cat and dog dander are major antigens at high altitude locations with low amounts of rainfall (Ingram et al., 1995). Mold is another important indoor allergen.

There is strong evidence of a relationship between multiple measures of asthma morbidity and exposure to high levels of inhalant antigens in sensitized children (Rosenstreich et al., 1997). Adverse factors in home environments of children with asthma have often gone unabated after routine clinical care and counseling (Finkelstein et al., 2002a). Exposure to adverse environmental factors in the home was found to be widespread and frequent among 638 children (age 3 to 15) with asthma (Finkelstein et al., 2002a). Trigger avoidance measures were infrequently adopted in these households even though nearly half of parents reported receiving written recommendations.

Benefits of remediation efforts in the home are well established (Saegert, Klitzman, Freudenberg, Cooperman-Mroczek, & Nassar, 2003; Somerville, Mackenzie,

Owen, & Miles, 2000). Efforts to reduce environmental tobacco smoke exposure in the home were associated with decreasing levels of urinary cotinine, improving lung function, and lessening morbidity (Berman et al., 2003). A randomized, controlled trial involving 937 children (5 to 11) with allergic asthma in seven U.S. cities demonstrated the effectiveness of tailored environmental interventions (Morgan et al., 2004). Decreasing antigen levels on the floors and bedding of intervention homes was associated with a significant decrease in asthma morbidity (fewer days of symptoms) during the intervention year and in the subsequent year as well.

Several researchers have found exposure to bacterial endotoxin associated with farm animals to be a mediating factor in the development of allergic sensitization in childhood. These data might explain lower prevalence of asthma and reduced asthma morbidity among rural children. Rural school-aged children who had regular contact with farm animals were less likely than other rural children to develop allergic asthma and allergy (Riedler, Eder, Oberfeld, & Schreuer, 2000). In a later study levels of endotoxin in the child's mattress were inversely related to the risk of allergic sensitization among 812 rural children (Braun-Fahrlander et al., 2002). The age of exposure to endotoxin is important. Exposure in the first year of life was associated with a greater protective effect than exposure in the school age years (Riedler et al., 2001).

#### *Human Factors in the Home*

Consideration of human factors in the home entails a complex set of issues. This section of the literature review focuses only on aspects deemed most relevant to the proposed study. Children depend upon their parents for many things. Children with asthma have additional needs that place added demands on the family (Annett, Bender,

DuHamel, & Lapidus, 2003). A child's experience of asthma is shaped by the way the family and the primary caregiver respond to a worsening illness pattern (Bender et al., 2000; Meijer, Griffioen, van Nierop, & Oppenheimer, 1995; Sawyer, Spurrier, Kennedy, & Martin, 2001). It is also reasonable to expect that families are significantly impacted by the child's disease. This section of the literature review will include (a) qualitative studies and the experiences of family members who cared for children with asthma, (b) the transfer of responsibility for asthma care from parent to child among children of school age, (c) adherence and appropriateness of care, (d) rural families with children who have asthma, and (e) caregiver quality of life.

#### *Experience of Family Members Caring for a School-Aged Child With Asthma*

In a grounded theory study Horner (1998) described the experiences of 12 families with a school-age child who had asthma. Through three in-depth interviews with each family Horner (1998) investigated how families incorporated asthma care into their daily routines. Families described a process of "catching the asthma" before serious problems developed. Horner (1998b) also identified major tasks associated with caring for a child with asthma, including "learning the ropes", "dealing with asthma", and "coming to terms with asthma" (p. 361).

In a study involving 101 parents of children previously hospitalized for asthma the relationship between parental perception of children's vulnerability and various behaviors associated with parental management of disease was examined (Spurrier et al., 2000). Spurrier et al. found that parental belief that the child was vulnerable (rather than asthma severity) predicted likelihood that the child would be kept home from school, would be taken to their primary care provider for acute asthma episodes, and would be

given a daily controller medication for asthma. This association remained after controlling for asthma severity over the preceding 12 months. In contrast, hospital visits were more strongly associated with asthma severity than with parental belief in the child's vulnerability.

In another study anxiety, fears, and behavioral problems were compared among children with asthma, children with congenital heart disease, and children without chronic disease (Gupta, Mitchell, Giuffre, & Crawford, 2001). Increased maternal fear in both disease groups correlated with increased child anxiety, medical fears, and behavior problems. In an interpretive phenomenological study, parental fear, embarrassment, and helplessness were dominant aspects of the experience of hospitalization of children with asthma exacerbations and for those at home with severe, poorly controlled asthma (Koenig, Chesla, & Kennedy, 2003).

While most studies of asthma have focused on the negative consequences of disease, one study surveyed positive aspects of having a child with a chronic disease. A group of 190 mothers each with a child experiencing a chronic illness (sickle cell disease, cystic fibrosis, diabetes mellitus, and asthma) were interviewed to determine if there were positive aspects to their experiences (Chernoff, List, DeVet, & Ireys, 2001). Of the sample, 98% identified at least one of three positive aspects (a) feeling better about themselves after learning to manage their child's health problem, (b) seeing their family as stronger having pulled together for the child, and (c) seeing other benefits that came to the family because of the illness. The authors advocated asking families about positive aspects of the child having asthma as a means of encouraging families as they face challenges.

In another study investigators used semi-structured qualitative interviews with 18 parents of children with diverse asthma severity, racial identity, and socioeconomic backgrounds. The study was designed to describe caregivers' experience of caring for children with asthma. Researchers identified 8 themes related to asthma management: "I know my child," "trial and error," "partnership," "need for education," "negotiating responsibility," "hassles with medication administration," "preferences," and "the benefits outweigh the risks of side effects" (Peterson-Sweeney, McMullen, Yoos, & Kitzman, 2003).

#### *Dependent Care and Transfer of Responsibility for Self Care to Children*

An important study has examined parental behaviors involved in the management of children who had asthma (Chiang et al., 2003). Construct validity was reported to be established for 21 separate behaviors deemed important in the experience of 16 parents. Subsequently these constructs were examined among 133 parents. The researchers concluded that parental self-efficacy, perceived effectiveness, and child's cooperation accounted for about 50% of the variance in self-management behaviors. The researchers posited that the findings from these validation studies should inform educational efforts aimed at improving parental skills. A striking aspect of the study is the apparent complexity of parental behaviors related to participating in children's asthma care. This was the only study I found in which the construct validity of self-management was examined.

Assumption and sharing of responsibility for a child's asthma in the home setting is a complex problem. In a study of 14 families, Buford (2004) found that transfer of responsibility between parents and children occurred "unevenly" with some identifiable

patterns and cues of readiness. Englund et al. (2001) reported characteristic differences between fathers and mothers in the transfer of responsibility in children's asthma care. Englund et al. used a phenomenological-hermeneutic method to describe what it meant to be a parent of a child with asthma. Unstructured interviews of 12 fathers and 12 mothers of Swedish children revealed conflicting intentions and feeling about children's asthma. Fathers were more inclined to want to liberate children and accept their illness, while mothers tended toward protection and felt sad about their child living with asthma. The authors suggested that the two views coexisted in a dialectic that brought both balance and contradiction into the experience of asthma for children (2001). The experience of asthma care for many children might be further complicated by the presence of multiple caregivers. Among 789 children aged 6 to 9 more than one-third of children received asthma care from four or more caregivers (Wade, Islam, Holden, Kruszon-Moran, & Mitchell, 1999).

#### *Adherence & Appropriateness of Care*

A major factor in the control of childhood asthma is adequate use of inhaled corticosteroids and other anti-inflammatory medications (NHLBI, 2002). Whereas, daily use of controller medications is necessary for optimal management, adherence has been shown to vary widely (Zuckerman, Stuart, Magder, Bollinger, & Weiss, 2000). Non-adherence was found to be a common and serious problem in the care of children with asthma (McQuaid et al., 2003). Parental misunderstanding of the role of anti-inflammatory medications (controllers) was a strong predictor of non-adherence among 571 children with asthma (Farber et al., 2003).

Inadequate dosing of inhaled corticosteroids among children was associated with parental fear of medication side-effects (Chan & DeBruyne, 2000). However, adherence to non-steroidal, orally administered asthma control medications has also been found to be very low (Sherman, Patel, Hutson, Chesrown, & Hendeles, 2001). In a case control study, parents who did not pick up adequate amounts of prescribed inhaled corticosteroids from the pharmacy were less likely to perceive the medication as effective, less likely to have an evening routine for medication administration in the home, and were reluctant to administer the medication according to the plan. Children of cases experienced more night-time asthma symptoms, exercise symptoms, and school absence than children of controls (Irvine, Crombie, Alder, Neville, & Clark, 2002).

Numerous interventions have been proposed to address the problem of non-adherence with limited success (Bender et al., 2003). In a qualitative study researchers found that children reported benefit from parental reminders and rewards for remembering to take medications (Penza-Clyve, Mansell, & McQuaid, 2004). Written treatment plans have been recommended in expert clinical guidelines as means of improving adherence (NHLBI, 1997). However, evidence supporting the effectiveness of written plans is inconclusive (Toelle & Ram, 2003). Focus groups with 28 school-age children and their parents found that preventive plans were not implemented (Meng & McConnell, 2002). Difficulties establishing daily medication routines at home and school barriers favored non-adherence. In addition, most medications administered at home were given in response to asthma symptoms rather than in adherence to a preventive plan of care. Meng and McConnell found that many parents did not believe treatment plans were appropriate or realistic. Low parental expectations for asthma control were associated

with poor adherence to treatment plans (Kuehni & Frey, 2002). Caregiver expectations predicted asthma outcomes, leading researchers to develop an instrument to measure parental expectations of asthma outcomes (Holden, Wade, Mitchell, Ewart, & Islam, 1998). Increased strain on family functioning among children with severe chronic asthma was associated with decreased adherence (Gavin et al., 1999).

#### *Rural Families of Children Who Have Asthma*

Rural families face particular barriers in efforts to care for their children, including inadequate access to specialists, lack of care at school, inadequate insurance or money for obtaining medications, and manual labor demands on family members (Barrett, Gallien, Dunkin, & Ryan, 2001). Rural families were found to enact asthma management behaviors, yet lacked basic resources for care. Their children had inadequate numbers of encounters with clinicians (Horner & Fouladi, 2003). Some rural families also lacked adequate educational support for managing their children's asthma (Resto et al., 2001).

#### *Quality of Life of Children with Asthma*

Preliminary development of quality of life (QOL) instruments for childhood asthma aimed to probe the impact of the disease on children's lives (Christie, French, Sowden, & West, 1993). Numerous disease-specific (Bender, 1996; Juniper, 1997) and general (Eiser, Vance, & Seamark, 2000) QOL instruments were developed and used in clinical research, including specific ones for parents to assess the QOL of children who have asthma (Juniper et al., 1996). Whereas QOL has been widely used as a construct and outcome measure in clinical research (Georgiou et al., 2003), many problems have been identified in relation to parental assessment of children's asthma (Annett, 2001; Bender,

1996; Cane, Pao, & McKenzie, 2001). It is unclear what construct QOL instruments actually measure.

Researchers found that parental QOL measures showed little association with objective measures of asthma status (Price, Bratton, & Klinnert, 2002). These investigators also found that caregiver negative affect predicted QOL scores, whereas health care utilization patterns did not. Annette et al. (2003) found that parental rating of QOL was more highly correlated with the perceived family burden of disease compared to asthma symptom score, sociodemographic characteristics, and child psychosocial adjustment. General lack of correlation between QOL and disease severity measures led to the development of a specific survey of caregivers that aimed to appraise factors associated with asthma severity (Asmussen, Olson, Grant, Fagan, & Weiss, 1999).

Another serious problem related to the use of QOL measures are differences between parental and child reports. In one study agreement between parent and child assessment of QOL varied widely and increased with the age of the child (Annett et al., 2003). Guyatt et al. (1997) investigated the relationship between QOL measures, age of the child, and clinical indicators of disease. Parent's ratings of QOL were found to correlate with clinical measures of airway state for children younger than 11 years. However, after age 11 children's QOL ratings correlated with clinical measures while parental ratings did not add to the level of agreement. Guyatt et al. concluded that by age 11 the clinical history could be derived from the child's report alone. Prior to age 11 parental report is likely to add to the clinician's assessment of disease in the child (Guyatt et al.). Comparison of parental and child reports by another researcher using a different QOL instrument found that parental reports were more reliable longitudinally in

association to children's functional status (le Coq, Boeke, Bezemer, Colland, & van Eijk, 2000). The empirical validity of parental assessments of QOL for children with asthma remains unclear at this point.

#### A Bracket on the School and Children's Experience of Asthma

##### *Physical Attributes of the School*

Numerous scholars have established the importance of inhalant exposures in the school setting in the childhood asthma. A 9-fold increase in the risk of having an asthma exacerbation after the start of the school year was found among cat-allergic children who were placed in classrooms with many children from homes with cats (Almqvist et al., 2001). Allergic children placed in classrooms with few cat owners fared much better. Classrooms with carpet or area rugs contained higher levels of antigen for cat, dog, and dust mites than rooms with bare floors (Amr et al., 2003). However, in another study dust mite antigen levels in school carpet were low and did not correlate with peak flow variability (Voute, Zock, Brunekreef, & de Jongste, 1994). An association between high levels of dust mites in children's mattresses at home and increased peak flow variability, suggested that home exposure to dust mite was the environment source of significant airway problems for this antigen.

Studies of the association between mold in school and the development of asthma in school-age children have failed to show a linkage (Immonen, Meklin, Taskinen, Nevalainen, & Korppi, 2001). However, mold exposure at school was found to be associated with increased risk of viral respiratory infections and asthma exacerbations (Taskinen et al., 1999). Rhinovirus was the most common of several respiratory viruses that were found to be associated with 80-85% of asthma exacerbations in school children

ages 9 to 11 years (Johnston et al., 1995). In a related study Johnson et al. (1996) demonstrated that the majority of viral infections and hospital admissions for asthma among children occurred during periods of school attendance.

### *Human Factors in the School Setting*

Asthma is a pressing issue for public schools. Asthma was identified as the top priority among 292 school nurses in Missouri who ranked 11 health information needs (Bachman, Brennan, Patrick, & Cole, 2000). It is likely that rural schools have fewer resources to care for children with asthma. A state-wide survey of schools in Maryland found rural schools to be less prepared than urban schools to manage the health needs of children with asthma. “We found that rural nurses used peak flow meters less often to assess and monitor asthma, requested fewer referrals for asthma, had fewer interactions with health room assistants, and had reduced access to asthma educational resources” (Huss et al., 2001, p. 325). Lack of appropriate school nurse practices related to student’s asthma is likely related to inadequate training. Missouri school nurses who attended continuing education programs designed to increase their knowledge and skills for the care of children with asthma later reported a significantly higher level of self-perceived competence (Bullock, Libbus, Lewis, & Gayer, 2002).

A survey of 550 school nurses identified three commonly cited problematic aspects of practice (a) delegation of responsibility for administering medications, (b) communications to build partnership with parents, and (c) lack of school policies supportive of asthma care at school (Calabrese, 1999). Among the other pressing issues evident in the literature related to human factors at school were (a) screening for undiagnosed asthma at school, (b) self-management education for children, and (c)

teacher and school staff readiness to provide care for children (Fillmore, Jones, & Blankson, 1997). These three topics are considered below.

### *Asthma Screening at School*

Asthma has been identified among children in the school setting through a number of different screening approaches. These efforts are important to the problem of disabling asthma among school children because early detection of asthma morbidity can lead to reduced disability (Clark et al., 2002). However, school-based asthma screening has been the subject of debate and controversy (Yawn, Wollan, Scanlon, & Kurland, 2002). Two issues have been divisive – how to screen and if screening is justified at all. Among methods tested for screening for asthma at school were (a) questionnaires (Redline, Larkin, Kerckmar, Berger, & Siminoff, 2003), (b) spirometry (Abramson, Wollan, Kurland, & Yawn, 2003), (c) exercise challenge (Feinstein et al., 1999), (d) and multi-step procedures combining methods (Gerald et al., 2002).

Screening by questionnaire emerged as a gold standard for school asthma screening (Demissie, White, Joseph, & Ernst, 1998). However, researchers have found that selection of the screening questionnaire is critical (Gruchalla et al., 2003; Redline et al., 2003). Controversy surrounding school-based screening arose with evidence that some screening efforts did not lead to the desired results of increased diagnosis of the disease, follow-up with more appropriate care by clinicians (Yawn et al., 2002), or a reduction in morbidity among school children with asthma (Hill, Williams, Britton, & Tattersfield, 1991). However, a more recent study focusing on identification of under-treated asthma involving 489 children demonstrated a significant increase in clinical visits and appropriate changes in medication (Yawn, Wollan, Scanlon, & Kurland, 2003).

Yawn et al. (2003) reversed their doubtful position on the value of screening, concluding that the approach was in fact more effective than an alternative intervention involving distribution and promotion of expert asthma guidelines to clinicians.

#### *Asthma Self-Management Education for Children*

School has been viewed as an ideal setting for asthma self-management education due to the availability of children for long hours in a setting with educators and computers (Guevara, 2003). Evidence also suggests that schools stand to gain from sponsoring self-management education programs due to reduced student absences, enhanced student participation, and increased school revenue (Krishna et al., 2003; Wolf et al., 2003). In addition to expected increases in knowledge and skills related to asthma, low-income and minority children who participated with their parents in an asthma educational program subsequently scored higher than controls in math, reading, and science as well (Clark, 1984). A number of different educational approaches for school have been developed, tested, and shown to be efficacious for improving selected outcomes. These will be briefly reviewed because of implications for reducing asthma disability among school-age children.

Open Airways for Schools (OAS) was developed and tested nearly 20 years ago (Indinnimeo et al., 1987b). The course involved several small group sessions for elementary school children and their parents. Barriers to the widespread use of OAS included the high demands on the time of a school nurse or other professional and the difficulty of scheduling a time when parents could also attend the sessions. Efforts to address these problems were apparent in the literature. The course was later shown to improve children's self-management skills when taught by college students rather than

professionals (Bruzzese, Markman, Appel, & Webber, 2001b). Evans (2001) evaluated use of sending asthma worksheets home for parents to complete in lieu of requiring parents to be present for the sessions. Parental completion of OAS homework was associated with significant improvement in parental management skills (Bruzzese et al.).

Whereas most educational interventions for asthma involved content specific to asthma, at least one program has focused on general aspects of chronic disease management. In a randomized trial researchers evaluated the effectiveness of chronic disease self-management training among school children with asthma (Tieffenberg, Wood, Alonso, Tossutti, & Vicente, 2000). Tieffenberg et al. employed weekly group programs with children and families that included games and activities designed to develop child autonomy and leadership skills. Improved outcomes included reduced school absences, decreased asthma attacks, and increased asthma knowledge. However, emergency room visits were not reduced.

Another course developed for Hispanic students focused on both knowledge and skill development. After students completed the course significant improvements were found in asthma knowledge and skill in the use of a peak flow meter and metered dose inhaler (Christiansen, 1997). In addition over the subsequent months, students in the treatment group demonstrated significantly greater reduction in asthma symptoms than controls. Other scholars have developed and tested computer-based, multimedia programs design for school-based asthma self-management educations. Use in the school setting has been associated with greater knowledge gain than among students using traditional classroom approaches (Yawn, 2000). Student participation in multimedia self-

management education was also associated with improvement in child asthma QOL scores (Young, 2001).

### *School Staff Readiness*

Results of a study of 212 rural elementary school teachers demonstrated favorable attitudes among teachers towards student with asthma, but a low level of asthma knowledge (Rodehorst, 2003). These findings were consistent those of several other researchers who found that teachers were supportive of students with asthma, but lacked adequate knowledge about the condition (French, 1997; Neuharth-Pritchett, 2001; Weschsler, 1975). Results from two studies demonstrated student benefit from educational efforts targeting teachers. One intervention involved one teacher from each of 48 schools attending a seminar about asthma (Hazell, 1995). Compared to schools that did not send a teacher representative, participating schools were more likely to enact appropriate medication policies as a result of the teacher's influence after attending the seminar. Carruthers (1985) found that increased teacher knowledge of asthma was associated with improved ability to help students with asthma lead normal lives and reduce risks during acute attacks. These data suggest that modifiable, school-associated human barriers to asthma care have bearing on the students' experience of asthma.

### A Bracket on the Community and Children's Experience of Asthma

#### *Physical Attributes of the Community*

“Social science theories of health and place posit that individuals perceive a relationship between characteristics of the geographic location in which they reside and their health, well-being, and self-identity” (Wind, Van Sickle, & Wright, 2004). Wind, et al. suggested that this is particularly true for rural communities undergoing rapid

development. Rural communities sometimes manifest particular environmental risk factors for asthma including chemicals and pesticides, agricultural dust, inhalant by-products of industries, high concentration of crop pollen, and mold (Wind et al., 2004). However, protective factors have also been recognized in rural communities with the association of increased endotoxin exposure and reduced risk for the development of asthma among children (Braun-Fahrlander et al., 2002).

Health risk for children with asthma has been associated with the geographical placement and demographics of communities. A large amount of evidence links asthma to the air quality and environmental health of particular communities (Linn et al., 1996; Peters et al., 1999). Residential wood burning was associated with a high level of small particles in many metropolitan neighborhoods in Seattle. Among 326 elementary students the rising concentration of ambient small particles was associated with proportionate decline in lung function (Koenig et al., 1993). Proximity to various industrial enterprises has been linked to worsening asthma among children living in the vicinity (Ginns & Gatrell, 1996). The quality of housing in communities has also been linked to childhood asthma morbidity (Saegert et al., 2003).

#### *Human Factors in the Community*

Data suggest that several aspects of the human community impact childhood asthma and contribute to disability. Adverse effects have been reported where asthma knowledge was lacking and when attitudes toward children with asthma were negative. Researchers described a community where the population had a very low level of awareness of asthma, held a number of erroneous beliefs about asthma, and exhibited non-supportive behaviors toward children with asthma (Hazir, Das, Piracha, Waheed, &

Azam, 2002). For children, increased asthma risks have been associated with rural residence (Yawn et al., 2001). Investigators found the rate of undiagnosed, frequent wheezing among school children to be higher among those with rural residence (Yeatts, Davis, Sotir, Herget, & Shy, 2001). Parents of children with asthma living in rural communities were far more likely than urban parents to report fear that their child would die of asthma and that they had little knowledge about the disease (Green, Greenblatt, Plit, Jones, & Adam, 2001). These data suggest that some rural residence is associated with unique risk factors related to childhood asthma.

Scholars contend that reduction of the burden of childhood asthma requires coordinated, community-wide efforts (Clark et al., 1999; Lara et al., 2002; Nies, Bickes, Schim, & Johnson, 2002). People have demonstrated the ability to provide community-based services that had positive effects on children's asthma. A community health center was effective in reducing asthma symptoms and improving self-care practices among children in a multiracial, working class neighborhood (Garrett et al., 1994). Community health workers were effective in providing education and in helping families lower reduce the level of allergic antigens in the home (Takaro, Krieger, & Song, 2004). In an inner-city setting community health workers were recruited to identify and combat underutilization of inhaled steroids among families of children with asthma (Butz et al., 1994). Collaboration among community agencies and non-profit groups favorably impacted the health status of children with asthma by promoting community-wide asthma education and increasing access to health plan benefits (Rolnick, Flores, O'Fallon, & Vanderburg, 2000). Partnerships with health care providers and communities groups was effective in reducing childhood asthma morbidity (Richman, Scott, & Kornberg, 1998).

## A Bracket on Clinical Settings and Children's Experience of Asthma

### *Physical Attributes of the Clinical Setting*

Consideration of physical attributes related to clinical settings differs from preceding analyses of home, school, and community. All other physical settings discussed up to this point primarily affect asthma through the influence of airborne inhalants or other factors associated with airway inflammation. However, in the context of this study, physical attributes in clinical settings pertain to the availability, correct use, and allocation of material resources that are essential in the care of children with asthma. A brief discussion of these resources is warranted because children's experience of disability due to asthma might be related to these factors. Clinical settings are the primary source for objects that children need for asthma self-care, such as peak flow meters, spacers, nebulizers, diaries, and educational materials (NHLBI, 1997). Use of these items will be considered along with behavioral requisites in a discussion of expert asthma guidelines later in this chapter.

In addition to materials supplied to the child in the clinical setting, a number of other resources should be part of the physical environment and services of the clinic. These materials facilitate asthma care and support appropriate decision-making by clinicians (NHLBI, 1997). Best practice guidelines have been published and widely distributed by the American Academy of Allergy, Asthma, and Immunology (AAAAI) in association with the American Academy of Pediatrics, the National Asthma Education and Prevention Program, and the NHLBI to improve clinical care of children with asthma. An discussion of key elements of asthma best practices is relevant to children's

experience of disabling asthma because lack of children's familiarity with these resources might be associated with substandard clinic care and worsening disease (AAAAI, 1999).

A spirometer makes possible detailed analysis of air flow, enabling more precise evaluation of the degree of airflow obstruction (AAAAI, 1999). Availability of this device increases likelihood of diagnosis and improves the treatment of asthma, particularly among the large number of children who do not otherwise provide a compelling history of breathing difficulty or associated asthma symptoms. Disability might be more common among children for whom health care providers do not perform spirometry (Joseph-Bowen et al., 2004).

An inspiratory flow meter is a device designed to evaluate and improve children's ability to inhale medications. Use of this device is associated with improved inhalation technique, greater lung deposition of drug, and reduced asthma morbidity (Amirav, Newhouse, & Mansour, 2005). Other key resources include: (a) instructional materials for families and children in written and multimedia format suitable for a range of reading levels, languages, age groups, and cultural backgrounds; (b) equipment, supplies, and medications to manage asthma exacerbations, including a pulse oximeter, a nebulizer, an oxygen source, and rescue medications; and (c) forms to guide review of the illness course and development of an asthma action plan (NHLBI, 1997). Readiness to provide appropriate care for children with asthma is largely dependent on the physical availability of such resources in the clinical setting (AAAAI, 1999).

#### *Human Factors in the Clinical Setting*

Many human variables in the clinical setting impact the delivery and effectiveness of asthma care for children. Health care provider behaviors contribute to sub-optimal

outcomes (Wissow et al., 1998). Non-adherence by caregivers was related to excess use of emergency services for children with asthma (Bauman et al., 2002). However, scholars have also documented the failure of health care providers to implement expert asthma guidelines, despite the weight of evidence behind these recommendations (Riekert et al., 2003). High rates of utilization of emergency services for asthma have been found to be related to the severity of the attack rather than barriers to accessing primary care (Lara et al., 2003). Lara et al. suggested their findings point to a pattern of under-treatment or inadequate preparation for self-care, rather than over-dependence on emergency services as had been widely postulated.

In a qualitative study of parents of children with asthma, a number of provider-related barriers to care were identified. “The study indicated problems in doctor-patient communication: differences in the conceptual vocabulary; the doctor's reluctance to consider the patient's story and rely instead on auscultation; as well as unexpected odd differential diagnoses. All contributed to the disturbed mutual understanding” (Ostergaard, 1998, p. 156). Parents and children had views about asthma care received and when asked were willing to comment on the quality of health care services, offering criticism and suggestions for improving services (Dixon-Woods, Anwar, Young, & Brooke, 2002). Dixon-Woods et al. found that children and parents were concerned about their relationship and communication patterns with their health care provider. In a qualitative study, Goeman et al. (2002) found that parents were burdened by substantial financial, social, and interpersonal asthma costs that they did not feel were addressed by health care providers. Semi-structured interviews with 20 participants, including parents of children with asthma and adult patients, revealed a wide range of opinion about the

types of services that would meet their needs. However, parents and children agreed on critical aspects of care. “These factors were encompassed by four themes: the accessibility of care, severity of asthma and dealing with uncertainty, self-knowledge and self-management, and expert knowledge and therapeutic relationships” (Paterson & Britten, 2000, p. 301).

Other evidence suggests that clinical settings in general are not prepared adequately to deliver culturally sensitive care, despite the availability of reliable and valid tools to accommodate differences in language and culture (Lara et al., 2000). Evidence of asthma disparities along ethnic lines (Lieu et al., 2002b) raises concern that cultural barriers exist that impair communication. These barriers might block the development of appropriate partnerships between health care providers, children, and their families, that are recommended by expert guidelines (NHLBI, 1997). Lieu et al. used the American Academy of Pediatrics’ Children’s Health Survey for Asthma (Asmussen et al., 1999) to examine variables related to asthma status among 1658 children. A critical finding in that study was the strong association between lower use of inhaled anti-inflammatory medications and worse asthma status among Black and Latino children compared to White children. On a wide range of other process of care variables ratings for minority children were equal to or better than ratings for White children.

Lieu et al. (2002) identified that health-care provider prescribing patterns for asthma control medications compared to quick reliever medications was a critical factor. Adherence to expert clinical guidelines entails use of controller medications for most children with asthma (NHLBI, 2002). Whereas, the national trend for prescription of controllers demonstrated an 8-fold increase from 1978 to 2002, overall rates for quick

reliever medications remain about equal to that controller medications (Stafford, Ma, Finkelstein, Haver, & Cockburn, 2003). These data and numerous other studies suggest that inadequate prescription of anti-inflammatory medications by health care providers is a widespread problem associated with excess asthma morbidity and disability among children (Courtney, McCarter, & Pollart, 2005; Kozyrskyj, Mustard, & Simons, 2001; Suissa, Ernst, & Kezouh, 2002).

Asthma education has been shown to change health-care provider behavior and improve several aspects of care. Clark et al. (1998) evaluated the effects of interactive seminars designed to improve asthma outcomes among children with asthma under the care of 74 pediatricians. Compared to controls, participating pediatricians demonstrated improved communication practices, more appropriate prescribing patterns, and greater efficiency in use of clinician time. Children who received care from participating pediatricians were more likely to use controller medications and had fewer asthma symptoms, emergency room visits, and hospital admissions (Clark et al., 1998).

Numerous interventions that focused on improving health care providers' knowledge and practices have proven effective in reducing the burden of childhood asthma. Practices that support early intervention at home to stop asthma exacerbations reduced emergency room use and hospitalization among children with asthma (Lieu et al., 1997). Successful efforts to improve children's asthma care and outcomes have been analyzed and characterized as containing key elements, including: (a) emphasis on adequate inhaled steroid use, (b) regular follow-up care, (c) attention to triggers, (d) use of oral steroids at home to stop asthma exacerbations, (e) use of spacer devices and

training to improve lung deposition of inhaled medications, (f) home peak flow monitoring, and (g) written care plans (O'Brien, 1997).

#### A Bracket on the Literature Pertaining to the Experience of Interest

Most of the published literature about the experience of children with asthma has been derived indirectly from studies in which parents were interviewed. Some investigators used psychometric instruments and quantitative approaches to examine associations between various constructs and clinical variables (Wamboldt, O'Connor, Wamboldt, Gavin, & Klinnert, 2000). However, a few researchers have used qualitative approaches to directly examine aspects of children's experience of asthma (Chadwick, 1996; Dixon-Woods et al., 2002; Ireland, 1997b; Pradel et al., 2001; Rydstrom, Englund, & Sandman, 1999; Wilkerson, 2002; Yoos & McMullen, 1996). These studies are presented first followed by an overview of pertinent findings from studies that examined only selected aspects or specific constructs related to children's experience of asthma.

#### *Review of Research Focused Upon Children's General Experience of Asthma*

Yoos and McMullen (1996) interviewed 28 children ages 6 to 18 years to elicit their stories of having asthma. The study was part of a larger study to understand how children perceive asthma symptoms. The descriptive study involved open-ended, semi-structured interviews with suburban and under-served urban children with moderate or severe persistent asthma. A convenience sample included 18 non-white children, 16 of whom were school-aged and 12 were adolescents. Most children were from impoverished families. In most cases interviews were conducted in each child's home and were audio-taped. Transcriptions were reviewed to identify emerging themes without a pre-existing schema for the data. Two investigators experienced in the care of children with asthma

and one chronic disease expert who was familiar with diabetes in children coded the text. There was a high degree of reported agreement between the three investigators (greater than 90%). The authors concluded that the themes children talked about in their narratives were easily agreed upon. These data demonstrated that school-aged children had clear ideas about their experience of asthma and were able to convey these to adults in a manner readily understandable by multiple observers (Yoos & McMullen, 1996).

Interviews began with the “grand tour question”: “Tell me about asthma, both the good things and the bad things” (Yoos & McMullen, 1996, p. 286). Focused questions were then used to explore the impact of asthma on children’s lives, things that bothered them about having asthma, and worries related to asthma. The authors identified five dominant themes in children’s narratives (a) “I can’t”, (b) “restrictions”, (c) “symptoms and treatments”, (d) “death”, and (e) “adaptation” (Yoos & McMullen, p. 289). In addition to open interviews, the authors used a visual analog scale to rate two aspects of children’s experience related to the amount of worry and the degree to which children felt different from others because of asthma.

The authors’ conclusions included a number of points relevant to this study. Children’s experience of asthma did not reflect the optimistic expectation of disease control reflected by national guidelines and health care professionals. A larger than expected burden of disease was apparent both in the illness themes and the analog scale for worry and perceived impact. Additionally, urban African-American children reported higher levels of worry and adverse impact, as well as more prevalent narrative themes related to death. The authors urged clinicians to consider children’s perceptions of asthma and their priorities in the routine course of care. Finally, the authors identified the need to

modify future studies to give children a chance to “clarify, critique, and challenge” (Yoos & McMullen, 1996, p. 290) investigators’ interpretations of their illness narratives.

In another study semi-structured interviews were employed with 20 families, including children and teens, in an evaluation of the views of users of pediatric asthma services (Dixon-Woods et al., 2002). Analysis using the constant comparative method, Dixon-Woods et al. demonstrated that children were fully capable of communicating their opinions and views about clinical services. They concluded:

Children and young people identified outcomes of care, quality of care, communication and the professional-patient relationship, and organization and access to healthcare as the key dimensions of their experiences of health services.

They were active and critical, judging the performance and delivery of health services against standards which drew on lay knowledge and experience. p. 503

The authors noted that younger children sometimes provided very brief answers, cautioning that semi-structured interviews with children less than 10 years of age could be challenging. However as the interviews proceeded most children became more relaxed and gave insightful answers.

Children remarked that asthma was a source of adverse social and psychological consequences for them. They also acknowledged that sometimes asthma afforded them more attention and privileges. However, their primary concern was keeping asthma under control so they could enjoy a normal life. Avoidance of triggers and proper use of their medications were two strategies often cited for controlling asthma (Dixon-Woods, 2002). Children in the study spoke of a number of things that they valued. They particularly appreciated having a professional pay careful attention to their asthma.

Children evaluated the competency of those who cared for them and interpreted attention to detail as an indication that the health-care provider knew what they were doing.

Another component of quality of care identified by children was sensitivity to their feelings and communication skills. Children often commented that clinicians directed questions towards their parents and ignored them. Some children felt intimidated and left out by this communication style. They felt valued when the discussion included their opinions and personal reports of symptoms and treatments (Dixon-Woods et al.).

Ireland (1997) interviewed 10 school-aged children ages 9 to 12 in a study using a grounded theory methodology to explore children's belief, attitudes, and perceptions. Analysis utilizing the constant comparative technique revealed the core variable to be the "normal for me" (p. 1062). The author suggested that the desire to establish normality sometimes led to compromise and sub-optimal control of asthma. Three other important categories described children's perceptions of asthma: (a) "discontinuity", (b) "paying attention", and (c) "leaving asthma behind" (p. 1062). Discontinuity was the experience of recognizing something is wrong as asthma disrupts daily activities. Paying attention had to do with self-monitoring changes in breathing in response to treatments. Leaving asthma behind was described as choosing to go on with one's life knowing that you can't be normal while you're stopping to deal with asthma.

Ireland (1997) concluded that children gradually become more internal in their locus of control as they learned to distinguish between environmental factors beyond their control and aspects of asthma self-care over which they were able to take control. Unfortunately, it is not clear whether the locus of control construct was validated by data that arose directly from the study or if it was a lens through which the data were viewed

and interpreted. Ireland (1997) stated in the introduction to her work that, in accordance with grounded theory tradition, a literature review was not undertaken prior to the work. No effort was made to bracket pre-existing constructs such as locus of control.

Ireland (1997) recognized that tension between deciding to pay attention to asthma and choosing to leave asthma behind had to do with empowerment issues. Children who were permitted to exercise responsibility over their asthma were more inclined to pay attention and take appropriate action. In contrast, children who had few opportunities to change their disease experience, as in the case of those attending schools with restrictive policies hampering access to asthma medications, were more likely to choose to leave the asthma behind, ignoring warning signs and failing to take action.

A final important aspect of Ireland's (1997) research has an important bearing on this study. Ireland noted at the outset that the intent of grounded theory as a qualitative research method was to produce a model or theory about the experience (children's perception of asthma). However, her conclusions suggested that descriptive, qualitative method is more appropriate at this stage of research into children's experience of asthma. "It is hoped that the key themes will assist in understanding children's experience of having asthma. This research provides a description of the children's reality rather than an integrated theory" (Ireland, 1997, p. 1064).

Further support for a descriptive qualitative approach to the study of children's experience of asthma was echoed by the findings of Rydstrom, Englund, and Sandman (1999). They used a phenomenologic-hermeneutic method to describe what it is like being a child with asthma. "The aim of this method is to uncover the meaning of lived experiences through interpretation" (Rydstrom et al., p. 590). Fourteen children between

the ages of 6 and 16 years of age with moderate or severe asthma and normal cognitive development were interviewed. All but one child chose to be interviewed without the parent present in a media room where an audio recording took place. Rydstrom et al. concluded that Hermeneutic phenomenology was not a good fit for the data obtained.

To describe and interpret the children's complex situation is difficult though, as words can never entirely render the nuances of reality. In the interviews, the children spoke about their experiences with such insight and interest that their narratives moved us most deeply. We have tried to put these experiences within brackets to make sure we do not over-interpret our material (p. 594).

The authors used the children's own words to report “meaning units” (p. 594). They implied that interpretation was neither necessary nor appropriate. These findings suggested that a descriptive approach is more appropriate for investigating what it is like for children to have asthma.

Rydstrom et al. (1999) concluded that the experience was largely described by children's efforts to live normal lives. They identified children's behaviors that posed health risks when they tried to be like others. The authors identified two sub themes that seem to exist in opposition to one another: “feeling that they participate in everyday life” and “feeling like outsiders in everyday life.” (p. 593). Conflicting emotions about having asthma were identified as abstractions such as “feeling confident in other people's wish to help” and “feeling guilty” (p. 594) about how their asthma affected others.

Pradel, Hartzema, and Bush (2001) interviewed 32 children, including a group of younger children (age 7) and a group of older children (age 12). The investigators examined age-related differences in the experience of asthma and its management. Two

home visits were used to collect data using two distinct procedures. During one visit children were asked to draw a picture of the last time they were sick. During the second interview children were shown a figure of a point on a horizontal line, were told that the point was the last asthma attack they had, and then were asked to describe their symptoms before and after that point and their actions to each symptom.

Pradel et al. (2001) reported differences between younger and older children. Older children tended to provide a comprehensive list of environmental causes for their attacks, while younger children were more likely to offer no explanation. Younger children identified medications using physical terms that described the appearance of their medications; older children were more likely to use biomedical terms to describe their medications. Younger children responded to breathing difficulty by telling their mothers, by resting, and by just not knowing what to do. Older children reported using relaxation and breathing techniques and taking medications to manage their attacks (Pradel et al.).

Pradel et al. (2001) found that younger and older children shared many things in common. Physical exertion was reported most often as the cause of an asthma attack. The most common symptom mentioned with an asthma attack was difficulty breathing rather than coughing, wheezing, or shortness of breath. Most children had experienced seeking urgent health care services during an asthma attack. Both age groups mentioned the benefit of quick relief medications during an attack. Younger and older children identified unwanted or unpleasant effects of their medication. Younger children were more likely to dislike the taste of their medication and the need to take medicines daily. Older children were more likely to mention unwanted side effects and lack of

effectiveness of medications (Pradel et al.). Wilkerson (2002), in a later commentary on this study, concluded that an important implication of the findings was that children needed re-education about asthma as they grew older since their concerns and experiences change.

In the last of six studies that bear directly on the proposed study, Chadwick (1996) conducted semi-structured interviews in a clinic to explore problems related to asthma at home and at school among 32 children. Eighteen of the children were in primary school. Many children (71.8%) cited having breathing problems at school as particularly troublesome. Most primary school children reported having trouble getting their medication when they needed it at school. All but one child held a negative view of asthma, although more than 80% thought their asthma was under control. Twenty-one children said smoke made their asthma worse, yet all but 3 of these children reported living in a household where someone smoked (Chadwick). These data provide insights into the experience of asthma among some school-age children.

*Review of Research Pertaining to Selected Aspects of Children's Experience of Asthma*

A large number of articles addressed limited aspects of children's experience of asthma. The following discussion will be limited to studies deemed most relevant to the proposed study. Inclusion of studies in this section was also based on the criterion that the research involved children directly or provided data that described what children experienced. Consistent with the intent to study children's intentions related to disabling asthma, this portion of the literature review is organized in three sections (a) children's knowledge and beliefs, (b) children's perceptions, and (c) children's behaviors.

Presentation of this material concludes a review of literature relating to what is known about children's experience of asthma.

*Children's Knowledge and Beliefs Related to Asthma*

Children with serious illness and a large amount of experience with the health care system have not necessarily had a more sophisticated understanding of what caused their asthma. In a study of 64 children ages 4 to 16, age and IQ were found to account for 59% of the variance in illness causality scores (Kury & Rodrigue, 1995). Serious medical experiences, as described by illness duration, frequency of hospitalization, and degree of life-threat, did not predict the level of understanding among these children. These data caution against the assumption that children who have had serious asthma problems for long periods of time are knowledgeable of the causes of asthma.

Children's explanatory models for asthma have been explored in an attempt to understand beliefs about asthma. Kieckhefer and Spitzer (1995) examined the relationship between the theoretical appropriateness of children's beliefs and their behavior during asthma flare-ups. The authors found relationships between appropriate beliefs and children's asthma knowledge, level of responsibility for asthma care, child's self-efficacy rating, and the frequency of specific self-care behaviors. Handelman, Rich, Bridgemohan, & Schneider (2004) interviewed inner-city children regarding their concepts about the cause of asthma and other factors related to their asthma home care. "Among children, contagion was the primary explanatory model for asthma etiology (53%). Twenty-five percent of children reported fear of dying from asthma" (Handelman et al.). These data suggest that children have unique conceptualizations about asthma that affect their intentions and actions.

### *Children's perceptions and asthma*

Ability to detect airway obstruction is not uniform among children (Fritz, McQuaid, Spirito, & Klein, 1996). Children who had experienced life-threatening asthma episodes demonstrated less sensitivity to airway resistance applied experimentally to simulate bronchoconstriction compared to normal children and children with asthma who had no history of life-threatening events (Davenport & Kifle, 2001). In another study 17 of 35 children with asthma subjected to airway resistance and bronchial provocation through a respiratory circuit did not perceive either airway obstruction or bronchodilation (Baker et al., 2000). During asthma exacerbations correct evaluation of symptom perceptions compared to peak flow measurements occurred in only one-third of children (Yoos, Kitzman, McMullen, & Sidora, 2003). Symptom reports have been found to show little correlation with objective measures of airflow (Couriel, Demis, & Olinsky, 1986).

Researchers have identified some children who are prone to a panic response. In two studies children feeling panic reported a higher level of symptoms and were treated with higher doses of inhaled corticosteroids independent of lung function measures (Baron et al., 1986; Boner et al., 1992). In a retrospective study researchers reviewed 23 cases of severe breathing episodes among children with asthma who did not demonstrate spirometric changes consistent with airway obstruction. Precipitating events were identified that led children to perception of a worsening of asthma. Children in the 10 to 12 age group predominated. Researchers postulated a panic response among these children (Park, Sawyer, & Glaun, 1996). In another study children with asthma who were falsely informed that their peak flow rate had fallen 30% below their actual rate reported significantly more dyspnea than normal peers who received equivalent false

reports (Rietveld, Kolk, & Prins, 1996). Rietveld and Prins (1998) found that negative emotions prior to exercise predisposed children with asthma to breathlessness.

Children's perceptions of their overall health status might not be based on their level of asthma symptoms. Kieckhefer (1988) found physical activity to be the most important criterion of good health among 71 children, ages 9 to 11, with chronic asthma. Feeling happiness and joy was the second most important criterion. Only 9% of children listed absence of asthma symptoms as the criterion of good health. These data suggest that views of health professionals and parents about good health for children with asthma might not be shared by children. Another study found that lower maximum aerobic power in children with asthma related more to self-perception than to asthma severity (Pianosi & Davis, 2004). Walsh and Ryan-Wenger (1992) found that among children with asthma not being good enough in sports and being left out of the group were important stressors related to self-concept. Children might not perceive the control of asthma as a health priority or experience intrinsic rewards for self-care behaviors.

Children with severe asthma likely experience high levels of stress and psychological distress. Among 134 children, girls with severe asthma were at higher risk for poor self concept (McNelis et al., 2000). In another study, asthma severity was correlated with physiological anxiety and medical fears. Less time since diagnosis was associated with more adverse effects on social interactions among children with asthma (Gupta et al., 2001). In a retrospective study of 12 child deaths due to asthma researchers found an association with depression and family problems.

For the analysis of the information concerning the 6 months before the attacks, the study patients had a greater frequency of respiratory failure requiring intubation, a

decrease in steroid use in the month before the attack, history of family disturbance, abnormal reaction to separation or loss, and expressed hopelessness and despair (Miller & Strunk, 1989, p. 1298).

### *Asthma and Sleep Disturbance*

School age children with asthma were found to be 7.8 times as likely to experience sleep disturbance (Yeatts & Shy, 2001). Among 351 children with mild to moderate asthma, up to one-third experienced sleep disruption during periods of relative stability (Strunk, Sternberg, Bacharier, & Szeffler, 2002). Nocturnal awakening in these children signaled a period of increased asthma symptoms and bronchodilator use in the days following the episode. Risk of awakening was associated with more severe disease and atopy, particularly among children sensitized and exposed to cat or dog dander. Sleep disturbance due to asthma and allergy had a significant effect on concentration and learning at school (Bender, 1999). Nocturnal awakening was related to school absence and parental work days missed, independent of other disease severity measures (Diette et al., 2000). Changes in asthma treatment were found to improve sleep and psychological function (Stores, Ellis, Wiggs, Crawford, & Thomson, 1998).

### *Children's Behaviors Related to Asthma*

Buston and Wood (2000) described children's self-reported reasons for not taking asthma medication. Reasons included forgetfulness, embarrassment, believing medications to be ineffective, difficulty using inhalers, inconvenience, fear of side effects, laziness, and denial. Coping behaviors identified among 39 school-age children with asthma who were experiencing dyspnea included: taking medications, changing positions, drinking fluids, relaxation, distraction, and seeking support from others

(Carrieri, Kieckhefer, Janson-Bjerklie, & Souza, 1991). Children attending an asthma camp were asked to describe their coping strategies. Children used the following four strategies most often: (a) try to relax or stay calm, (b) watch TV or listen to music, (c) do something about it, (d) say I'm sorry or tell the truth (Ryan-Wenger & Walsh, 1994).

Analysis of cross-sectional data from the 1988 National Health Interview on Child Health revealed that children 5 to 17 with severe asthma were three times as likely as normal children to have severe behavior problems (Bussing, Halfon, Benjamin, & Wells, 1995). Comparison of 37 children with asthma to a group children without asthma demonstrated significantly more anxiety disorders, psychiatric problems, and intra-familial stress (Bussing, Burket, & Kelleher, 1996). Another study comparing scores on the State Trait Anxiety Inventory for Children between 92 children with asthma and normal controls found anxiety disorders to be significantly more frequent among children with moderate to severe asthma (Vila et al., 1999).

The relationships between body weight, physical activity, and asthma are complex. A reasonable concern is that children who have asthma might avoid strenuous physical activity due to breathing problems. The resultant decrease in physical activity would be expected to result in lower energy demand and increased weight gain. In a study of more than 4000 Scandinavian children ages 7 to 17 there was no significant difference between children who had ever had asthma and those with no history of asthma on two measures of physical activity (Nystad, 1997). Exercise frequency and hours of exercise weekly were similar for both groups with more than half reporting participation in an organized sport. However, in another study, overweight children demonstrated greater limitation in physical activity and were prescribed more asthma

medications compared to weight-appropriate peers with similar asthma severity (Pianosi & Davis, 2004).

### Technology and Children's Experience of Asthma

Evidence supports the premise that technology, defined as the capable application of knowledge, is critical to asthma self-care. Asthma knowledge alone, as it is currently defined and measured, is not strongly associated with treatment adherence or improved outcomes (Ho et al., 2003). A strong body of evidence demonstrates the effectiveness of many educational interventions aimed at preparing children for asthma self-care (Guevara, Wolf, Grum, & Clark, 2003). Whereas the critical aspects of self-care for children who have asthma have not yet been clearly identified (Abdulwadud et al., 2001), use technology is an important feature of these behaviors (AAAAI, 1999). Self-management interventions have employed a wide variety of modalities, program components, and outcome measures (Wolf et al., 2003). Therefore, the specific merits and effects of self-management interventions are not well understood (Wolf et al.). Significant developmental differences among children were demonstrated in regards ability to engage technology in asthma self-care activities (Pradel et al., 2001).

The existence of technological inadequacies is suggested by the trend toward increased asthma morbidity in the United States over the last two decades (Beasley, 2002) and by marked uncertainty described by those who experience the disease firsthand (Cicutto, 1998; Horner, 1997; Paterson & Britten, 2000). Uncertainty among people with asthma is not surprising, given the serious knowledge gaps that exist in relation to asthma. There remain many unanswered questions about the genetic basis (Borish, 1999), etiology (Doull, Williams, Freezer, & Holgate, 1996; Melen, Wickman, Nordvall, van

Hage-Hamsten, & Lindfors, 2001), natural history (Celedon et al., 2003; Weinberger, 2003), and diagnosis and treatment of asthma in children (Allen et al., 2003; de Jongste, Janssens, & Van der Wouden, 2002). Treatment outcomes for asthma are complex and difficult to measure (Silverman, 1999).

Review of literature pertaining to technology will be organized around six broad themes: (a) etiology of asthma, (b) detection of disease, (c) pharmacological advances, (d) inhalation devices, (e) co-morbidities, (f) asthma risks and associations, and (g) other treatment modalities. Theories and research pertaining to the etiology of asthma will be briefly considered. An overview of issues related to the detection of asthma will be explored particularly as it pertains to uncertainty in diagnosis and management. Other treatment modalities not currently incorporated into expert guidelines will be reviewed. Diseases associated with asthma in childhood will be discussed. Known and suspected risks and associations will be examined. Finally, technical and behavioral issues pertaining specifically to inhalation therapy will be reviewed.

### *Etiology of Asthma*

Increased prevalence of asthma in recent decades sharpened interest in the etiology of the disease and spawned a number of theories. Many theories have been entertained and later discarded when evidence failed to support beliefs. For example, it was once believed that parasitic infestation by intestinal worms such as *Ascaris* afforded protection against the development of asthma. This was eventually proven not be the case (Carswell, Meakins, & Harland, 1976). However, the underlying observation, that modernization and improving hygiene correlated with increasing prevalence of asthma,

was not abandoned. The parasite theory was a forerunner of the more recent hygiene hypothesis that has recently gained widespread support (Liu & Murphy, 2003).

Virtually all contemporary theories about the development of asthma focus on the interplay of genetic and environmental factors (Hjern, Haglund, & Hedlin, 2000). However, many pieces of the asthma puzzle appear to be missing. Mapping of the human genome provided new insight into an extraordinarily complex pattern of inheritance related to asthma and allergy (Borish, 1999; Lin et al., 2003). Claims of the existence of subtypes of asthma await further confirmation from both genetic and epidemiological research (Guilbert & Krawiec, 2003; Martinez, 2002). Other research focused on the identification of markers in infancy that would predict persistence of asthma in the school age child (Klennert et al., 2001) and the role of early viral infections in the development of asthma (Kotaniemi-Syrjanen et al., 2003; Martinez, 2003) have not yet provided practical predictive and preventive capabilities. Altered response of the human immune system to early allergen exposure has been investigated as a mechanism of asthma development, but without the discovery of new therapeutic options (Braun-Fahrlander et al., 2002; Hesselmar, Aberg, Aberg, Eriksson, & Bjorksten, 1999).

Theories about an emotional basis for asthma have been longstanding, though unproven. Pathogenic mothering (Madrid & Schwartz, 1991; Meijer, 1979), child temperament (Lilljeqvist, Smorvik, & Faleide, 2002), and other psychological factors (Baron et al., 1986; Faleide, Galtung, Unger, & Watten, 1988) have been viewed as causative in development of asthma, yet research has not supported these claims. Instead evidence suggests that psychological problems and dysfunctional behavior are more likely the result rather than the cause of asthma (Gustafsson, Bjorksten, & Kjellman,

1994. However, researchers continue to examine the relationship between early behavioral problems, problematic parenting, and the later development of asthma in childhood (Stevenson & Group, 2003).

#### *Detection of Disease*

The detection of asthma is a complex problem. No precise definition for the disease exists today. There is no single biophysical or biochemical test that can establish with absolute certainty the presence or absence of asthma. Current diagnosis and treatment is based largely on a person's reported symptom pattern. Spirometric data are considered the most objective source of information about lung function in asthma (Fuhlbrigge et al., 2001; Mostgaard, Siersted, Hansen, Hyldebrandt, & Oxhøj, 1997). However, spirometry yields data about only the instantaneous, functional state of the airway. The value of spirometry is also limited in value because it does not directly measure inflammation, the primary mechanism of asthma. Instead, spirometry measures airflow obstruction without fully differentiating its various causes (Enright et al., 2000).

A number of other problems are associated with spirometry (Linna, 1996). The test is relatively expensive and technically difficult to perform, so these data are not widely used in the clinical management of asthma except by specialists. Spirometric data are not generally available when deficits are most likely to manifest, such as in the middle of the night and after an individual has been running in cold air. This fact is important since the expression of asthma is highly variable in individuals over time. A lack of technology to support ongoing monitoring and differentiation of airway inflammation from constriction leads to imprecise methods of identifying, classifying, and treating asthma. Resulting uncertainty is a pervasive factor for those who have

asthma (Baker et al., 2000) and for healthcare providers (Werk, Steinbach, Adams, & Bauchner, 2000) and caregivers (Cicutto, 1998).

Newer non-invasive biomarkers, including exhaled nitrous oxide and sputum eosinophils (Gibson et al., 2001), have been useful in therapeutic trials (Buchvald & Bisgaard, 2001; Chung, 1999). However, at this time, none has gained acceptance for routine use at home for self-management or for conventional clinical care. There are a number of other promising approaches for the detection of asthma, such as automatic wheeze detection devices. A clinical trial recently employed an acoustic device that monitored lung sounds overnight (Bentur, Beck, Shinawi, Naveh, & Gavriely, 2003). Acoustic data were used to calculate percent wheezing in sampled 30-second respiratory cycles. The data were represented by a nocturnal wheeze index for the total night. It is reasonable to expect major technological innovations in the future that will increase capacity to collect and analyze objective respiratory data relevant to asthma.

Another longstanding problem in the diagnosis and management of asthma has been the evaluation of an array of associated airway symptoms. Historically, wheezing was held to be nearly pathognomic for asthma (Mak, Johnston, Abbey, & Talamo, 1982; Martin et al., 1982; Peckham & Butler, 1978). However, current definitions incorporate a range of respiratory symptoms including wheezing, persistent coughing, shortness of breath, and chest tightness. Many researchers continue to favor wheezing as the more convincing symptom (Forastiere et al., 2000; Yeatts et al., 2003). Others even designate chronic cough as bronchitis and hold this symptom pattern to be entirely distinct from asthma (Belousova, Toelle, Xuan, & Peat, 1999). However, both exercise-induced

wheezing and chronic cough correlate with lung function deficits consistent with the diagnosis of asthma in school-age children (Droste et al., 1999).

Recognition of wheezing and its clinical interpretation are not straightforward. Identification of wheezing is complicated by its intermittent pattern, by acoustic subtleties that make detection difficult without a stethoscope or amplifier, by widely varying meanings ascribed to the term (Cane, Ranganathan, & McKenzie, 2000), and by differences in children's ability to detect their own wheezing (Fritz et al., 1996). Wheezing and bronchial hyper-responsiveness (BHR) are not always associated (Belousova et al., 1999). Wheezing might be present as an acoustic phenomenon with no clinical response to tests for BHR. During these tests a bronchoconstrictive agent such as histamine, methacholine, or hypertonic saline is inhaled in increasing concentrations and correlated with spirometric evidence that a person's airways narrow abruptly. Neither wheezing nor BHR in infants is reliably predictive of persistence of asthma in later childhood (Delacourt et al., 2001). Finally, not all wheezing is due to asthma (Nystad et al., 1999).

Evaluation of cough and other respiratory symptoms in children entail difficulties similar to those identified for wheezing (Fuller, Picciotto, Davies, & McKenzie, 1998). Issues related to recognition and interpretation of asthma symptoms pose serious barriers to clinicians, caregivers, and children alike. Current solutions to technological shortfalls depend on behavioral interventions and purposeful communication. Use of asthma symptom diaries, peak flow monitoring, and education for self-care are principal means by which better data for the detection and management of asthma are obtained (AAAAI, 1999). Provider and community education are also important in efforts to improve

communication and treatment approaches. Each of these measures is dependent on human initiative in effort-intensive strategies to monitor subtle signs and symptoms and to respond to changing patterns (Myers, 2002a). Children's experience of disabling asthma is likely shaped by an interaction of human factors pertinent to technological gaps in the detection of asthma.

### *Advances in Pharmacology*

Over the last 15 years since publication of the first national asthma guidelines, clinical emphasis shifted dramatically to the management of asthma as a chronic inflammatory disease of the airways (NHLBI, 2002). This is significant because asthma was first understood and treated as a disease of episodic airway constriction. Early asthma therapies employed bronchodilator medications as the mainstay of therapy (Chervinsky, 1975). Unfortunately, this historical precedent has continued to influence the widespread use of bronchodilators alone in the treatment of persistent asthma, despite proven efficacy and cost-effectiveness of inhaled steroids (Rutten-van Molken, Van Doorslaer, Jansen, Van Essen-Zandvliet, & Rutten, 1993). Failure to employ anti-inflammatory therapies has been a common, costly, and in some cases, a life-threatening problem (Suissa et al., 2002). Correct use of inhaled corticosteroids has been associated with dramatic reduction in disease severity (Allen et al., 2003).

Much of the scientific literature over the last 15 years focused on elucidating inflammatory mediators involved in cellular changes in the asthmatic airway (Allen et al., 2003). As a result, many new anti-inflammatory medications became available for the treatment of asthma (Holliday, Faulds, & Sorkin, 1994). The evolution of NHLBI asthma guidelines reflected a growing awareness that it was possible to arrest the chronic

symptom pattern of asthma by reducing airway inflammation and hyperresponsiveness. Dramatic advances in the treatment of asthma gave rise to the bold theme of the National Institutes of Health (NIH) public information campaign slogan: “Your asthma can be controlled. Expect nothing less” (NIH, 1991). Yet, despite major progress in the understanding and treatment of asthma, delays in implementation of new treatment guidelines by clinicians were widespread (Adams et al., 2003; Riekert et al., 2003). Barriers persisted to the adoption of these newer and more effective treatments in the day-to-day care of children who have asthma (Yeatts, Maier, & Shy, 2000).

#### *Inhalation Devices and Technique*

The advent of nebulizer use at home in the 1980’s was associated with reduced emergency room visits and decreased days in the hospital for children with asthma (Ryan, Willan, & Wherrett, 1988). Over the last decade the most effective asthma medications available existed in forms that must be inhaled into the airway. A wide range of devices, including metered dose inhalers (MDI), dry powder inhalers (DPI), and nebulizers, were developed and used (AAAAI, 1999). Use of a spacer with MDI, compared to MDI alone, was associated with earlier resolution of wheezing in a randomized controlled trial involving 84 children who presented with asthma at an emergency room (Cunningham & Crain, 1994). Family preference in selection of MDI with spacer versus nebulizer for administration of inhaled medications was found to affect compliance with the medical plan of care (Cheng, Browne, Lam, Yeoh, & Oomens, 2002).

Whereas inhaled medications are very effective, a high level of skill and motivation is required to properly use inhalation devices (Pedersen, 1987). Inhalation technique largely determines if optimal inspiratory flow and time parameters are attained

that favor deposition of medication deep into the airways (Amirav et al., 2005).

Evaluation of individual inhalation technique is critical to the management of the child with difficult asthma (Mazur, de Ybarrondo, & Miller, 1999). Numerous sources of error exist even for more passive inhalation devices, such as a spacer with face mask commonly used for young children (Marguet et al., 2001). Technique was found to be flawed among more than 40% of children using a MDI with or without a spacer (Scarfone, Capraro, Zorc, & Zhao, 2002). An interactive method of instruction has been shown to lead to more rapid skill acquisition than a didactic approach (Turgeon et al., 1996). Repeated training has been shown to be necessary for children to attain reliable technique (Bisgaard, Pedersen, & Nikander, 1994).

#### *Comorbidity*

A serious problem that adversely impacts the diagnosis and treatment of asthma is the identification of contributing diseases. Current technological limitations make it difficult to clearly delineate the complex relationships between asthma and associated health problems. Asthma alters the structure and function of the airways, leading to an increased risk for other illnesses such as recurrent pneumonia (Ciftci, Gunes, Koksall, Ince, & Dogru, 2003; Heffelfinger et al., 2002) and atelectasis (Sekerel & Nakipoglu, 2004). Various diseases co-exist with and contribute to childhood asthma, including allergy (Sicherer, Noone, & Munoz-Furlong, 2001), gastroesophageal reflux disease (Gilger, 2003), sinusitis (Dykewicz & Fineman, 1998), and obesity (Gilliland et al., 2003; Tantisira, Litonjua, Weiss, & Fuhlbrigge, 2003).

Other diseases occur more frequently among children who have asthma, such as anxiety (Katon, Richardson, Lozano, & McCauley, 2004), depression (Mrazek, 2003),

croup (Castro-Rodriguez et al., 2001; Nicolai & Mutius, 1996), and vocal cord dysfunction (Tilles, 2003). It is often difficult to establish whether a second disease is the result of asthma, a cause of asthma, a contributing factor in asthma severity, or merely coincidental. Whatever the particular relationship between asthma and a concomitant illness, the simultaneous presence of two or more diseases complicates the illness experience. For example, a child's coughing might be due to croup, an upper airway problem, asthma, a lower airway problem, or gastroesophageal reflux.

The presence of multiple disorders increases morbidity and complicates the treatment of asthma (Rietveld & Creer, 2003). A child's efforts to understand and reduce the effects of asthma is likely to be confounded by the presence of a second disease (Hogan & Wilson, 2003). Health-care providers also have difficulty distinguishing the effects of co-existing diseases. Whereas the diagnosis and treatment of childhood asthma is primarily based on symptom frequency over time (NHLBI, 2002), the symptom pattern is difficult to interpret when the source of the problem is unclear. This problem is illustrated by the case of a child with nocturnal cough that is due to both sinusitis and asthma. A single treatment will not be effective. Both diseases require intervention. Such complex interrelationships are commonplace among children who have asthma (Sicherer et al., 2001).

Another concern is the assessment of quality of life issues in a child who is experiencing two illnesses simultaneously. For example, a child who has asthma and rhinosinusitis might experience significant ill health and activity limitations due to either condition. It is difficult to determine which disease is the greater source of ill health,

since rhinosinusitis alone has been shown to have a marked adverse effect on children's quality of life (Cunningham, Chiu, Landgraf, & Gliklich, 2000).

Some relationships between asthma and other illnesses are less certain. For example asthma has also been found to be an independent risk factor for headache (Wilkinson, Halliday, Henry, Hankin, & Hensley, 1994). However, the basis for the association is not understood. Even when an association between two illnesses is entirely coincidental, there is a need to distinguish the source of morbidity and impairment in considering disability among children with asthma. Disabling asthma might be associated with the cumulative effects of multiple related and unrelated illnesses.

Family co-morbidity is also an important factor. The ill health of caregivers or other family members might adversely impact a child's experience of asthma. Children with asthma whose caregivers had mental health problems were hospitalized at twice the rate of those whose parents did not have significant mental health problems (Weil et al., 1999). Children of adults with panic disorder were also found to exhibit a higher rate of atopic disorders, including asthma (Slattery et al., 2002). Serious physical or mental illness among caregivers and other family members should be considered when exploring the experience of disabling asthma among children.

#### *Risks Associated with Asthma*

Several risk factors have been associated with asthma. In my experience parents and children raise many questions about asthma arising from concern about these factors. Children ask why they have asthma. Parents question why their child has asthma in the absence of a family history for the illness. Parents might ask why their child ended up in the hospital with asthma when so many other children have mild disease. Children and

parents inquire about what can be to reduce asthma problems without taking more medication. They ask if asthma medicines make a person gain weight. A review of known asthma risk factors is particularly relevant to a study of disabling asthma because the existence of risk prone conditions might be related to children's experience.

### *Risk of Developing Asthma*

A complex interaction of genetic and environmental factors is associated with the development of asthma. Inheritance (Borish, 1999), ethnicity (Hjern et al., 2000; Kivity, Sade, Abu-Arisha, & Lerman, 2001; Sacher, Laor, & Danon, 1994), low birth weight (Wjst, Popescu, Trepka, Heinrich, & Wichmann, 1998), atopy (Ponsonby et al., 2002), viral infections (Martinez, 2002), and smoking (Mannino, Moorman, Kingsley, Rose, & Repace, 2001; Yarnell et al., 2003) have been found to be strongly associated with asthma among children. Bronchial hyperresponsiveness (BHR) was found to be associated with male gender in the first few years of life (Ernst, Ghezze, & Becklake, 2002). However, throughout childhood, the risk of BHR decreased in males and increased in females. Other factors postulated to be associated with the development of asthma have not been proven to have a role. Vaccination of children against Hemophilus influenza type B has not been found to be associated with asthma (Laubereau et al., 2002). No association has been found between handedness and atopic disorders including asthma (Stanton, Feehan, Silva, & Sears, 1991).

Predictors in infancy of persistent asthma at school age included a high number of respiratory infections in the first year of life, elevated IgE at 6 months of age, and high ratings of parental difficulties when the infant was only 3 weeks of age (Klennert et al., 2001). Having two or more episodes of wheezing in the preschool years was associated

with lung function deficits among school-aged children with no current asthma for at least 2 years (Strope et al., 1991). This likely represents a sub-clinical presentation of asthma-like airway changes among apparently healthy children. The presence of eczema in early childhood was associated with a marked increase risk of developing asthma and allergic rhinitis (Gustafsson, Sjoberg, & Foucard, 2000). In utero exposure to maternal smoking has been found to increase the risk of asthma (Gilliland, Li, & Peters, 2001).

#### *Risk of Asthma Morbidity*

Increased emergency admissions of children to the hospital due to asthma were associated with low socioeconomic status, Black race, and ethnic minorities (Gilthorpe et al., 1998). Under-use of controller medications is common among Medicaid-insured children, particularly among ethnic minorities and children of parents with lower levels of education (Finkelstein, Lozano, Farber, Miroshnik, & Lieu, 2002b). Emergency room visits by asthmatic children were associated with high levels of atmospheric nitrous dioxide and sulfur dioxide, and high barometric pressure (Garty et al., 1998). Emergency room visits for children with asthma were also more common at the beginning of the school year (Garty et al.). Risk for admission to a hospital for asthma exacerbations was associated with younger age of asthma onset, longer time since diagnosis, worse airway obstruction, and lower patient IQ (Bacharier et al., 2003). As a coexisting condition, asthma is a significant risk factor for surgical complications resulting in an increased need for hospital services (Dornhoffer & Manning, 2000).

#### *Environmental Factors and Asthma Risk*

Exposure to a pet dog in the first years of life was found to be associated with a reduced risk of developing asthma among children of allergic parents (Holscher, Frye,

Wichmann, & Heinrich, 2002). The presence of pinworm infestation in primary school children has been found to be associated with reduced presence of asthma and allergic rhinitis (Huang, Tsai, & Yeh, 2002). The major determinant of BHR (Ernst et al., 2002) and the development of asthma has been reported to be sensitization to dust mite (Kuehr et al., 1995). Other studies have demonstrated differing associations between specific populations groups and selected environmental risk factors (Findley et al., 2003).

Sensitization to some inhalant antigens (aeroallergens) might be mediated by specific level of exposure. Dust mite and cockroach levels in the homes of more than 1000 children ages 5 to 12 years correlated with increased risk of sensitization as evidenced by a positive skin test (Huss et al., 2001). This was not true for other inhalant antigens such as dog, cat, and mold. Month of birth has been found to correlate with allergic sensitization and asthma in a climate where wide seasonal variation in tree pollen levels occurred (Saitoh et al., 2001). Exposure to rodents in public housing in East Harlem was associated with an increased risk of asthma among Puerto Ricans (Findley et al., 2003). Exposure to cigarette smoke and high levels of ambient small particles less than 10 microns was associated with self-reported asthma in the Arizona and Mexico (Stephen et al., 2003). Poverty was found to be associated with increased risk of exercise-induced bronchospasm (Ernst, Demissie, Joseph, Locher, & Becklake, 1995). However, specific environmental factors were found to mediate the increased risk, including cats living in the home and a higher rate of lower respiratory infections before 2 years of age.

Among more than 3000 7 to 8 year old school children risk factors for asthma included a family history, living in a damp house, being male, and having a mother who smokes tobacco (Ronmark, Lundback, Jonsson, & Platts-Mills, 1998). Setting aside

gender, when none of the other three risk factors were present, no child had asthma. When all three risk factors were present 38% of those children were using asthma medications (asthma medication use rate was 7% among all children in the study). In follow-up studies at one and two years the cumulative incidence of newly diagnosed asthma among the same population was 1.7% (Ronmark, Perzanowski, Platts-Mills, & Lundback, 2002). “Significant risk factors for incident asthma were a positive skin test, OR 5.64 (3.10-10.25); rhinitis, OR 3.53 (1.80-6.90); eczema, OR 2.19 (1.26-3.82); a family history of asthma, OR 2.83 (1.75-4.56); low birth weight, OR 3.38 (1.61-7.54); respiratory infections, OR 2.12 (1.24-3.63); male gender, OR 1.71 (1.06-2.81); and a smoking mother OR 2.00 (1.07-3.73).” (p. 1006)

Living on a farm and consuming cow’s milk in the first year of life have been associated with a dramatically lower risk of developing asthma, allergy, and atopic sensitization (Riedler et al., 2001). The effect was even greater if the exposure to farm life continued for the first five years of a child’s life. Moving to a farm later in childhood did not afford similar protection against the development of asthma, though rates remained lower than urban-dwelling children. Exposure to farm animals was found to mediate the lower rate of asthma and atopy among farm children (Riedler et al., 2000). Endotoxin levels in children’s bedding was found to be inversely related to the incidence of atopic asthma and sensitization to aeroallergens in a study of farming and non-farming households (Braun-Fahrlander et al., 2002).

#### *The Association of Diet and Asthma*

Low intake of vitamin C was associated with a seven-fold increase risk of BHR and low intake of vitamin E was associated with a five-fold increase risk of wheezing

among adults with asthma (Seaton & Devereux, 2000). Consumption of fresh fruit was associated with lower rates of wheezing among children (Forastiere et al., 2000). A diet high in omega-3 fatty acids (cold water fish, soy and canola oil, walnuts, and flaxseed) and low in omega-6 fatty acids (meat, most seeds, many oils including corn, peanut and safflower) was found to be protective against asthma morbidity (Covington, 2004; Oddy, de Klerk, Kendall, Mihrshahi, & Peat, 2004). Low intake of magnesium and potassium has been associated with lower lung volumes in children and might be a factor in asthma severity (Gilliland, Berhane, Li, Kim, & Margolis, 2002). Prevalence of asthma at age 3 years was lower among children who consumed dietary sources of milk fat, such as whole milk and butter, and brown bread at age 2 years (Wijga et al., 2003). In the absence of a family history for asthma, epidemiological evidence suggested that breastfeeding afforded some protection against the development of asthma (Romieu, Werneck, Ruiz Velasco, White, & Hernandez, 2000).

#### *The Association of Weight Status and Age with Asthma*

Asthma in children was associated with increasing body mass index (Figueroa-Munoz, Chinn, & Rona, 2001), and maternal obesity was associated with increasing body mass index among children. The coexistence of childhood asthma and maternal obesity was associated with a marked increased risk for obesity in children (Epstein, Wu, Paluch, Cerny, & Dorn, 2000). Obesity was found to be a risk factor for asthma among girls, but not boys (von Kries, Hermann, Grunert, & von Mutius, 2001).

The age of onset of asthma might be a significant variable in disease expression. In a study of differences among children whose asthma began before two years of age and those with later onset, the impact of psychosocial factors including stress, worry,

anger, excitement, and laughter was significantly greater for children with a late diagnosis (Sarafino, Gates, & DePaulo, 2001). No difference was found between the early-onset and late-onset groups in reported response to physical triggers including allergens, cigarette smoke, respiratory infection, humidity, and pollution. Asthma that developed before school age was found to be less associated with atopy and more associated with viral respiratory illness. In that study asthma in early life was a transient illness in two-thirds of infants with wheezing (Martinez, 2002).

#### *Factors Associated with Asthma Severity*

Duration of disease appears to be related to several measures of asthma severity among school-aged children, including bronchodilator use, asthma symptoms, BHR, and large airway obstruction (Zeiger, Dawson, & Weiss, 1999). Atopy, as defined by positive skin prick test, was found to be associated with more frequent wheezing and hospitalization (Ponsonby et al., 2002). Among 14 children who died of asthma in Brooklyn, New York 10 were identified as having severe asthma; yet only 1 had been evaluated by spirometry, 2 had good medical follow-up, and only 2 were taking corticosteroids (Rao, Kravath, Abadco, Arden, & Steiner, 1991).

Emotional stress, in the form of severely negative life events and chronic stress, has been associated with worsening asthma in children (Sandberg et al., 2000). Occurrence of an acute stressor was associated with an increased risk of a delayed onset of asthma symptoms 2 to 4 weeks later. However, when experiencing a high level of chronic stress, children who encountered an acute source of stress were three times as likely to have an immediate asthma exacerbation as children with asthma who had no

major sources of chronic or acute stress. The severity of asthma symptoms trended towards greater severity when acute stress was superimposed on chronic stress.

Positive events in the life of children who had asthma were found to mitigate the effects of acute and chronic stress (Sandberg et al., 2002). “The results showed that, provided they occurred in close proximity to severely negative life events, positive life events, generally related to the child's own achievements, afforded protection against the increased risk of a new asthma exacerbation precipitated by severe events in children whose lives were marked by low to medium levels of chronic stress” (p.152). Children experiencing high levels of chronic stress did not exhibit a protective effect from positive life events. Children with separation anxiety were found to exhibit a higher rate of atopic disorders than normal peers (Slattery et al., 2002). Children with asthma who had higher levels of anxiety had lower asthma quality of life scores (Annett, Bender, Lapidus, Duhamel, & Lincoln, 2001).

Whereas significant differences exist in disease severity among children with mild asthma and those with moderate disease, both groups appear to experience little functional or psychological impairment due to asthma (Annett et al., 2001).

Psychological difficulty was not increased among 1000 children with mild to moderate asthma (Bender et al., 2000). Psychological adaptation among those children was related to the psychological functioning of the family, not to asthma-specific variables.

Neurocognitive performance among 1000 children with mild or moderate asthma was not different than national norms (Annett, Aylward, Lapidus, Bender, & DuHamel, 2000).

*Anatomical Airway Changes Associated with Asthma*

Some children with asthma develop irreversible airway obstruction believed to be the result of remodeling of airways due to chronic, untreated inflammation (Fish & Peters, 1999). Small declines in lung function (large airway flow) were found in about a quarter of children studied over a 4 to 6 year period (Covar, Spahn, Murphy, & Szefer, 2004). Decline was more common among males, those with an early age of asthma onset, and those with greater eosinophilic inflammation. Benefit might be afforded by early and sustained treatment of asthma with anti-inflammatory medication (Pauwels et al., 2001). However, to date, little evidence supports the claim that most children with asthma will experience progressive, irreversible airway obstruction if not treated with inhaled corticosteroids (Konig, 2002).

#### *Risks Associated with Inhaled Corticosteroids (IC)*

Expert clinical guidelines have clearly advocated use of IC as first-line therapy in the treatment of persistent asthma (NHLBI, 2002). However, the use of IC has not proven to be entirely risk-free. Despite an excellent overall safety profile, sudden withdrawal of high doses IC has been associated in rare cases with life-threatening adrenal crisis that involved hypoglycemia, convulsions, and coma in children (Todd et al., 2002). Bone metabolism and vertical growth were suppressed slightly only in the first year of therapy among 60 children taking IC (Kannisto, Korppi, Arikoski, Remes, & Voutilainen, 2002). Higher dose IC use was associated with biochemical markers of increased bone turnover, but there was no effect on bone density at conventional doses (Jones et al., 2002). The possibility of osteoporosis, increased risk of cataracts, and other chronic effects with high dose therapy cannot be entirely set aside (Allen et al., 2003). However, benefits of IC clearly outweigh risks in the treatment of persistent asthma (Skoner, 2002).

In one study young adults who used IC in childhood demonstrated mild growth retardation as adults (Van Bever, Desager, Lijssens, Weyler, & Du Caju, 1999). However, researchers did not control for asthma severity so they could not distinguish between medication effects and disease effects. Use of nasal corticosteroids and hospitalization were associated with greater deficits in final adult height in the study (Van Bever et al.). Others have concluded that asthma has little significant effect on attained adult height (Doull, 2004), particularly mild to moderate persistent asthma (Kelly et al., 2003). The interaction between genetic inheritance patterns for atopy, asthma, delayed puberty, linear growth, short stature, and disease patterns is extremely complex (Baum, Schneyer, Lantzsich, & Kloditz, 2002). These factors make precise analysis of growth effects in asthma difficult (Price, Hindmarsh, Hughes, & Efthimiou, 2002). Additional research is needed to examine long-term outcomes that bear upon reduction of the burden of disease, as well as prevention of adverse disease effects and adverse medication effects (Pedersen, 2002).

#### *Asthma Treatment Modalities*

Treatment modalities for asthma are a key aspect of technology. These include accepted, emerging, and equivocal medical interventions, behavioral and educational interventions, complementary and alternative approaches, and unconventional therapies. Accepted medical modalities are those therapies recommended by expert asthma guidelines. (Current expert guidelines will be considered in detail in a personal bracket later in this chapter, related to self-care demands imposed on children with asthma.) Other medical therapies are either emerging or equivocal. Emerging therapies are too new to be fully proven (Bousquet et al., 2005). Equivocal therapies lack conclusive

evidence of effectiveness (Reider, 2005). Individual children might be exposed to any of these types of treatment modalities, because large numbers of health-care providers do not treat asthma according to expert guidelines (Riekert et al., 2003; Zuckerman et al., 2000). Behavioral approaches are treatments aimed at changing asthma directly by manipulating physiologic processes or indirectly by reducing risk factors and increasing the effectiveness of treatments (Kotses, 1999).

Among caregivers of children with asthma there is widespread and growing adoption of non-medical ways of treating the illness. These treatments often arise from views of the illness that do not conform to biochemical models of asthma (Peterson, Sterling, & Stout, 2002). Collectively these other approaches are labeled by the medical community as complementary and alternative medicine (CAM) (Madsen et al., 2003). However, use of the term “medicine” here to describe an extremely diverse array of beliefs and practices arises from a medical paradigm. The CAM label does not necessarily reflect the point of view of those who are living with asthma day-by-day (Doerr, 2001). For the purpose of this review, CAM will be used to describe treatments for asthma not prescribed or recommended by medical practitioners. Some examples of CAM are included below because children are often encouraged by influential others to use those approaches. However, this information should be considered in the context of culture and the associated belief systems. This perspective will be explained later in this chapter in a discussion of culture as a pervasive influence on children with asthma.

#### *Emerging and Equivocal Therapies*

A number of emerging medical therapies are in use for the treatment of asthma. Use of anti-IgE injections has been shown to reduce the morbidity of poorly controlled,

severe persistent asthma among children who suffer from a perennial allergen (Bousquet et al., 2005; Bush, 2002). Management of asthma exacerbations by increased doses of inhaled steroids in combination with beta-2 agonist four times daily has reduced the need for oral steroids and hospitalization when initiated by the child and caregiver (Volovitz et al., 2001). In a small 7-year follow-up study, high-risk infants who received respiratory syncytial virus immune globulin had significantly better lung function, less atopic disease, and fewer missed school days than controls (Wenzel, Gibbs, Lehr, & Simoes, 2002). Use of sublingual drops for desensitizing children with asthma has gained popularity among families. A meta-analysis failed to demonstrate efficacy of this therapy in the treatment of childhood asthma (Reider, 2005). A review of the effectiveness of manual treatments for childhood asthma, including chiropractic interventions, found no evidence for these treatments (Hondras, Linde, & Jones, 2005).

### *Behavioral Interventions*

More than 25 years ago researchers first identified the value of behavioral interventions in asthma (Creer & Burns, 1979a). Specific problem behaviors likely to worsen asthma have also been identified (Creer, Wigal, Tobin, & Kotses, 1989). Kotses (1999) distinguished between direct and indirect behavioral intervention. Direct behavioral interventions are postulated to alter airway state through changes brought about in the central nervous system by conscious effort (Miller & Wood, 1994). In contrast indirect interventions lead to behaviors that favor a reduction in airway pathology through avoidance of triggers, increased awareness and reporting of airway changes, appropriate use of medications, and similar favorable changes likely to diminish the severity of asthma (Kotses, 1999).

*Direct behavioral interventions for asthma.* Interest in direct behavioral interventions for the treatment of childhood asthma has been evident in the literature for many years. However, such interventions have not been proven to be effective and practical. Methods studied have included relaxation training (Vazquez & Buceta, 1993), hypnosis (Kohen & Wynne, 1997), guided imagery (Peck, Bray, & Kehle, 2003), biofeedback-induced relaxation (Erskine-Milliss & Schonell, 1981), and massage therapy (Field et al., 1998). The search for evidence that modification of psychological factors affords benefit in asthma has been founded largely on belief that emotional state influences airway caliber (Erskine-Milliss & Schonell, 1981). Linkages between the parasympathetic nervous system, anticholinergic pathways, and airway pathophysiology of asthma have been demonstrated (Reed, 1974). However, after nearly three decades of research the promise of direct psychological treatments for asthma (Larsson, 1992) has not been realized (Kotses, 1999).

*Indirect behavioral interventions for asthma.* In contrast, many indirect behavioral interventions have proven to be effective. Prevention and self-management have been identified as two broad categories for indirect behavioral interventions (Creer, 1991). Prevention aims to avoid asthma morbidity or lessen the burden of disease. Research suggests that exercise (Szentagothai, Gyene, Szocska, & Osvath, 1987) affords both psychological and physiological benefits (Engstrom, Fallstrom, Karlberg, Sten, & Bjure, 1991; van Veldhoven et al., 2001) for children who have asthma. Some dietary factors reduce the effects of asthma (Forastiere et al., 2000; Wijga et al., 2003), while other factors increase risks of more severe asthma (McKeever & Britton, 2004; Mickleborough, Gotshall, Cordain, & Lindley, 2001). These data provide a basis for

designing dietary interventions for maintaining a healthy body weight, increasing consumption of foods known to improve lung health, and avoiding foods known to worsen asthma (Seaton & Devereux, 2000).

Environmental and psychological approaches have been effective in asthma prevention. Modification of environmental factors in the home has also been demonstrated to be a useful means of lowering exposure to inhalant antigens and decreasing the number of asthma attacks (Takaro et al., 2004; Wilson et al., 2001). Psychological treatment modalities have proven useful in the prevention of adverse effects of childhood asthma on family functioning. Families experienced reduced psychosocial burden of having a child with asthma after individual family meetings, group meetings for families, or school-based intervention (Gustafsson, Olofsson, Andersson, Lindberg, & Schollin, 2000).

As discussed in Chapter One, interventions aimed at improving children's self-management skills have been advocated. A wide array of approaches have been developed and tested. Use of an electronic device that promoted asthma self-care activities and facilitated symptom reporting was associated with improved self-care skills and better asthma outcomes among children (Guendelman, Meade, Benson, Chen, & Samuels, 2002). A program that employed self-teaching at home for improving management of asthma proved helpful (Weiss & Hermalin, 1986). Formal asthma educational programs for children have been valuable (Wolf et al., 2003). Multimedia programs promoting asthma self-care skills have shown benefit (Bartholomew et al., 2000; Homer et al., 2000; Krishna et al., 2003). Disease management approaches were employed that used remote interventions to promote self-management among large

populations of children and caregivers. Educational mailings, case management by telephone, educational videos, and provision of a peak flow meter were shown to be effective in improving some asthma outcomes (Georgiou et al., 2003). For children less than seven years of age, parental education for the management of asthma has improved caregiver skills and asthma outcomes (Wilson et al., 1996).

### *Complementary and Alternative Medicine and Asthma*

CAM includes herbal drugs and dietary supplements (Ottolini et al., 2001), as well as alternative treatments, such as meditation, prayer, homeopathy (Doerr, 2001), acupuncture, and chiropractic (Graham & Pistolese, 1997). In a recent convenience sample of inner-city parents in the United States of diverse ethnic backgrounds, 35% reported using herbal treatments and religious practices in the care of their child's asthma (Handelman, Rich, Bridgemohan, & Schneider, 2004). CAM is sometimes used in addition to conventional therapies. However, folk remedies (*zumos*) were used instead of prescribed medication among 72% of interviewed Dominican-American mothers of children with asthma (Bearison, Minian, & Granowetter, 2002).

A limited number of CAM approaches have been systematically studied to evaluate efficacy. In a recent evidence-based review of CAM for asthma, there was little or no difference between placebo and treatment groups in 15 reported clinical trials (Markham & Wilkinson, 2004). Homeopathy was not an effective adjunct to conventional asthma therapies (White, Slade, Hunt, Hart, & Ernst, 2003). Some herbal preparations have been shown to improve lung function, symptoms, or both (Giles, 2001). However 81% of multicultural parents surveyed in Texas reported use of one of three herbs with potential toxicity (Mazur, De Ybarrondo, Miller, & Colasurdo, 2001).

Despite a lack of evidence of effectiveness and potential risks, popularity of CAM for asthma has been reported around the world. In Denmark 53% of over 600 parents surveyed reported having tried CAM for their child at least once (Madsen et al., 2003).

#### Culture and the Context of Children's Experience of Asthma

Culture is multifaceted concept that is difficult to distinguish from specific racial, ethnic, national, linguistic, social, and economic factors. Many beliefs about children, asthma, and medical care are rooted in distinct, culturally mediated views (Handelman et al., 2004). Cultural views of asthma are important to this study because these appear to mediate morbidity among children (Swadi, 2001). More than 25 years ago researchers first noted that among children with asthma and their families there were serious barriers to care, including poor understanding of asthma, inadequate grasp of the role of medication, major fears and anxieties, and resignation to disability (Reddihough, Jones, & Rickards, 1978). Some of the reasons for excess morbidity and disability in childhood asthma are likely related to cultural views of the illness. Evidence of growing disparities in asthma outcomes demand further inquiry into the role of culture (Weis, 2005).

#### *Culture and Access to Health-Care for Asthma*

Evidence suggests that culture impacts asthma outcomes among children even when socioeconomic status and health care access are equal (Weitzman, Byrd, & Auinger, 1999). Barriers have been identified among specific cultural groups in relation to care of children with asthma (Rose & Garwick, 2003). The experience of caring for such children has differed widely among cultural groups (Svavarsdottir & Rayens, 2003). Low expectations for treatment outcomes were identified among some cultural groups (Kuehni & Frey, 2002; Sawyer & Fardy, 2003). Cultural differences might prevent access

to care of children with asthma. Among American Indians living in a large Midwestern city a number of barriers to care for children with asthma were identified (Rose & Garwick). Caregivers faced difficulties that arose from socioeconomic, environmental, disease-related, health system, and family-caregiver factors. Researchers reported that the impact of culture on those caring for children with asthma was apparent and complex (Rose & Garwick). Another study of 22 Navajo families with 29 children who had asthma employed an ethnographic approach to examining beliefs, practices, and health care utilization patterns (Van Sickle & Wright, 2001). Important beliefs included: (a) fear of addiction to medications, (b) belief that nebulizer medications given in the emergency department were the strongest available medication, and (c) belief that controller medications had the same effect on the lungs as quick relievers. The authors identified what they believed were underlying reasons among the Navaho beliefs for excessive use of the emergency department, under-treatment of asthma, and excessive hospitalization rates among children with asthma (Van Sickle & Wright).

#### *Culture and Asthma Beliefs*

Coherent systems of asthma beliefs and practices are sometimes shared among culturally distinct groups. Some of these differ from a biomedical model of disease. The influence of “ethnomedical practices” (Pachter, Cloutier, & Bernstein, 1995, p. 983) and alternative “explanatory models of disease” (Kieckhefer & Spitzer, 1995, p. 149) are important (Handelman et al., 2004). Culturally derived views of asthma might (a) favor adherence with conventional medical treatments, (b) conflict with adherence to conventional care, or (c) favor use of additional treatments. Alternatively, cultural awareness and responsiveness by health-care providers might mitigate adherence barriers,

draw upon the strengths of a culture, and facilitate a strong partnership for better asthma care (Flores, Rabke-Verani, Pine, & Sabharwal, 2002).

Puerto Rican children experience the highest asthma prevalence of any ethnic group in the United States, so their experience is of particular interest. Cultural views of asthma that explained home care practices were apparent among caregivers of 118 Puerto Rican children (Pachter, Cloutier, & Bernstein, 1995). Caregivers described a number of home remedies for asthma based on belief that expulsion of mucus from the body was important to treatment. Approaches for expelling mucus included attempts to maintain emotional and physical harmony, religious practices, use of the botanical agents, and other therapies. Potentially harmful treatments were uncommon among these Puerto Rican families. From a biomedical perspective most treatments were not likely to be effective. However, these treatments were harmless so researchers advocated inclusion of practices that were not discordant with biomedical treatments (Pachter et al.).

Whereas research within selected ethnic groups has substantiated the existence of culturally-specific perceptions of asthma, expressed beliefs might not be unique to that group. For example, in a study of mothers of children with asthma from three ethnic groups in London, all groups shared concerns about using medications (Cane et al., 2001). Cane et al. also noted that individuals within cultural or ethnic groups do not always share similar views. Bangladeshi, White English, and Black Caribbean mothers responded to six questions after viewing a video clip of a boy with wheezing and cough. Marked differences were noted within groups related to expectations for the symptomatic child having a normal life. All mothers agreed that parental beliefs about asthma would likely determine functional restrictions on the child more than the asthma itself.

Generalizations about culture might also oversimplify how families view asthma. Explanatory models among 20 African-American adult caregivers of children aged 9 to 12 years were found to be highly individualized (Peterson et al., 2002). Whereas cultural context was important to the experience of caring for a child with asthma, each family's unique explanatory model drew upon personal experiences, trusted family and friends, and explanations provided by health-care providers. Differences between African-American mothers of children who had asthma were described in an ethnographic study. Six themes were identified that characterized unique aspects of each woman's experience in caring for their child: (a) knowledge about the child's asthma; (b) gatekeepers to the child's care; (c) being religious; (d) support; (e) roles as teacher, counselor, and advisor to the child; and (f) self-sufficiency and industriousness (Sterling & Peterson, 2003). Differences among the women's views on these six themes demonstrated a high degree of variability among a culturally similar group.

Evidence supports the assertion that parental beliefs related to expectations about the effects of asthma are likely important to the individual child's experience. Australian parents of children without asthma held more pessimistic attitudes towards the impact of asthma on children, family lifestyle, and relationships than parents whose children actually had asthma (Donnelly, Donnelly, & Thong, 1987). The study suggested that experience and education improved parental attitudes toward childhood asthma. These findings suggest that cultural effects might be mediated by other factors such as experience and education (Donnelly et al.).

Some beliefs about asthma among some cultural groups have been shown to stand in opposition to conventional medical management. Among 25 Dominican-American

mothers, trust in medical providers and adherence to prescribed regimens was very low (Bearison et al., 2002). Most mothers did not believe asthma was present when the child was free of symptoms, while 88% percent believed that physicians hid information and over-prescribed medications. Three-fourths of mothers used folk remedies rather than control medication to prevent asthma attacks from returning (Bearison et al., 2002). Among Hispanic mothers biomedical knowledge of respiratory illnesses in general was found to be lacking (Robledo, Wilson, & Gray, 1999). Caring behaviors were related to cultural views of disease. Implications for nursing care included the needs to incorporate culturally held views and practices into the treatment of sick children (Robledo et al.).

#### *Barriers Related to Language and Ethnicity*

Cultural and linguistic barriers have been identified as serious obstacles to asthma care for Latino children seeking emergency care for asthma (Flores et al., 2002). Lack of Latino health care professionals likely contributes to the problem. Flores et al. found that when health provider and patient do not share cultural context, communication decreased in both quantity and quality. Cultural differences in health-seeking behavior, expectations, and quality of care have been postulated to account for an increased number of emergency admissions for asthma among Black and minority ethnic groups (Gilthorpe et al., 1998). Support for the claim that ethnicity is an independent predictor of morbidity can be found in a large study of middle class children with private health insurance. The prevalence of current asthma for Black children was found to be significantly higher than rates for White children (Weitzman et al., 1999). Whereas the high rate of poverty and environmental risk factors among ethnic minorities was an important predictor of asthma morbidity (Wood, Hidalgo, Prihoda, & Kromer, 1993), ethnic background was more

important in hospital admission rates than socioeconomic deprivation (Gilthorpe et al., 1998). This trend was mediated by important determinants including type of treatment received in primary care and referrals patterns to specialists.

Evidence suggests that ethnicity as an asthma variable and a component of culture co-exists as one of several factors in a complex natural array. The independent effects of ethnicity, poverty, gender, and environmental factors on the disease expression and diagnosis of asthma were apparent in a study of more than 120,000 school children in North Carolina (Yeatts, et al., 2003). Researchers sought to identify factors associated with undiagnosed asthma (defined as the presence of frequent wheezing symptoms among students). “Undiagnosed frequent wheezing was independently associated with female gender, current smoking, exposure to household smoke, low socioeconomic status, allergies, and African American, Native American, and Mexican American race/ethnicity” (Yeatts, p. 1046). The health consequences of having undiagnosed frequent wheezing included emergency room visits, hospitalizations, sleep disturbance, limited physical activity, and increased school absences (Yeatts, et al., 2003).

#### *Other Views of Culture Relevant to this Study*

Other views of culture are relevant to this study and the experience of children with asthma. Handelman et al. (2004) described views of asthma among children and parents living in a multiracial, inner-city neighborhood. Participants were from a variety of ethnic backgrounds; yet they shared some beliefs as a community. Some inner-city parents held culturally-specific understandings of asthma, but most described asthma in conventional biomedical terms. However, shared explanatory models of the treatment of asthma that differed from a biomedical model (Handelman et al.). Contagion was the

primary explanation for the cause of asthma given by 53% of children. Fear that the child would die due to asthma was reported by 76% of parents. Most mothers knew the name of their child's medications, but nearly half did not grasp the different effects of controller and quick reliever medications. Parental discontinuation of medications was reported by more than two-thirds of families for a variety of reasons, including: (a) fears of unknown side effects (53%) and addiction (18%), (b) belief that a medication was no longer effective (18%), and (c) feeling that the child was on too many medicines (23%). Handelman et al. proposed that implications for improving adherence and tailoring asthma education among participants were apparent and striking.

Age groups also share common beliefs and values that constitute another dimension of culture. Research among teens has demonstrated the existence of explanatory models of asthma and health behaviors that shaped self-care more than biomedical knowledge (Rich, Patashnick, & Chalfen, 2002). Participants used a video camera to create a visual narrative of day-to-day routines and environment to describe how they lived with asthma. Whereas biomedical knowledge was apparent in their narratives, understanding of key aspects of asthma was based more on personal experience, cultural beliefs, and stories they heard. The researchers concluded that improvement of adherence and asthma self-care behaviors would be better affected by health-care professionals exploring and responding to the personal explanatory models of disease than by emphasizing only patient education.

#### A Personal Bracket for this Study

#### *The Influence and Role of Theory in this Study*

Theory is important whenever precise knowledge is lacking and when complex processes are involved (Dickoff & James, 1968). Both of these conditions exist in this study. Furthermore, because asthma is a complex disease that manifests over months and years and imposes varying action demands on children, theory is useful for conceptualizing the dynamic and chronic course of the illness experience. Two theories in particular guided my efforts over the last years as I sought to identify (a) knowledge that was relevant to the context of the experience of childhood asthma, (b) aspects of the lived experience that should be investigated, and (c) relationships that might exist among various components of the illness experience. These theories raise questions about the illness experience, but they are not the focus of the proposed study. Articulation of relevant theories, constructs, and concepts serves to guard against collecting data to validate vaguely defined, preconceived ideas (Husserl, 1929/1975). The following description of two theories serves the objective of further explaining my personal bracket related to the proposed research.

My interest in childhood asthma is based on a large amount of clinical experience gained through more than 15,000 outpatient encounters as a nurse practitioner caring for children who have asthma. Much of the care I rendered in this setting was delivered in an “educative-assistive role” (Orem, 1995, p. 121) in an ambulatory setting where I worked in collaboration with a pediatric pulmonologist. In this clinical context, I found Orem’s Self-Care Deficit Nursing Theory (SCDNT) particularly helpful. However, over time I discovered that a theoretical framework for viewing asthma as a chronic disease added an important set of additional considerations to both clinical practice and research.

#### *Orem’s Self-Care Deficit Nursing Theory*

Orem's Self-Care Deficit Nursing Theory (SCDNT) includes three inter-related theoretical frameworks – the Theory of Self-Care, Theory of Self-Care Deficit, and Theory of Nursing System (Orem, 1995). The Theory of Self-Care proposes that humans have an ability to take deliberate action for regulating life, health, and well-being. An individual's capacity and ability to take effective action is termed self-care agency. The Theory of Self-Care Deficit proposes that to maintain life, health, and well-being, each person must take many self-care actions in an adequate and timely manner throughout the course of each day (Orem, 1995).

A self-care deficit exists when a person's ability to perform the required actions is inadequate to meet all or part of the total need for self-care action. The term dependent-care agent refers to a caregiver who takes action on behalf of an individual who does not have the capacity or ability to take required self-care action, as in the case of young children. The Theory of Nursing System proposes that properly educated and experienced nurses are needed to identify and design a plan of care for individuals whose demands for self-care exceed their ability to perform required actions. Thus, a nursing system is the design and implementation of a plan that bridges the identified gap between the action requirements necessary for the regulation of life, health, and well being and the individual's ability to accomplish those required actions (Orem, 1995).

SCDNT is well suited for conceptualizing the action demands of children with asthma. Application of the theory to this research was facilitated by a personal discussion with the theorist. Orem stated that the critical step in employing SCDNT in a nursing system for children with asthma is to clearly describe and address what needs to be

regulated (Orem, 1998). That is, what aspects of asthma must be understood and actively managed by the child?

Orem (1995) identified a number of relevant, self-regulatory needs including lack of knowledge, skill, or psychological readiness to perform self-care actions. These needs are accentuated when actions involve multiple steps that must be performed continuously over a long time, when actions are technically complex, and when actions require informed judgments and decision-making at several steps of execution. Self-regulation is also challenging when it requires attention to both internal, bodily conditions and external, environmental conditions that are in flux.

In addition, the regulatory requirements of self-care change over time for children with growth, development, decreasing dependency upon others, and variations in general state of health. Orem (1995) also pointed out that self-care actions are dictated by the specific technologies available to aid regulation of functioning for a particular disease, as with the numerous inhalation and monitoring devices for asthma. Time, energy, money, supplies, and motivation is necessary to sustain the work of self-regulation. Therefore, asthma self-care involves specific regulatory processes that require psychological readiness and persistence, essential knowledge, appropriate skills, and adequate resources continually employed to sustain functioning in response to internal and external factors that are constantly changing.

What is the role of a nurse caring for children who have asthma? Among the types of SCDNT nursing systems that Orem (1995) has identified is the supportive-educative system (SES). Orem described particular nursing roles that are relevant to a SES, including provision of support and guidance, fostering an appropriate developmental

environment, and teaching. Support and guidance address the regulatory requirement of fostering the child's psychological preparedness and ability for problem solving to sustain the work of self-care. Specific aspects of support include counseling a child who encounters barriers to self-care at home or school, aiding the child in setting and achieving realistic goals, and strengthening the child's ability to communicate effectively with adults and peers who impact their efforts at self-care (Orem, 2001). The support dimension of a SES is not well conceptualized due to a lack of research into the experience of school age children who have asthma. Qualitative research methods could better describe this aspect of nursing practice in the context of school age children, peers, caregivers, and other adults who impact care.

#### *Chronic Illness Trajectory Framework*

Whereas SCDNT was especially helpful for identifying the short-term needs of children and families, it did not lead me to a robust long-term view of asthma. A second theory, chronic illness trajectory framework (Corbin & Strauss, 1991), provided a more dynamic model of chronicity and prompted new insights and questions about children's experience of asthma. Chronic illness trajectory framework (CITF) is based on a view that some diseases manifest as a changeable illness course that extends over a long period of time with no absolute point of cure. This course passes through various phases that reflect differing degrees of expressed illness. The course is not usually predictable. "Much depends upon the individual, the action taken to shape that course, and the turn of events that occur" (Corbin & Strauss, 1992, p.16). Major phases of chronic illnesses identified by Corbin and Strauss (1992) include (a) pretrajectory (before signs and

symptoms appear), (b) onset, (c) crisis, (d) acute, (e) stable, (f) unstable, (g) downward, and (h) dying. Diseases differ in phase patterns.

Corbin and Strauss (1992) pointed out that in addition to major illness phases there can also be short-term fluctuations or “sub-phases” during which the illness moves in a direction contrary to the overall phase. For example, a patient who is experiencing unstable asthma might have a day or two with very few symptoms are present. Asking this person at this point in the trajectory “How is your asthma today?” would probably not reveal the more important overall phase. Therefore, both short-term and long-term patterns are important in ascertaining the course of a chronic illness. The two patterns must be carefully distinguished. The experience of chronic illness would be expected to include phenomena related to phase changes (Corbin & Strauss, 1992).

The CITF suggests that people who are experiencing a long term disease hold a personal vision of how the illness course will likely progress in the future (Corbin & Strauss, 1991). This vision or disease outlook is influenced by various factors, including the person's biography or larger life events, the severity and frequency of symptoms previously experienced, meaning and significance ascribed by the individual to the illness, and family and community interactions. Corbin and Strauss (1992) termed this vision of the illness course “the trajectory projection” (p. 16).

An important implication of embracing the concept illness projection is the inference that it is important to ascertain each person’s projection. One has to ask specific questions to explore a person’s vision of how the asthma will progress over time. Corbin (1998) suggested that persons hold unique views of chronic illness. In addition an illness projection is not static for the same individual over time. Implicit in the concept that each

person entertains ideas about how a disease will impact their life is the likelihood that these beliefs will shape a person's intentions and behavior. These views must be uncovered through direct discussion with individuals.

Furthermore, the illness projection concept also poses the possibility that a person's expectations about the course of an illness might not match the actual severity and risks of the disease. Health care providers should be concerned that similar behaviors might be rooted in very different projections about an illness. For example, one child with severe disease might believe that asthma will just go away as they grow older. Another child who has experienced severe dyspnea, respiratory failure, and mechanical ventilation might believe that they are eventually going to die of asthma. Both children in these hypothetical situations might fail to use effective medications to control their asthma. However, intentions leading these two children to fail to respond appropriately to asthma would be quite different. One child's ill-conceived optimism and another child's despair should be recognized as distinct motives for not engaging in self-care behaviors. Interventions to improve the health of these children would need to employ different approaches for such divergent asthma projections.

The concept of intentionality is specifically addressed in the CITF (Corbin & Strauss, 1992). This semantic link to descriptive phenomenological research is pertinent to this study. Corbin and Strauss (1991) advanced the idea that chronicity evokes a long-term plan for dealing with continuing illness. "Trajectory scheme refers to the plan designed to: (a) shape the overall illness course, (b) control any immediate symptoms, and (c) handle disability" (Corbin & Strauss, 1992, p. 17). Use of the term *scheme* rather than *plan* seems to arise from a broader concept of what persons do to manage their

illness. Corbin and Strauss (1992) suggested that the trajectory scheme includes much more than the medical plan of care. For instance, they pointed out that technology is often an important part of a person's experience of chronic illness. This technology often changes people's lives and their view of themselves, thus having an influence far beyond direct applications in managing illness. Persons adapt technology to their way of life in an attempt to go on with living despite the disruptions brought on by illness. In addition to a medical plan of care and related technologies persons often incorporate other responses into their long-term plan. Rituals, diversions, meditation, prayer, special nutritional practices, use of vitamins, supplements, and minerals, and other forms of alternative therapy might play an important part in a person's strategy for managing illness. Collectively all illness responses constitute the trajectory scheme.

Perhaps understated, but clearly present in this component of CITF is acknowledgement of the larger concerns of living one's life while trying to reduce the burden of illness. This point of view places living, rather than managing the illness, at the center. From my perspective this aspect of a trajectory scheme seems entirely appropriate for asthma. Use of an asthma action plan, peak flow meters, and inhalation devices are commonplace. However, children and families also widely use additional strategies to manage asthma (Madsen et al., 2003). "The focus of care in chronicity is not cure but first of all on the prevention of chronic conditions, then on finding ways to help the ill manage and live with their illnesses should these occur" (Corbin & Strauss, 1992, p. 22). The clear implication is that health care professionals can build stronger and more effectual partnerships with persons by endeavoring to provide health care for chronic illness in the larger context of living one's life.

In summary, SCDNT and CITF raise several important questions about children's experience of disabling asthma. What is the larger context within which children experience asthma and live with disabling illness? What are the child's intentions related to their illness? Do a child's intentions result in specific behaviors? What are the child's perceptions and beliefs about these intentions and behaviors? How does the child view others as impacting these experiences? If there is a medical plan of care, how is it viewed and acted upon by the child and by others? What phenomena describe a child's intentions to respond to asthma and the illness experience?

*NHLBI Asthma Guidelines and Behavioral Requisites for Self-Care by Children*

Asthma changes dramatically over time with seasonal increases in viral respiratory infections, weather changes, and fluctuations in the levels of airborne irritants and allergens. Individual patterns of disease expression must be ascertained through communication between a clinician and a child and family. Evaluation of therapies for asthma must occur over long intervals of time during which the child's developmental level changes a great deal. These changes often directly impact clinical capability: (a) to use objective tests to diagnose airflow obstruction; (b) to incorporate self-monitoring into the care plan; (c) to support an increase in the child's participation in self-care; and (d) to select alternative inhalation techniques and medication devices that are more effective, less costly, less likely to cause side effects, or less time-consuming (NHLBI, 1999).

Treatment of a child's asthma is often complicated and disrupted by the occurrence of related diseases, especially allergic rhinitis, sinusitis, and gastroesophageal reflux. Co-morbidities can directly or indirectly worsen asthma symptoms and are often a source of confusion for children and families. Finally, with rapid innovations in asthma

therapy, alternative therapeutic options emerge each year, requiring a reevaluation of treatment plans at regular intervals. For all these reasons, successful clinical assessment and management depends in large part on a continuing relationship between clinician, child, and family built on trust and good communication and oriented towards increasing the child's capacity for self-care (AAAAI, 1999).

Component One of the guidelines states that “to establish whether the goals of asthma therapy have been achieved, ongoing monitoring and periodic assessment are needed” (NHLBI, 1997, p. 4). Asthma is a disease of widely varying severity within the same patient over time and from patient to patient. The diagnosis of asthma is dependent upon the presence of symptoms of airflow obstruction that are at least partially reversible and episodic in nature. Specific measures are required to initially assess and then to monitor over time the degree to which asthma impacts an individual’s health. Diagnosis and severity determination in turn support decision making about the types and level of therapies that are indicated. A four-level classification system denotes initial asthma severity: (a) mild intermittent, (b) mild persistent, (c) moderate persistent, and (d) severe persistent asthma.

Currently, asthma cannot be assessed adequately without the cooperation and active participation of the child. Unlike many other disease states, such as hypertension, there is no passive physical or biochemical marker of severity for asthma. Three critical aspects of assessment and monitoring depend upon the patient’s ability: (a) to observe, recall, describe, and record their own breathing pattern over time; (b) to recognize and report factors associated with worsening or improving symptoms; and (c) to perform forced breathing maneuvers for peak flow determination and spirometry (AAAAI, 1999).

Written asthma symptom diaries and peak flow records are important self-monitoring tools that increase the likelihood that appropriate medications and care will be initiated by clinicians. It is unreasonable to expect that all patients are similarly motivated or capable in these tasks (Koh, Choi, & Lim, 2001). Perceptions about the importance of these activities are expected to vary widely among people who have asthma. Attitudes and behavior are likely shaped by factors such as age, gender, race, and belief systems.

Breathing is a very personal and subjective experience. Physical measures alone do not adequately describe asthma. It is evident in the stated goals of Component One of the EPR-2 guidelines that a person's beliefs, intentions, and behaviors are integrally related to the process of assessing and monitoring asthma. Component One goals include the following: (a) "prevent chronic and troublesome symptoms," (b) "maintain (near) normal pulmonary function," (c) "maintain normal activity levels," (d) "prevent recurrent exacerbations of asthma," (e) "provide optimal pharmacotherapy with minimal or no adverse effects," and (f) "meet patients' and families' expectations of and satisfaction with asthma care" (NHLBI, 1999, p. 4). These criteria require a very high level of participation, interpretation, and communication by children.

Component Two addresses the control of factors that contribute to asthma severity. There are two major types of contributing factors: (a) other diseases that commonly complicate and worsen the course of asthma and (b) environmental exposures that trigger airway obstruction. Important concomitant illnesses include allergic and chronic rhinitis, sinusitis, gastroesophageal reflux disease, and vocal cord dysfunction. Each of these diseases has the potential to adversely impact airway health and asthma control. Current therapies for these diseases require regular medication use, vigilance,

and modification of lifestyle over weeks, months, or even years. The presence of one or more of these conditions is very common among children who have persistent asthma. (Hogan & Wilson, 2003). Each disease imposes a significant additional demand for self-care. The prevalence of obesity is also higher among children who have asthma (Epstein et al., 2000). The treatment of asthma is complicated by obesity.

Reduction of exposure to environmental triggers is an important way that asthma control can be improved. Day-to-day responsibility falls on the person who has asthma to avoid airway irritants including tobacco smoke, exhaust from motor vehicles, industrial pollution, and strong chemical fumes, such as hypochlorite (bleach). In addition, allergen-specific airway sensitivity often plays a critical role in the activation of airway inflammation. The process of identifying allergic triggers and lowering exposure to inhalant antigens such as pet dander, dust mites, mold spores, pollen, and cockroach require considerable attention and effort on the part of the person who has asthma. Significant behavioral changes are often necessary to reduce these exposures.

Respiratory viruses are another major asthma trigger. Reduction of the number and severity of infections requires action by the individual who has asthma. The person must chose to engage in health promoting activities, including regular hand-washing, getting the influenza vaccine each year, exercising regularly, eating a healthy diet rich in fruits and vegetables, maintaining an appropriate body weight, and getting enough sleep. These steps contribute to reduced rate of viral infections, better overall health status, and improved asthma control (NHLBI, 1999).

Component Three addresses the role of pharmacotherapy in asthma care. Inhaled corticosteroids (ICS) are the primary controller therapy for persistent asthma. These

potent medications are available in low, medium, and high doses. Guidelines suggest that ICS be used in a step wise manner at higher levels to initially gain control over airway inflammation, then at lower maintenance doses to prevent reactivation of inflammatory cells and mediators (NHLBI, 1999). Adherence is a serious problem limiting the effectiveness of inhaled corticosteroid therapy (Bender et al., 2003). Lack of immediate, perceptible effects associated with use of ICS likely contributes to low adherence rates.

Combination therapy is usually required to control moderate and severe persistent asthma. Two drug classes, long acting beta agonists and leukotriene modifiers, are currently available for use with inhaled corticosteroids to further reduce airway obstruction without increasing steroidal exposure and risk of side effects. Quick reliever medications that produce rapid bronchodilation are the only type of drugs required for management of intermittent asthma. The two classes of quick relievers, inhaled adrenergics and anticholinergics are also important in the treatment of the troublesome airway symptoms for those who have persistent asthma. Albuterol is the most widely used adrenergic, quick reliever medication (AAAAI, 1999).

Considerable knowledge, skill, and discipline is required for the daily administration of asthma medications. Inhaled medications are a departure from the ordinary oral medication route that is widely accepted in American culture. While a pill can be merely swallowed in a manner that is no different than ingesting food or beverage, the act of inhaling a medication is a unique and potentially problematic maneuver. (Of course even swallowing a pill can be a challenge for a young child.) Each major type of inhalation device has unique features and requires a prescribed inspiratory flow rate and time to optimize deposition of the medication into the lungs. A large number of people

fail to master the requisite inhalation technique resulting in inadequate pharmacotherapy and poor asthma control (Marguet et al., 2001).

Current pharmacotherapy is effective only when the person who has asthma can exercise a significant amount of knowledge and skill. A high degree of motivation and problem-solving is involved in sustaining maintenance therapies and responding to periodic changes in the level of airway obstruction that might occur with weather changes, seasonal and perennial inhalant allergens, incidental exposure to airway irritants, respiratory infections, and airway co-morbidities. Many human factors influence the desired end point of an appropriate dose of inhaled medication.

Some of these factors are contextual, linked to the home or school environmental (Barrett et al., 2001). Other factors are imbedded in personal beliefs, emotions, knowledge, skills, intentions, and behaviors that are unique to the individual. A paradoxical relationship has reported between increasing age, and adherence among school-age children (McQuaid et al., 2003). While knowledge and responsibility increased with age, younger children demonstrated better adherence. Adherence rate among 106 school age children involved in this study was 48%. Current expert guidelines and clinical practice focus heavily on knowledge and skill with little attention to other behavioral antecedents to effective asthma control (AAAAI, 1999).

Component Four states that “education for an active partnership with patients remains the cornerstone of asthma management” (NHLBI, 1997, p. 5). EPR-2 further describes this effort as focused on self-management education.

Asthma self-management education should be tailored to the needs of each patient, maintaining sensitivity to cultural beliefs and practices. New emphasis is

placed on evaluating outcomes in terms of patient perceptions of improvement, especially quality of life and the ability to engage in usual activities. (NHLBI, 1997, p. 5)

Recommendations suggest that clinicians provide patients with written self-management plans that provide instructions for managing exacerbations and emergencies. The guidelines also suggest that these plans should be individualized, reviewed, and adjusted with family involvement and an emphasis on individual goals and outcomes.

The four components approach is an important step away from a purely clinical view of asthma, but does it go far enough? In the four components approach is there sufficient acknowledgement of the critical role of the one who has asthma? Do the guidelines understate the central position of the child and family in the successful management of asthma? Does the patient education component of the guidelines adequately acknowledge the contributions of the patient and family across all four components of therapeutic interventions? Have clinical guidelines addressed individual differences that might influence the degree of success with self-care? Are we still ignoring crucial factors that shape how individuals become aware of and motivated to change their experience of asthma? Why are some people better able sustain efforts to control asthma while other relapse with life-threatening exacerbations? Do we adequately understand the experiences of individuals who have asthma? Would we learn how to better promote positive behavioral change and improved health outcomes through careful study of individuals' actual experiences of asthma?

*Expert Asthma Guidelines, Evidence, and Translational Challenges*

The importance of the expert guidelines is in large part due to credibility arising from strict criteria applied in the formal review of published research. Over the last decade the standards for scientific evidence have become more carefully defined by the NAEPP expert panel through classification of evidence by levels. This culminated in the 1997 update with adoption of a systematic method used to review asthma literature that reflects prevailing views on standards for evidence in scientific work (NHLBI, 1997). Four hierarchical categories of evidence were recognized when justification for recommendations was set forth in the 1997 update.

Evidence Category A was assigned to recommendations that could be supported by several randomized controlled trials (RCT) demonstrating consistent findings and involving large numbers of participants that were representative of the populations for whom the recommendation was intended. Evidence Category B reflected support from RCT with only a limited body of data where the concern of adequate representation for target groups cannot be set aside or when findings were inconsistent. Meta-analysis of RCT was also included in this category. Evidence Category C was assigned to recommendations based on nonrandomized trials and observational studies. Evidence Category D was used when “some guidance was deemed valuable, but the clinical literature addressing the subject was insufficient to justify placement in one of the other categories” (NHLBI, 1997, p. 6).

Whereas current NAEPP guidelines clearly state that a high degree of participation by patients is required for asthma control, rational steps for promoting this involvement are largely missing. Relative silence on the subject reflects both a strong

bias towards quantitative research (that has not answered the relevant questions) and a general lack of criteria for soliciting and judging applicable qualitative and behavioral research. Lack of guidance about how to bring about behavioral change is a very serious problem in light of the rationale for developing guidelines. The purpose of EPR-2 is both comprehensive and patient-focused. “We ask for the assistance of every reader in reaching our ultimate goal: improving asthma care and the quality of life for every patient and their families” (NHLBI, 1997, p. xi). However, the charge to the panel was to advocate a general approach based on definitions arising entirely from a quantitative perspective characteristic of the biomedical sciences. Therefore, qualitative researchers face serious translational challenges in their efforts to communicate findings.

There are important parallels between current views of what constitutes science in the study of asthma and my personal views on the need for human science research in the field. A supplement to the *Journal of Allergy and Clinical Immunology*, entitled simply “Science”, Spahn, Covar, and Stempel (2002) set forth a basic paradigm for generation of asthma knowledge. To explain the intellectual processes required by an evidence-based approach, the authors set forth a logistical framework.

The basic science understanding of the pathophysiology of a disease often serves as the basis for clinical investigations. This knowledge is used to propose new directions in care and confirm initial concepts. These hypotheses are next answered in clinical trials with selected patient populations. Finally, the use of observational databases, including medical and pharmacy claims, permits the further confirmation of the findings of clinical trials in a more generalizable population. (Spahn, Covar, & Stempel, p. S496)

The implications of such an approach are straightforward. Basic science describes the underlying nature and processes of the disease state we know as asthma. The focus of study is the fundamental makeup of cells that compose the respiratory structures and the biochemical responses of those cells to changing conditions expressed within the airways. From this understanding arise opportunities to alter disease processes by modifying the biochemical environment in which cells function. Randomized controlled clinical trials of pharmaceutical agents are used to establish the efficacy of new therapeutics that target selected biochemical aspects of the disease.

Science that explores human experience has a similar mission to the one described above for basic science. Initial work must be descriptive (Morse, 1994). The focus of study is not cells, but persons in the context of their daily lives. Just as it is important to understand the response of cells to changes within the airway, it is important to understand how people respond to airway changes and to the complex interpersonal, social, and physical environments in which illness is experienced. Appropriate research methods can reveal how people experience asthma – their perceptions, beliefs, intentions, and behaviors. It is reasonable to expect that out of this understanding will also arise opportunities to design and test therapeutic interventions aimed at reducing the burden of disease. Future testing of proposed interventions could be accomplished by randomized controlled clinical trials, as in basic science and pharmaceutical research.

In the final analysis the value of a medication or any other asthma intervention lies in the degree to which the human burden of disease is diminished. Biochemical changes are not adequate end-points. Desirable outcomes are embedded in human experiences of the disease state. Biological measurements such as airflow parameters are

important in the evaluation of asthma, however the individual's experience, conscious appraisal, and report are paramount (Fuhlbrigge et al., 2001; Spahn et al., 2002).

Unfortunately, the human perception of asthma is often blunted and judgment of serious airway changes can be impaired (Kendrick, Higgs, Whitfield, & Laszlo, 1993).

Therefore, study of the human experience of asthma is warranted to look for ways to improve individuals' capacity for detecting and managing their own asthma, to generate new person-focused interventions, and to improve general understanding of asthma outcomes in human, experiential terms.

#### *Barriers to Qualitative Research Pertaining to Asthma*

More empirical evidence about why and how individuals recognize and attempt to reduce the adverse effects of asthma would increase the relevance and utility of expert guidelines. Unfortunately, there are very few studies in which these questions have been probed. Why has this type of scientific work not been pursued? There are two likely explanations: the importance of understanding the human experience of asthma has not achieved deserved attention in the national health agenda and scientific methods for conducting this type of research are not widely known, accepted, or utilized.

In a recent policy statement the Department of Health and Human Services (DHHS, 2000) articulated a plan for reducing the national burden of asthma. Four priority areas for future work were identified: (a) determine the causes of asthma and develop interventions to prevent its onset, (b) reduce the burden of asthma for people with the disease, (c) eliminate the disproportionate health burden of asthma in minority populations and those living in poverty, (d) track the disease and assess the effectiveness of asthma programs (DHSS, 2000). These objectives, like the four components of the

EPR-2 guidelines are clearly focused on the human impact of asthma. However, the document fails to call for research that would increase understanding of this dimension of asthma. Within the section entitled “the science of asthma,” there is no discussion of behavioral or experiential factors that bear upon the course of asthma. The opening sentence sets the tone and direction of the paper. “Over the past 15 years, biomedical research has produced major advances in the understanding of asthma” (DHSS, 2000, p. not assigned). The entire science section is devoted to a discussion of research about inflammation, genetics, and environmental factors.

The significance of this omission can be better understood in light of a review of the purpose for which the agency exists. In the section entitled “DHHS Capacity to Address Asthma,” the department’s mission is stated.

The mission of DHHS is to enhance the health and well-being of Americans by providing for effective health and human services and by fostering strong, sustained advances in the sciences underlying medicine, public health, and social services” (DHSS, 2000, p. not assigned).

This is further articulated in the last of the DHHS' six strategic goals - to “strengthen the nation's health sciences research enterprise and enhance its productivity” (DHSS, 2000, p. not assigned). I believe that the overshadowing influence of basic science on thinking about asthma has clearly had an effect on research funding and health policy. Recent evidence that asthma deaths are associated with psychosocial factors and health behaviors underscores the urgent need for a widening of the asthma lens (Sturdy et al., 2002). We must look beyond the favored biomedical themes that have held the attention of researchers over the last decade.

A second possible explanation for the lack of research examining the human experience of asthma might relate to obstacles for conducting this type of research. There remains today a general perception in academic settings that quantitative methods are inherently more precise and scientific than qualitative approaches (Ginzberg, 1995). However, are quantitative methods, arising out of a traditional, basic science framework, adequate for understanding human experience and behavior? A poverty of research publications and the recent emergence of numerous qualitative approaches for this purpose suggest that traditional quantitative methods generally do not meet the need.

*Special Considerations Related to the Method of Choice for This Study*

*Bracketing, Juxtaposition, and Abutment*

A clear rationale is needed for selecting a particular qualitative methodology when the intent is to understand human experience. Each method has special requirements related to the philosophical underpinnings. Preparation for using Porter's (1998) nursing research method that was inspired by Husserl's phenomenology (1913/1962) required an exhaustive review both current knowledge and relevant theories and careful consideration of my personal orientation to the study. Husserl (1929/1975) clearly prescribed this bracketing step calling it the "phenomenological reduction" (p. 32). I believe that the power and potential of the methodology arise from what Porter (1998a) termed juxtaposition and abutment.

The scientific theories and constructs that were held apart from the stream of experience are brought back in juxtaposition with the structures of experience, serving as points of comparison and contrast. Creating this abutment of experiential structures and the body of knowledge enhances the clarity with which the structures

are seen and invigorates conventional understandings of the experience (Porter, 1998a, p. 22).

What I learned was that successful application of Porter's method (1998a) to describe the experience of disabling asthma among school children depends on three factors. These considerations will be briefly explained. First, application of the method to the study of participants' experience of a chronic disease would require a researcher to have expertise with the disease state. Insight into the relevance of data and potential applications of new knowledge would hinge in large part on that base. Second, in the case where a very large body of knowledge exists pertaining to the context of the experience, the height of the desired juxtaposition and abutment would depend on a thorough review of that knowledge domain. A low level of knowledge would not allow an adequate backdrop for understanding the significance of newly discovered structures of experience. Later dialogue about the research with scholars and practitioners depends on both clinical expertise and a grasp of the relevance of new knowledge. Finally, the degree to which participants recruited for the study adequately represent the larger public health problem as well as the quality of the study would determine the potential impact of the research. These methodological issues will be discussed in Chapter Three. Therefore, in practical terms the demands of this type of research are quite high.

#### *Consideration of Potential Sources of Error*

If fair or true representation of children's experience is the goal, then error could occur in this study from a failure to fully or accurately describe observations. For this study I considered potential sources of error. Deeply held beliefs or allegiance to concepts about the experience of disabling asthma could become a source of bias and

error. Porter's (1998a) method includes specific provisions to identify appropriate sources of data, describe the data, analyze the data, and reconfirm the data by representing these to the participant for reflection and clarification or correction. These steps reduce the likelihood of several types of error, including filtering, projecting, abbreviation, truncation, and misrepresentation.

I will briefly identify types of error I have considered in relation to this study. Filtering occurs when the researcher selects some data that is valued, while rejecting other data that is not valued. Valuing in this example might be based on what the researcher hopes to find or wants to report. Filtering can also occur by the participant, influencing which data are presented or withheld from the researcher. In the case of asthma, a child might not share their negative feelings about taking medications, fearing that this could displease the researcher. Projection is another type of error that involves interpreting data in a way that erroneously assigns meaning. This would occur if I reported that a child was not taking a medication because it tasted bad, if this assumption was based on the researcher's own repulsion toward taking inhaled medications. Data abbreviation would occur if I omitted complexities to render data more manageable. For example if distinctions between a child's experiences in a two-household family were not adequately spelled out in the interest of simplifying the data. Again, the participant could commit the same type of error. Truncation involves failure to maintain critical links between the data or dropping branching phenomena for convenience. Finally, misrepresentation entails the presentation of data inaccurately or out of context with a result of leading one to erroneous impressions.

*Reflections on the Proposed Study*

Over the course of several years of preparing to conduct this research I struggled to conceptualize the work in a way that would balance the need to treat each participant as an individual while recognizing the possibility that some aspects of experience might be similar or shared. I came to think of asthma (the illness experience) as a landscape that has topographical features that people might experience in different ways. Much like visitors to a national park or a foreign destination, people with asthma gain first hand experience about their disease by exploring the lay of the land. Just as visitors to a park do not take in every sight or walk the same path under the same weather conditions, so children with asthma do not have identical exposures, encounters, or experiences. Yet if the views of many park visitors are described, true to the experience of each, a composite image of the place emerges.

Each individual account is legitimate. It would not be unusual for the personal stories to differ widely. Even if the focus of the study were narrowed, diversity in experience would likely prevail. If for example the study were to focus on park visitors who had a bad experience on their journeys, one would expect differing explanations. Inclement weather, high cost of the vacation, car problems, getting lost due to lack of signage, conflict with park employees, and disappointment with the sites visited might be on the list of reasons for a spoiled vacation. A combination of these factors could explain most negative reactions to the park. A thorough description of each person's experience would likely yield a useful composite list of problems that park officials could examine and respond to in efforts to improve the experience of park visitors.

Similarly a descriptive study of the experience of rural school children with disabling asthma could reveal ways in which care and support can be improved. To build

a useful composite view of these experiences it is important to start with unbiased descriptions of individual experiences. If asthma is like a landscape that is experienced differently by each person, then a number of considerations are important. The natural view of children used to guide the preceding literature review affords some insight into the major settings and landmarks of their experiences. Technology dictates many constructed experiences, such as use of a peak flow meter or inhaler. Yet, an individual child with disabling asthma might not have had exposure to particular devices.

Likewise, some rural children might have received no support from a school nurse, while others have found a school nurse to be their closest advisor and caregiver for asthma. In my view descriptive phenomenology holds the promise of being a powerful tool for mapping the diverse landscape of asthma as it is described by rural children with disabling asthma. The motivation for describing asthma experiences is not construct-driven, but simply the making of a map. There is no preconception driving me to seek to prove any particular associations, such as one between disease severity and degree of disability. Rather the motivation for mapping the asthma landscape in this study is to understand the particular and composite experiences of children with disabling asthma.

I find the metaphor of asthma as a landscape far more instructive and interesting than the concept of “having asthma” that is held so tightly by health care professions. The static image is not well suited to highly interactive and dynamic airway condition(s) we call asthma. A fascinating image of “catching the asthma” (Horner, 1992), referred to by some families is certainly more apropos, as it better captures the illusive, changeable nature of the illness. An animated view of asthma as a moving, unpredictable thing makes more sense to children and families. Somewhere along the way as I prepared for

this work a stirring image from Porter's article "Staying Close to Shore" came to mind, reinforcing the value of seeing the context of experience as landscape metaphor. In this important work Porter (1998b) describes a participant's experience in her own words quoted above to reveal an important feature of her life-world (Porter, 1998). Perhaps descriptive phenomenology moves people to reach out of their immediate circumstances and stirring wider views of their lives. Porter's description of her own work seems to call up this imagery. "When I do research in the homes of older widows who live alone, it seems our mutual interests cover a lot of territory. Moving together across that ground, there is a sense of freedom" (Porter, 1998b, p. 25)

#### *A Long Road and a Steep Ascent*

There is a tension between getting a thing done and doing it right. The challenge of descriptive phenomenology was clear to me from the onset. A number of my peers asked "Why are you doing qualitative research? Aren't you afraid you'll never get through?" My response was always the same. "This is the time and place I have been given to learn to really listen to children who have asthma. As a nurse, I think this is what I must do." Along the way I found encouragement in Porter's words that seemed to resonate with my research convictions and life circumstances. "With the participants, I stand on nurses' turf, 'going forward step-by-step' [Husserl, 1931, p. 180]" (Porter, 1998b, p. 25).

It seems important to further comment briefly on why my journey from doctoral candidacy to committee review of a research plan was so long. First, I treasure with Porter (1998b, p. 19) the words of Edmund Husserl regarding descriptive phenomenology. "It is all of it hard" (Husserl, 1931, p. 113). As I read and reread

Husserl's *Ideas*, I found the text a vexing mix of cryptic and succinct writing. While I worried that something was lost here and there in the translation from German to English, the greater gaps seemed to fall between my high speed Internet thinking and Husserl's subterranean probing of consciousness. Analogies fall short of describing a thing fully. In this case I don't know if this intellectual pathway took me down to subterranean places or up to new heights as the title of this section suggests. It is likely both, since I can see my own journey, like the experience of children who have asthma, as distance traveled and places visited across a landscape and over time. The terrain and vistas changed along the way.

My deeply held personal convictions held me on course through the experience of a difficult passage. I relate these views because these are relevant to my work. My consciousness and inquiry stretch toward higher standards. "God's ultimate goal for your life on earth is not comfort, but character development." "You wonder, 'Why is this happening to me? Why am I having such a difficult time?' One answer is that life is supposed to be difficult! It's what enables us to grow" (Warren, 2002, p. 173). I did not expect this work to be easy, yet I did not fully understand in the beginning that three major elements were critical to the culmination of this research. However, as a masters prepared nurse I did hold tightly to the ideal of nursing as a triad with clinical practice, research, and education as interwoven dimensions of professional life. Still, I had to come to more deeply appreciate that the value of this research would be stirred in a crucible where (a) professional and personal knowledge of the experience of interest, (b) a generous appraisal of the body of existing knowledge on the subject, and (c) careful rendering of the day-to-day experiences of participants in their world would produce new

understanding that could truly “aid science” (Porter, 1998, p. 23) by “strengthening it internally” (Husserl, 1931, p. 75).

*Reverence for the Experience of the Child*

A recurring theme in my rationale for pursuing a qualitative study of children with asthma has been that their voices need to be heard. Recently, I was encouraged to see publication of an article entitled “Hearing children’s voices: Methodological issues in conducting focus groups with children aged 7-11 years” (Morgan, Gibbs, Maxwell, & Britten, 2002). Whereas the article primarily focused on methodological issues pertinent to focus groups, it also touched on the core issues of effectively talking with and listening to children. The researchers explored the experience of asthma for 42 children. This was a source of encouragement to me, stirring hope that the work I planned was reasonable, valuable, and methodologically promising in what it might uncover.

For this study an expanded view of the capacity of the child was required. To realize the aim of understanding the experience of children who have asthma it was necessary to first enlarge my expectations. My many years of clinical experience working with children in various institutional settings were not held to be sufficient to prepare me to discover and describe children’s experience of asthma. Nor would my experience of parenting five children for the last 25 years fully equip me for the task. Finally, although I had worked closely with large numbers of young children and families in their homes and communities in more than a dozen different countries and cultural groups over two decades, I was not adequately prepared by these experiences.

Each of these life experiences provided something of value to my role as researcher, however none opened a window large enough to catch a view of the inner life

of children required for a study of this depth. Only a new reverence for the thoughts and gifts of children brought me to a point of readiness to open my eyes a bit wider and to listen with a more patient ear. This meant a willingness to see the child's world beyond the clinical context. Listening with a patient ear meant being with the child in a way that communicated an "enduring, tolerant, long-suffering, and serene attitude" (adjectives from the Word™ 2003 thesaurus). To accomplish these goals a coherent philosophy was required.

Florence Nightingale wrote a little known piece entitled the "Health of Houses" (Seymour, 1954) in which she advanced the notion that the physical and emotional environments surrounding a person are critical to health. Her thoughts were revolutionary at a time when even the practice of hand-washing was held in disdain. Many years passed before her insights became integral to health care. Household factors are still poorly understood, but very much the subject of investigation, particularly in the field of asthma. Research into the role of a host of environmental factors is proceeding.

What do we know about the health of children with asthma and the intrapersonal factors that impact their response to disease? As reflected in the literature review, a surprisingly small number of studies have explored these questions directly with children. An important barrier to this type of research might be the lack of respect for the capacity of children to reflect upon and to communicate their experiences. This raises a more serious question about the western view and treatment of children, particularly in relation to health. I realized the need for a more generous appraisal of the capacity of children.

An Italian physician, Maria Montessori (1966), is credited for the emergence of an educational method that held a different view of the child. Dr. Montessori's work

echoed Florence Nightingale's concerns about the shaping role of the environment. In an attempt to improve the desperate conditions of children living in tenement housing in the early 1900s, Montessori turned her attention to the potential of the child and the importance of creating an environment in which the child could escape the cycle and culture of poverty through experiential learning. Her work bears on this study. Over the last 100 years, through the contributions of her close associates, Montessori's philosophy has been articulated as it relates to the education of young children and in relation to her deep respect for children and their capacity for deep thought and reverence (Gobbi, 1998). What has not received attention are two keys to the relevance of this work to research involving children: (a) her philosophy advances an awareness of the capacity of children to learn and to live their lives fully, and (b) Montessori held that a scientific approach is essential for realizing the potential of the child (Montessori, 1966).

Over the last 100 years Montessori's (1966) educational approach has spawned the development of theory and philosophy to guide pedagogy. Within the educational agenda proposed by Montessori were guidelines for the adult who would spend time with children. Attitude was highlighted as critical to success with the approach. Much emphasis was placed by Montessori on the need for the adult to respect the child and to commit to an observational process that did not insert adult views and conclusions. Herein lay the relevance of her work to this study. These are perspectives I view as essential to the conduct of research aimed at understanding children (Montessori, 1966).

#### Conclusion of the Literature Review and Brackets

I believe there is strong intuitive support for research aimed at describing the experience of disabling asthma among rural children. Preliminary work is currently

lacking, therefore descriptive research is needed. Answers to proposed research questions could bring a new understanding of this dimension of childhood asthma to society and to the health-care enterprise. In Chapter Two I have provided evidence that these data are not adequately known or proportionately explored by existing research. The experience of asthma, as reported by children themselves, has been generally overlooked. The existing body of research and current literature do not provide a balanced examination of asthma as both a biochemical disease process and a human experience. The proposed research is warranted to respond to these problems and to generate new knowledge.

There is strong experimental evidence that within children's experience is untapped potential to reduce the burden of disease. The efficacy of asthma interventions that have been specifically designed to enhance a child's ability to engage in self-care is well established (Bartholomew et al., 2000; Homer et al., 2000; Krishna et al., 2003; Rubin, Bauman, & Lauby, 1989). Better understanding of the child's lived experience might provide support for more effective, child-centered asthma interventions. There is the potential that findings might guide future efforts to improve technologies pertaining to asthma self-care for children. This study also responds to a longstanding, unanswered call of researchers for additional studies aimed at improving our understanding of the behavioral factors that influence childhood asthma (Clark & Starr-Schneidkraut, 1994).

## CHAPTER THREE

### METHODS

#### Design

In this chapter, I will describe the design, data collection plan, and analysis procedures used in the study. The approach described in this chapter is consistent with a life-world (Schutz & Luckmann, 1973) paradigm for nursing research (Dahlberg & Drew, 1997; Porter, 1995, 1998a). This holistic perspective views both practice and research roles of nursing as arising from a commitment to understand the world as it is experienced.

The overall aim of phenomenological research is the description and elucidation of the everyday world in a way that expands our understanding of human experience. In holistic nursing, the aim of such research is to assure that patient's experience of their life situation is not overlooked or relegated to less importance than clinical concerns. (Dahlberg & Drew, 1997, p. 304-5)

The need for descriptive qualitative research pertaining to children is evident. "The bulk of published research on young children has been quantitative" (Graue & Walsh, 1998). The literature review in Chapter 2 confirms a preponderance of quantitative research related to childhood asthma. I found that quantitative methods have not produced adequate explanations of children's experiences of disabling asthma. The neglect of descriptive, narrative approaches to childhood asthma is not unusual in the larger arena of children's research. Graue and Walsh stated:

The literature related to young children is filled with reports of studies in which children have been the objects of inquiry. Given the amount of work focused on

children, it is surprising how little we know about their lives. Little if any attention is paid to the contexts in which children live. Where is the understanding of, or even interest in, children's lived experiences? (p. 1)

Little is known about the experience of disabling asthma from children's perspectives. This study was designed to respond to the lack of descriptive studies. A descriptive phenomenological approach was used based on Porter's (1998a) method to generate knowledge about rural children's experience of disabling asthma. The first aim was to describe children's intentions related to asthma. A second aim was to examine their perceptions about the varied contexts of their experiences at home, at school, in their community, and in places where they receive health care. A third aim was to compare and contrast the phenomena of children's experience of disabling asthma with pertinent theoretical frameworks and constructs found in the research literature and with current expert guidelines for clinical practice. This study was designed to strengthen the scientific basis for understanding and responding to the needs of children with disabling asthma.

A series of three interviews were conducted for each of 8 rural children with a total of 24 interviews (Morse, 2000; Sandelowski, 1995). School nurses, who identified disabling asthma as a serious problem among their students, distributed recruitment materials to appropriate families. Only one child per school participated in the study. A parent consented to participation of each child in the study. Children included in the study assented to participate after parental permission was obtained. Interviews took place in participants' homes. A parent was present in the home throughout each interview. A cross-sectional design that was appropriate for small-scale qualitative

studies was used for data collection (Morse, 1989). Interviews occurred on a consecutive, weekly basis with one exception that was arranged to accommodate a family's needs. In this single case a third interview took place after a 2-week interval. This longer time interval between interviews did not appreciably affect the study.

This preliminary study was designed to generate in-depth knowledge of children's experience, rather than to generalize findings to larger populations (Porter, 1999). Step 4 of Porter's (1998a) method was used for data collection, whereas Steps 5 to 7 of the method were used to guide data analysis. Findings from emerged from interviews with 8 rural, Midwestern children. The study was designed to extend the approach in the future to include other populations of children who have disabling asthma (Sandelowski, 1995). High priority was placed on selecting procedures and software that support extension of the study. This research design facilitated efforts to collect, analyze, and present data in a format that was compiled in preparation for inclusion in a more comprehensive dataset based on future research, while protecting the confidentiality of participants.

#### Data Collection

##### *General Procedure*

The fourth and fifth steps of Porter's (1998a) descriptive phenomenological method provided guidance for my plan to observe and describe the life-world (Schutz & Luckmann, 1973) and experience of participants. A general plan for data collection supported this method in that I employed appropriate procedures for sampling, recruiting, and interviewing rural children with disabling asthma. Non-probability sampling is appropriate for qualitative studies and was used in this study (Luborsky & Rubinstein, 1995; Sandelowski, 1995). "Because the research goal is to describe the common features

of an experience, it is important that participants share certain demographic characteristics, which represent inclusion criteria for the sample” (Porter, 1999, p. 796). Purposeful sampling was used to identify rural children ages 7 to 12 with disabling asthma (Porter, 1999; Sandelowski, 1995). For this study 8 school-age children were recruited who were attending public schools with known excessive rates of disabling asthma. Schools were selected from rural communities in a 19-county area including and surrounding Boone County, Missouri. The research method required regular access to the participants in their natural settings (Husserl, 1929/1975; Porter, 1998a), therefore consideration of travel time and distance dictated restriction of the geographical area from which potential participants were recruited (Porter, 1999). Data were collected by interview and observation in children’s homes to explore the experience of disabling

Table 1. *Plan for Data Collection and Analysis*

Activity	Weeks						
	1-3	4-6	7-9	10-12	13-15	16-18	19-21
Recruit and interview participant No. 1	■						
Transcribe and analyze No. 1 interview set	■	■					
Recruit and interview participants No. 2 and 3		■	■				
Transcribe and analyze No. 2 and 3 interview sets			■	■			
Recruit and interview participants No. 4 and 5				■			
Transcribe and analyze No. 4 and 5 interview sets				■	■		
Recruit and interview participants No. 6, 7, 8					■		
Transcribe/analyze No. 6, 7, and 8 interview sets					■	■	
Finalize Data Analysis						■	■

asthma. Data were analyzed using Porter's method (1994, 1998). The data collection timetable is shown in Table 1.

### *Characteristics of Prospective Participants*

Rural children, ages 7 to 12, with disabling asthma were eligible for participation. Selection of rural children with disabling asthma was based on evidence that marked differences related to urban versus rural residence exist both in the context of asthma (Barrett, Gallien, Dunkin, & Ryan, 2001; Horner & Fouladi, 2003; Huss et al., 2001; Resto et al., 2001; Rodehorst, 2003; Saywell, Zollinger, Schafer, Schmit, & Ladd, 1993) and in the context of childhood in general (Nairn, Panelli, & McCormack, 2003). Scholars have urged researchers to examine the geographic context of children's experiences (O'Brien, Jones, Sloan, & Rustin, 2000).

The rationale for inclusion of children ages 7 to 12 was supported several related factors. Children 7 to 12 share developmental traits and have demonstrated readiness to participate in semi-structured interviews (Fine & Sandstrom, 1988). First, children in this age group have provided meaningful data in studies that employed interview and observation techniques (Dixon-Woods, Anwar, Young, & Brooke, 2002; Ireland, 1997; Yoos & McMullen, 1996). Children 7 to 12 are capable of comprehending their rights as research participants (Hurley & Underwood, 2002). Children in this age group are accessible because they attend school and can be identified by school nurses and others as experiencing asthma disability based on school attendance and performance (Newacheck & Halfon, 2000). Finally, new knowledge about the experience of children 7 to 12 might inform early intervention and prevention efforts to reduce the burden of childhood asthma.

A definition of disability due to asthma for the proposed study was derived from the National Health Interview Survey on Disability (NHIS-D), National Center for Health Statistics, Centers for Disease Control and Prevention (1994). The survey was designed to provide information about a range of disabilities to promote better understanding of disability, to inform public policy, to establish prevalence rates for disability due to selected health conditions, and to provide descriptive statistics about the effects of disability. The NHIS-D incorporated various definitions of disability including functional limitations, health conditions, emotional and mental disorders, and communication, sensory, and mobility problems.

Newacheck and Halfon (2000) analyzed data from the 1994-1995 National Health Interview Survey involving 62,171 children younger than 18 years. They reported that asthma was the single most prevalent cause of childhood disability, affecting 1.4% of US children. “Disability is a long-term reduction in the ability to participate in children's usual activities, such as attending school or engaging in play, due to a chronic condition” (p. 288). Newacheck and Halfon further noted that disabling asthma resulted in an annual average of 20 restricted activity days, including 10 days lost from school. “Prevalence of disability due to asthma was higher for adolescents (odds ratio [OR], 1.64), black children (OR, 1.66), males (OR, 1.23), and children from low income (OR, 1.46) and single-parent families (OR, 1.37)” (p. 292). They also reported a dramatic increase of 232% in the rate of disabling asthma among children since 1969. Disability due to all other chronic conditions increased by 113% in the same time period.

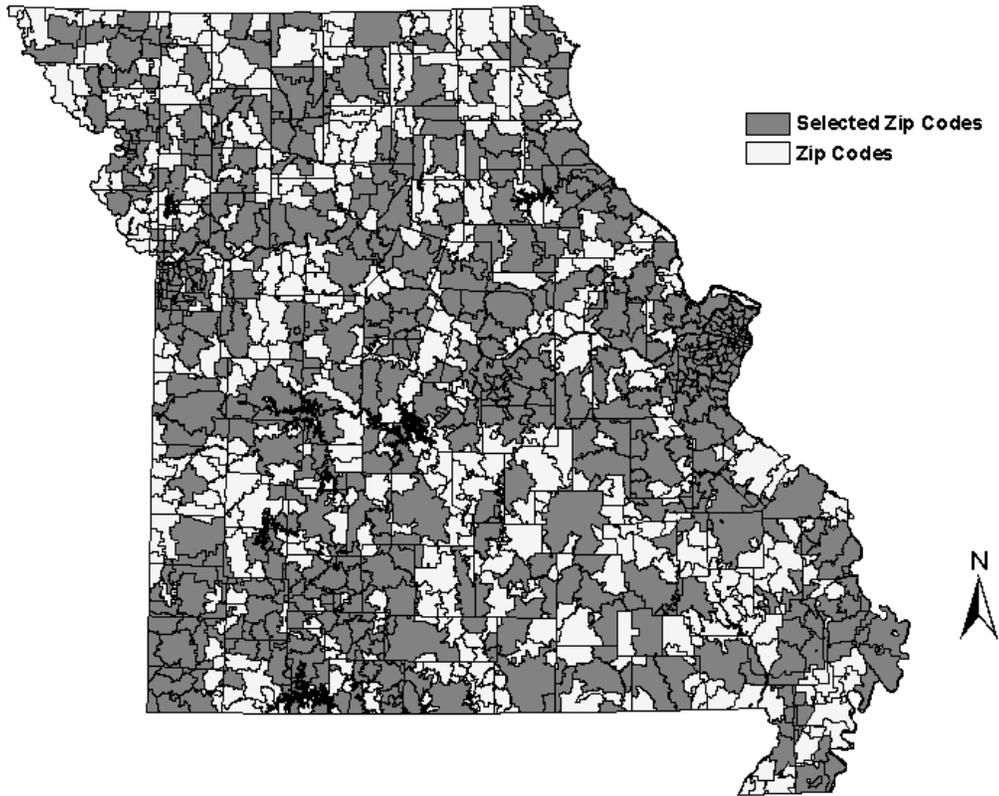
### *Sampling Technique*

Porter (1999) described a method for determining the eligible, accessible population (EAP) for a phenomenological study. "When a relatively rare clinical population is the focus of a proposed study, and inclusion criteria are to be employed in sampling, the number of potentially eligible participants is a critical concern" (p. 796). Porter (1999) pointed out that the feasibility of a study that requires travel to participants is first determined by the "geographically accessible population (GAP)" (p. 797). A geographic plan for sampling will be based on recent survey data from Missouri school nurses' appraisal of disabling asthma among students. Francisco and Konig (2005) developed a survey for Missouri school nurses based on the NHIS-D definition of disabling asthma. The purpose of the disabling asthma survey (DAS) was to evaluate the need for interventions to assist selected schools and communities address the problem of disabling asthma (IRB project 1048936, School Nurse Appraisal of Disabling Asthma Among Missouri Primary & Secondary Students).

The survey was designed to (a) identify the number of students with disabling asthma by school zip code, (b) determine the rate of disabling asthma among populations of students served by reporting school nurses, and (c) allow school nurses to assign a priority score based on perceived health risk associated with disabling asthma among affected students. Fourteen hundred surveys were mailed in the spring of 2005. Over 1000 school nurses responded. Data pertaining to 520,000 Missouri students were obtained and analyzed for 487 of the 669 zip code tabulation areas (ZCTA) in the state (Figure 5) (Francisco & Konig, 2005).

Analysis of the DAS and determination of the geographic sample for this study were based on data obtained for ZCTA from the Missouri Census Data Center (MABLE

## Response To Disabling Asthma Survey by School Zip Code



*Figure 5.* Missouri zip codes for which DAS results were analyzed

Geocorr 2K: Geographic correspondence engine with census 2000 geography, 2005). The Geocorr engine generated requested target data for specified variables (geocodes). I selected ZCTA as the source variable and county and urban-rural portion as the target geocodes. ZCTA were developed for the first time for 2000 census data. Census blocks were aggregated to create geographic boundaries corresponding to existing postal zip codes. ZCTA sometimes cross county lines because zip codes follow roadways that facilitate access to places where persons live, work, or receive mail. Geocorr 2K defines urban-rural portion based on whether a ZCTA meets the urban criteria of being within a major city or the suburbs of a major city, or in a town of 2500 or more. A more precise

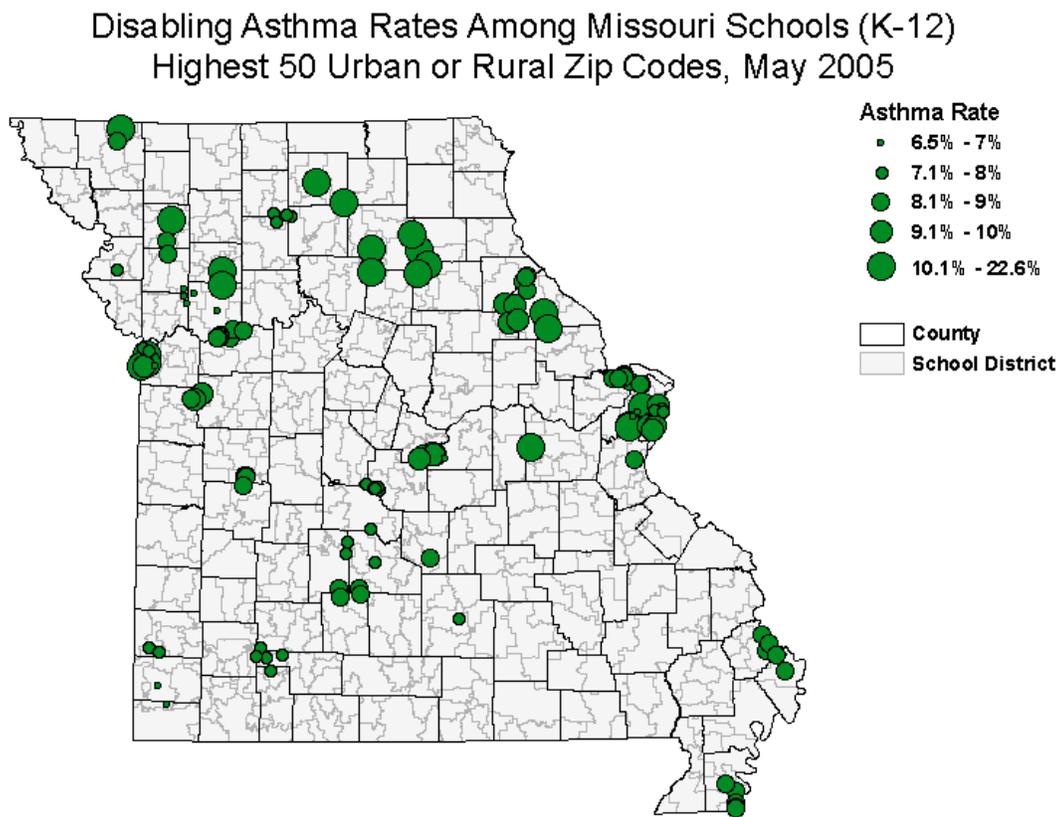
mathematical formula is actually applied to the determination. Urban areas are those with more than 1000 persons per square mile (Office of Social and Economic Data Analysis, Master Area Geographic Glossary of Terms, 2005). For the purpose of this study rural zip codes were those for which Geocorr assigned a 100% rural portion to the ZCTA.

In the DAS nurses were asked to complete a 5-item survey for all schools for which they provided professional services. If their schools were located in multiple zip codes, they were asked to complete a separate survey for each zip code. A brief definition of disabling asthma was provided. If a child met any one of three criteria, the nurse was asked to include that child in the count of students with disabling asthma: (a) absent from school more than a day a month or 10 days a year, (b) reduced capacity for physical activity resulting in restrictions in curricular or extracurricular activities, or (c) serious asthma symptoms that interfere with school participation several times a year (Newacheck & Halfon, 2000). Nurses reported the total number of students and the number with disabling asthma. Two additional items were rated on a Likert scale 1 to 6 (ranging from never to always): (a) “Asthma poses serious health risks for these students”, and (b) “If a student in my school has disabling asthma I would be aware of the problem”. Survey development and the addition of the final two items were facilitated by a review group of 45 Missouri school nurses who critiqued a draft version.

DAS results revealed a disabling asthma rate among rural Missouri school children of 2.1%, compared to a rate of 3.4% among urban children (Francisco & Konig, 2005). However, the median rate was 1.4% for the state of Missouri, a rate nearly identical to the national mean reported by Newacheck and Halfon (2000). The distribution of rates by school zip code was skewed, with some demonstrating very low

rates and others very high rates. These findings suggest an unequal geographic distribution of disabling asthma. Compared to the national rate, DAS data identified 50 Missouri zip codes with rates 4 to 15 times higher (Figure 6). Many rural school foci of disabling asthma were apparent in the analysis of the DAS. More than 3200 rural children with disabling asthma were identified.

A priority score was calculated next to incorporate nurses' appraisal of health risk as a weight to be multiplied times the number of students with disabling asthma. The rationale for this calculation was that perceived risk (a) was an important criterion for identifying communities with children who had more urgent needs and (b) was likely a

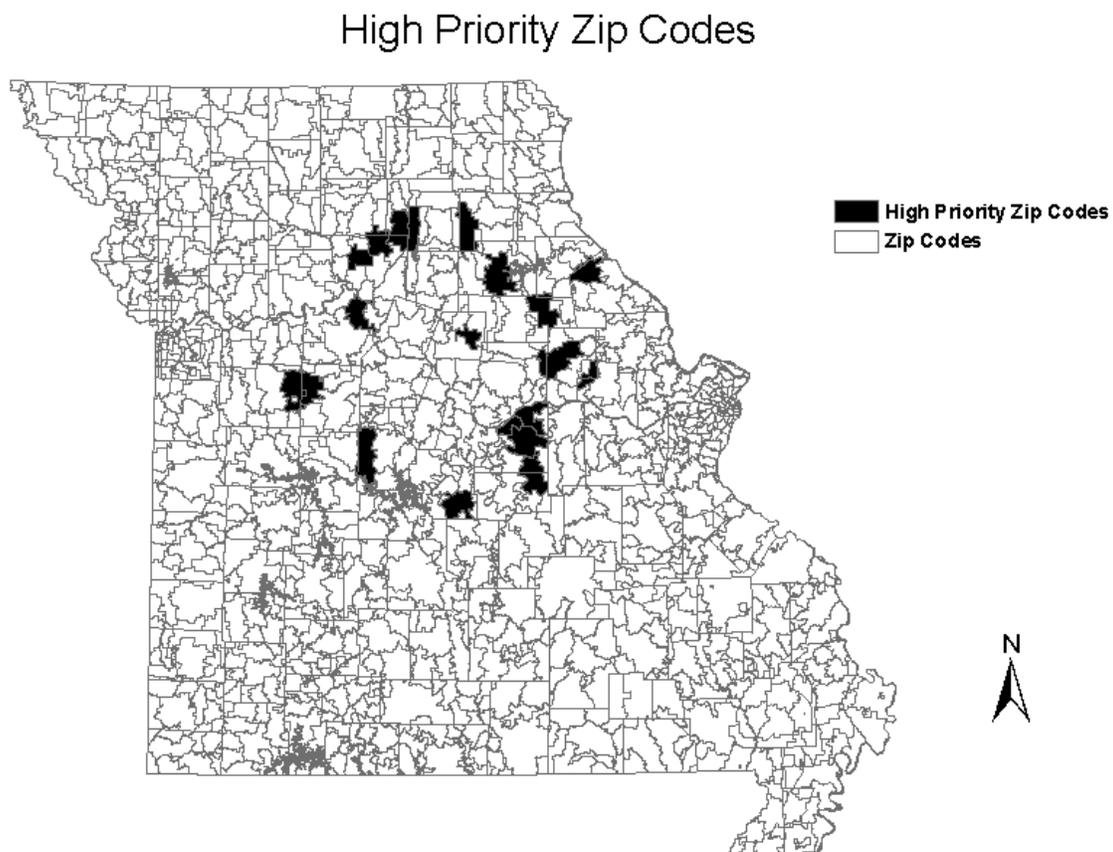


Source: Francisco, B. and Konig, P., 2005. School Nurse Survey of Disabling Asthma in Missouri, Unpublished Data, University of Missouri, Columbia.

*Figure 6.* Missouri schools reporting and excess rate of disabling asthma

motivating factor that would predict nurses willingness to participate in interventions aimed at reducing disability among students.

DAS data were available to allow a good estimate of the GAP for rural zip codes in a nineteen-county area in mid-Missouri, including and surrounding Boone County. DAS data for twenty rural zip codes with the highest priority scores were selected for analysis from among the 19 counties (Figure 7). The total number of students with disabling asthma for this group of schools was 271. The mean disabling asthma rate among these schools was 2.8%, twice the mean U.S. rate reported by Newacheck and Halfon (2000). The average distance to the 20 schools was 72 miles from my home in



*Figure 7.* 20 rural schools with highest priority scores for disabling asthma

Columbia, Missouri. The mean number of students with disabling asthma among the 20 schools was 14. The 20 high priority zip codes were located among 16 of the original 19 counties deemed accessible for this study.

Porter (1999) recommended calculating the estimated accessible population (EAP) for phenomenological studies by applying additional inclusion criteria to the GAP. Whereas the GAP for these schools was 271 students with disabling asthma, not all students met the age requirements of 7 to 12 years. From Missouri census data (2000), I calculated the approximate percentage of school children ages 7 to 12. This calculation required extrapolation from age range data. Missouri census data listed the following percentages of the total population for the listed age ranges: (a) 5 to 9, 7.1%; (b) 10 to 14, 7.4%; and (c) 15 to 17, 4.4% (2000). An assumption of equal contribution of the ages within each age group produced an estimate that children 7 to 12 made up 46% of the school age population. Therefore, 46% of the GAP (271 students) or 125 students constitutes the EAP for the proposed study. The intent to recruit 8 students or 7% of the EAP was deemed feasible. The total number of students 7 to 12 in the 16 target counties was 37,521 (Kids Count, 2004). Therefore the estimated total number of students 7 to 12 with disabling asthma in the 16 counties is 788 (assuming the DAS rural rate of 2.1% of 37,521).

### *Recruitment*

Recruitment proceeded from school to school until eight students were enrolled. School nurses were asked to distribute recruitment materials to as many as five families per school who had a child with disabling asthma. I considered it likely that at least 40%

of school nurses for the 20 selected schools would distribute recruitment materials to one interested, eligible family. I predicted that if 40% of nurses did so, then I would reach the goal of enrolling 8 students from 8 different schools. I located the 20 townships associated with the selected high risk zip codes by inserting push pins into a Missouri highway map mounted on cork board. The townships were those designated by the U.S. postage system as place names for the zip code data accessed in the MABLE Geocorr 2K database (2005). I assumed that these townships would often correspond to the location or names of schools.

Four geographic clusters were noted with 19 of 20 townships falling in groups oriented on the map east, north, west, and south of Columbia. The remaining township was a very short distance from Columbia, suggesting an ideal starting point for the preliminary interview. To the east in the vicinity of Mexico, Missouri were four townships. To the north in the vicinity of Macon, Missouri were six townships. To the west in the vicinity of Sedalia, Missouri were four townships. To the south in the vicinity of Jefferson City were five townships. This cluster pattern suggested a strategy for recruitment. I proceeded from cluster to cluster, contacting school nurses for all schools in that group to reduce travel costs and to coordinate interviews when possible. This approach helped to avoid long delays between the time that families were contacted by a school nurse and the time interviews began in the home for interested, eligible children.

#### *Minority and Gender Inclusion*

High priority zip codes selected for inclusion in the sample represented schools in Audrain, Benton, Boone, Chariton, Gasconade, Macon, Maries, Miller, Monroe, Montgomery, Osage, Pettis, Pike, Randolph, Saline, and Warren County. Census data

(Missouri Kids Count, 2004) indicated that the total school age population for these counties was 81,568. Minority children in the 16 counties comprised 8% of the child population in 2004 (compared to a Missouri rate of 10.5%). Among the selected counties, two were described as metro by the Beale Urban-Rural Continuum Codes (MAGGOT, 2003), eight were non-metro, and six were rural. (These data point to the fact that “rural” has been variously defined.) The percentage of minority children in the 6 rural counties ranged from 1.4 to 8.5% with a mean of 4.7%. Therefore a representative sample for a study involving 8 rural participants would include no more than 1 minority child.

However, purposeful sampling for more than one demographic characteristic in a preliminary study with a sample size of only 8 participants was not feasible. Rural residence, rather than race, was selected as the inclusion criterion for this study of childhood asthma disability. (An additional sample of rural minority participants would be required to explore the experience of disabling asthma among this population. This was not feasible in the current study.) Whereas race was not considered a key factor influencing recruitment, I enrolled 2 rural minority participants in this study. Both males and females were eligible for inclusion in this study. Efforts were made through the screening procedure to include at least three participants of each gender.

### *Sample Size*

Whereas statistical power is a determining factor in sample size for quantitative methods, Luborsky and Rubinstein (1995) argued that “qualitative clarity” (p. 91) is the equivalent standard for qualitative research. “The term clarity was chosen to express the goal of making explicit the details of how the sample was assembled, the theoretical assumptions, and the practical constraints that influenced the sampling process”

(Luborsky & Rubinstein, p. 91). Evidence of qualitative clarity in the study is supported by my detailed description of the sampling technique and previous discussion of the philosophical basis of Husserl's (1929/1975) phenomenology and Porter's (1998a) nursing research method in Chapter Two.

An appropriate sample size for preliminary, descriptive phenomenology was determined to be 6 to 10 participants (Morse, 2000). Sandelowski (1995) pointed out that sample size can refer to either the number of participants or the number of interviews. An adequate sample size permits in depth analysis of a common experience and recognition of diversity within the experience among participants (Porter, 1999; Sandelowski). Smaller sample sizes are consistent with the goal of Husserlian phenomenology to describe in depth the experience of participants and the features of their life-world (Schutz & Luckmann, 1973; Porter, 1999). Large sample sizes are not consistent with the purpose of qualitative research. "Qualitative analysis is generically about maximizing understanding of the one in all its diversity; it is case-oriented, not variable oriented" (Sandelowski, p. 180).

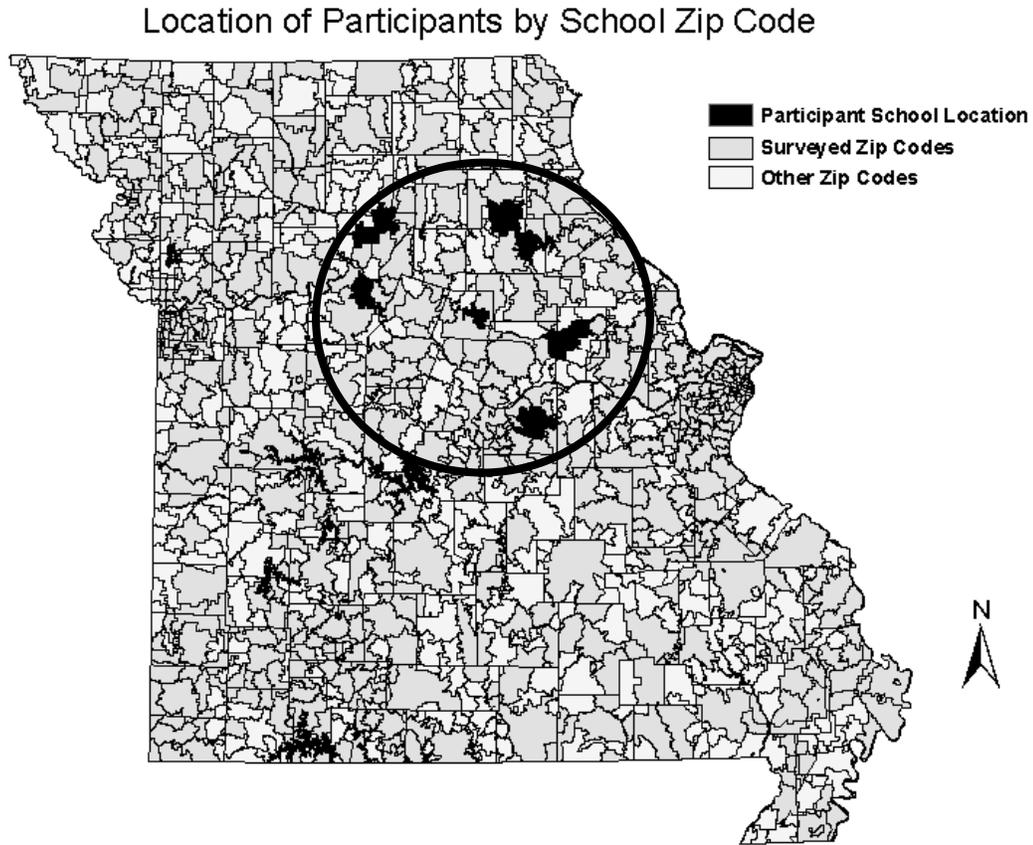
### *Recruitment*

I contacted the superintendent of each school district for the 20 high priority zip codes. I then met in person first with the superintendent and sought permission to request assistance from the school nurse in identifying children who might be appropriate for the study. All except one superintendent granted permission. I met with these 19 nurses individually and asked if they were willing to send recruitment materials home with children whom they believed were likely to be eligible to participate. Age and illness criteria were provided each nurse. I left 5 recruitment packets with each school nurse

volunteer. Recruitment materials included a brief letter explaining the purpose of the study, the activities involved, and the timeframe of the study. A brief screening form was enclosed with a postage-paid return envelope. The screening form assessed the parent's perception of a child's disability due to asthma, established the age and gender of the child, and obtained the home phone number, name of parent, and preferred time for phone contact regarding participation in the study. Assessment of the parent's perception of disability was based on a questionnaire and scoring system devised by Usherwood, Scrimgeour, and Barber (1990). A Likert scale from 0 to 4 for 6 child-specific aspects of asthma disability was used to confirm disability and to aid in selecting child participants. Interpretation of the questionnaire was based on the assumption that a score of 24 indicates a very high level of disability, whereas a score of 0 indicates the absence of disability.

### *The Participants*

Ten screening forms were returned to me by parents. Eight children were eventually recruited and consented to participate in the study. All 8 children completed 3 interviews and finished the study. The age range of the children was younger than expected. Six children were 7 years old. One child was 8 years old and one child was 10 years old. The mean age of the children was 7.5 years. Five of the children were girls and 3 were boys. Two of the children were Black and 6 were White. One minority child was male and one was female. Household income level fell into three categories. The household income for both minority children fell below \$14,999 annually. Household income for one White child fell in the \$15,000 to \$30,000 range. The remaining 5



*Figure 8.* Location of the 8 Participants

children lived in household with a reported income level of greater than \$30,000 and less than \$60,000 annually. The range for the number of years of having asthma was 2 to 7 years for the children, with a mean of 4 years.

*Human Subjects Considerations: Special Reference to Children as Participants*

Research involving children requires careful consideration of ethical principles and conduct. Federal regulations specifically address research involving child participants (Code of Federal Regulations, 1991). The Code of Federal Regulations, section 97.402 provides the following definitions pertinent to the proposed study.

- (a) Children are persons who have not attained the legal age for

consent to treatments or procedures involved in the research, under the applicable law of the jurisdiction in which the research will be conducted.

(b) Assent means a child's affirmative agreement to participate in research. Mere failure to object should not, absent affirmative agreement, be construed as assent.

(c) Permission means the agreement of parent(s) or guardian to the participation of their child or ward in research.

(d) Parent means a child's biological or adoptive parent.

(e) Guardian means an individual who is authorized under applicable state or local law to consent on behalf of a child to general medical. (p. 311)

Federal code specifies regulations according to the level of risk to the child. Section 97.404 addresses regulations for research that poses minimal or no risk.

[The Department of Education] conducts or funds research in which the IRB finds that no greater than minimal risk to children is presented, only if the IRB finds that adequate provisions are made for soliciting the assent of the children and the permission of their parents or guardians, as set forth in Sec. 97.408. (p. 311)

Section 97.408 (p. 313) further specifies that assent shall be obtained whenever children are deemed capable. For research involving minimal or no risk the permission of one parent or guardian is required. Guidelines for obtaining parental permission are the same as those for informed consent of competent adult participants (Section 97.117, p. 309).

#### *Children as a Vulnerable Research Population*

Children were viewed as a vulnerable research population by the Federal Code of Regulations, section 96.107 (1991, p. 304). Kipnis (2003) provided a detailed analysis of

seven vulnerabilities associated with children as research participants. “But this analysis of seven varieties of pediatric vulnerability shows that not one of them is unique to children” (Kipnis, p. 119). Rather than treating children as a unique population, Kipnis advocated that researchers be prepared to accommodate their needs.

We can drop the goal of developing special sets of standards for children and each of the other vulnerable groups. We can aim at being prepared to deal with vulnerabilities wherever they are manifested. Though children are characteristically more vulnerable than adults, there is nothing special about their vulnerabilities and the accommodations researchers need to make for them (as opposed to the rest of us) (p. 119).

Kipnis (2003) identified and described seven types of vulnerability that might “affect the permissibility of participation in a study” (p. 110). I will summarize these vulnerabilities by posing a question for each concern Kipnis raised. Does the child have the capacity to consider her or his self-interest when deciding whether to participate in the study? Is the child under the jurisdiction of a parent or other adult who might have a vested interest in the child’s participation? Is the child’s deliberation about participating in the study impaired by a dispositional willingness to let others make decisions for her or him? Is the child a member of a social group that has been subjected to mistreatment or manipulation such that the child’s concept of freedom of choice might be disturbed? Is the child’s medical condition so urgent that the normal process of learning about a study and considering participation is hindered? Is the child’s selection for the study related to the presence of a health-condition for which there are no satisfactory treatments? Will the choice to participate be influenced by a compelling reward that is highly valued?

Recruitment of children for the proposed study incorporated a consideration of these possible vulnerabilities, the need for accommodations, and the advisability of exclusion from the study of children whose rights can not be adequately protected.

The Children's Health Act of 2000 authorized federal funding for child health programs, established a pediatric research initiative in the National Institutes of Health and mandated a review of federal guidelines for research involving children to ensure adequate protection of children. Ross (2003) summarized challenges that arose from a review of the federal regulations that were based on the National Commission for the Protection of Human Subjects. Report and Recommendations: Research Involving Children (1977) [National Commission]. Whereas standards for determining the ethical basis of research with children are similar to those applied to studies involving adults; special considerations arise when children participate in research (Ross). Allmark (2002) reviewed specific ethical criteria pertinent to qualitative research involving children. Allmark cited "scientific validity, welfare of participants, and respect for the dignity and rights of participants" (p. 9) as primary concerns. These three concerns were addressed in relation to the proposed study.

#### *Scientific Validity*

Allmark (2002) identified three circumstances when scientific validity of research involving children would raise ethical concerns: (a) research that merely duplicates prior work, (b) research that primarily provides a learning opportunity for an investigator, and (c) research that could be conducted with adult participants rather than children. My extensive review of the literature suggested that the proposed study of children's experience of disabling asthma did not duplicate prior work. The aims of this research

held reasonable potential for contributing to efforts to improve understanding of children with disabling asthma. The purpose of the research was not primarily the creation of an opportunity for learning by an investigator. The proposed study could not be conducted with adults because children's intentions and life-world are the focus of the investigation.

Allmark noted:

Clearly, adults are unlikely to be as reliable as the children themselves if we seek accurate information on children's views and feelings. For example, when parents and children were asked to compare two types of pain scales, parents preferred one, the children the other (Ramritu, 2000). (p. 11)

Allmark (2002) also pointed out that qualitative work with children needs to be performed for the same reason that quantitative, biomedical research should be performed with children. Omitting children from scientific studies that have the potential to improve the health of populations is unethical (Oesterheld, Fogas, & Rutten, 1998). Finally, the scientific validity of research involving children is contingent upon the quality of the design and by the experience of the research team. My advisor, Dr. Porter, has had extensive experience using the method I selected for this study with a vulnerable population (Porter, 1998b; Porter, 2003).

#### *Welfare of Child Participants*

The welfare of child participants in the proposed study was another ethical concern. Welfare of child participants was appraised by a risk/benefit analysis. The National Commission identified a classification system assessing level of risk and the prospect of direct benefit for participants (Ross, 2003). A rationale for applying a minimal risk standard for participation of children in non-therapeutic, qualitative research

was articulated by scholars. Allmark (2002) pointed out that empirical evidence of direct benefit of qualitative research for child participants is lacking. Therefore potential benefit for the child who participates in qualitative research is assumed to be minimal. Ethical qualitative research with children should involve only minimal risk commensurate with the likelihood of minimal benefit. The National Commission defined minimal risk as placing the participant at no greater likelihood of harm or discomfort than everyday life (Ross).

The risk to children who participate in the proposed study will be minimal. Low risk can be attributed to the plan to conduct interviews in the familiar home environment and the slim chance of introducing disturbing psychological factors associated with talking about asthma (Rietveld & Colland, 1999). Allmark cautioned that not all qualitative studies are low risk:

Qualitative research is generally thought to be low risk, but it is not always without risk. In particular, exploring people's feelings and experiences has the potential to be psychologically damaging. However, in the main, even those sorts of risks are likely to come into the realm of 'minimal' except where the research is probing particularly delicate areas (such as child abuse). (p. 12)

Interviews were not be conducted during periods of asthma exacerbations of sufficient severity to alter a child's speech pattern (Kerem et al., 1990).

#### *Respect for the Rights and Dignity of Children as Participants in Research*

Respect for the dignity and rights of child research participants are important ethical considerations. Respect for the child is exhibited by measures to ensure proper consent and confidentiality (Allmark, 2002). Ethical concerns related to the giving of

consent will be considered first. Consent is legitimate when three criteria are met: (a) it is given by a competent individual, (b) the person giving consent has been adequately informed, and (c) the consent is given voluntarily (Beauchamp and Childress, 2001).

Young children are not legally competent to give consent. Parents have a right to consent to their child's participation in research; however school-age children 7 to 12 also have a right to assent or dissent to their participation (Society for Research in Child Development, 1990).

Rossi, Reynolds, and Nelson (2003) described parental permission (consent) and child assent as bound together and serving different purposes. Parental permission protects the child from assuming unreasonable risks. Assent shows respect for the child. However, the authors cautioned that the assent might not be entirely voluntary if authority figures urge the child to participate in research (Rossi, Reynolds, & Nelson). The authors ascribed current standards for assent to the recommendations of the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research (1978).

Four criteria were considered essential in obtaining assent from individuals with limited capacity for informed consent. The person must (1) know that procedures will be performed, (2) choose freely to undergo the procedures, (3) communicate this choice unambiguously, and (4) be aware of the option to withdraw. (p. 132)

Denying children the opportunity to assent to participate in non-therapeutic research raises concerns. Kennedy and Grubb (1998) pointed out that adult participants involved in non-therapeutic research are allowed to be altruistic. They are allowed to consent to

participate in research for the general good when the risks are minimal. Children have a similar right to assent to participate in non-therapeutic research that poses minimal risks.

Scholars have assessed children's ability to comprehend their rights when assenting to research participation (Hurley & Underwood, 2002). Hurley and Underwood investigated comprehension of research rights among 178 children ages 8, 10, or 12 who freely assented to participate in qualitative research. The vast majority of children demonstrated accurate understanding of their rights before and after the study. Eight-year-old children were less likely than older children to understand the purpose of the study. Whereas children were usually unable to define "confidentiality", a large majority accurately expressed the understanding that what they said and did during the study would not be known by their teachers, parents or friends. Children indicated they felt free to stop answering questions and quit the study without consequence at any time. Gender differences in comprehension of research rights were not apparent in any age group (Hurley & Underwood, 2002).

#### *The Initial Interactions with Potential Participants*

Ten potential participants were identified when parents returned the Request for Additional Information form. Necessary conditions for a face-to-face meeting with the parent and child included (a) a disabling asthma score of 12 or above on parental responses for items 6-11 of the *questionnaire to measure perceived symptoms and disability in asthma* (Usherwood, Scrimgeour, and Barber, 1990), (b) an expressed interest in learning more about the terms of participation in the study confirmed verbally by the parent, (c) stated willingness of the parent to extend to the child the right to refuse to participate in the study, and (d) the parent's willingness to schedule a meeting when

the child and parent could be present for up to 90 to 120 minutes within 2 weeks to review information about the study. Eight of 10 potential participants met these criteria. One parent further described her child's asthma in terms that were not consistent with disabling asthma. This child was not considered for the study due to apparently mild disease. A second family could not be available within the requested time frame.

### *Gaining Informed Consent*

At the initial meeting with each of the parent and child in the home, a detailed explanation of the study was provided in writing and read aloud to the parent and child (Appendix B). Each of the 8 parents indicated a willingness to consider permitting the child to participate in the study *and* each of the 8 children stated an interest in taking part in the study. A consent form was provided and read aloud to each parent and child. A few parents had procedural questions about the study. Their questions were answered. Each parent was then asked if they wanted to take time to think about their decision. Each of the 8 parents felt ready to grant permission for her or his child to participate. *Gaining*

### *Informed Assent*

Each parent signed the consent form, granting permission for her or his child to participate in the study. I then asked the child the following questions verbally before asking the child to sign the consent form. "Do you think you want to be in the study?" If the answer is "yes" then I read the following script to each child prior to seeking her or his signature.

I would like to review with you some of the important things you need to know before you decide whether you want to be in this study. To be sure you understand what is involved I would like to ask you a few more questions. Is that

OK with you? (If the answer is ‘yes’ the following additional questions will be asked.) (1) There are no wrong or right answers to the questions I will ask you if you agree to be in the study. Adults don’t know much about what it is like be a kid and to have asthma. I am here to learn from you. Do you understand that you and I will be talking about what it is like for *you* having asthma? (2) Do you understand that we will talk for about one hour on 3 separate days? (3) If you need your parent you will always be able to get their attention immediately. Do you understand that your parent will always be in the house when we are talking? (4) You can decide to stop being a part of the study at any time or you can ask that we talk on another day if you just don’t feel like talking. Do you understand that you can change your mind about talking with me at any time? (5) Do you understand that when I tell other people about what I learn in this study I will not use your name or in any other way let people know that you were the person who told me what I learned? (6) Do you understand that talking with me will not make your asthma go away or get better? (7) I will give your parent \$10 after each interview. That’s a total of \$30 if we talk together 3 times. Do you understand that after talking with me each time there is a small payment of \$10 to your parent?

Each child answered yes to questions 1-7. I then asked question 8.

(8) “Do you need more time to think about this decision?”

Each of the eight children answered no. I then asked question 9.

(9) “Do you want to take part in the study?” Each of the 8 children responded yes.

I then asked each child to sign the consent form, showing that they wanted to take part in the study.

### *The Instruments*

The primary instrument in phenomenological research is the consciousness of the researcher (Husserl, 1929/1975; Porter, 1998a). Husserl's phenomenology and Porter's method were premised on the idea that new knowledge about human experience can be derived from direct observation and the researcher's intuition. Therefore, using the phenomenological approach a researcher seeks evidence and holds to the axiom that "science demands proof by reference to the things and facts themselves, and that these are given in actual experience and intuition" (Husserl, 1929/1975, p. 6). However, Husserl (1929/1975) also held that the specific intent of phenomenological investigation was to strengthen science. Therefore, phenomenology advances two complementary purposes: to gain new evidence and to strengthen science.

Both in depth analysis of scientific conceptualizations and careful consideration of personal perspectives were necessary before I could use Porter's method (1998a). I considered various aspects of childhood asthma to (a) examine the chronological development of influential scientific concepts, (b) critically analyze self-management as a widely accepted construct used by scholars and clinicians, (c) review relevant research findings in the scientific literature, (d) identify behavioral requisites suggested by expert clinical guidelines, and (e) describe theories, concepts, and life experiences that shaped my understanding of children with asthma. These steps reflect my participation in the phenomenological reduction whereby all preconceptions are set aside as constituting a "naïve objectivism" (Husserl, 1929/1975, p. 5).

#### *Development of the Interview Guide*

Use of semi-structured interviews to study rural children's experience of disabling asthma was consistent with Porter's (1998a) method. The primary purpose of the interview guide was to facilitate description of the experience of disabling asthma among rural school-children and various contexts of that experience. The phenomenological framework of the study shaped the development of questions that serve as probes in the interview (Porter, 1998a). A secondary purpose of the interview guide was to seek data to critically review scientific conceptualizations pertaining to rural children's experience of disabling asthma. This intention influenced the inclusion of some probes that were used as open-ended opportunities for children to describe aspects of their experience for which constructs or theories have been advanced explanations. I also developed the interview guide to help maintain consistency in data collection from participant to participant. This approach increased the reliability and validity of data (Brink, 1991). It also increased the likelihood that all participants would share similar aspects of the experience, so that the findings of the study would reflect both diversity and commonality among the data.

#### *Content Validity of the Interview Guide*

Content validity of the interview guide was appraised in three ways. First, Porter critically reviewed the initial draft to determine if the guide was consistent with her method (1998a). After questionable items were revised or eliminated based on methodological concerns, the guide was next reviewed by a qualitative researcher with extensive experience interviewing children with asthma (H. L. Yoos, personal communication, November 9, 2005). Additional suggestions for revisions were discussed and incorporated into the guide based on suggestions by Yoos. Next, an expert asthma clinician reviewed the interview guide to determine if the questions probed

relevant and unknown aspects of the experience of disabling asthma (P. Konig, personal communication, November 14, 2005). Further suggestions were incorporated in the guide based on the comments of Konig. Finally, the interview guide was reexamined by Porter to ensure that methodological concerns had not been reintroduced through the revisions. The interview guide appears in Appendix H.

### *Children's Health Survey for Asthma*

My efforts in this study to understand rural children's experience of disabling asthma logically related to a wider area of inquiry that includes children's various experiences pertaining to asthma. The potential value of this research might be based on differences between children's experience of disabling asthma and the experience of well controlled asthma with no disability. To increase the likelihood that comparisons could be made in the future between findings from this study and similar work with other populations of children with asthma there was a need to describe each child's illness experience in outcome terms. The American Academy of Pediatrics initiated a program to develop disease-specific measures of functional status for children to aid efforts to understand and improve care. A survey for parents designed to assess the functional status of children with asthma entitled "Children's Health Survey for Asthma" (CHSA) has been subjected to reliability and validity studies, with favorable findings (Asmussen, Olson, Grant, Fagan, & Weiss, 1999). An 8-week recall version of CHSA was used in this study to capture longitudinal data pertaining to level of symptoms, effect on child functioning, and use of health care resources. Use of this survey in this study improved understanding of the characteristics of participants and provided comparative demographics.

### *Setting*

Interviews with children in this study took place in the child's home. A parent was present in the home for the entire interview. The child's right to privacy and the need for protection were balanced. This called for a parent to be adjacent to but not in the interview space. During one interview only a parent remained in the room for the interview at the child's request. During the second and third interview, the same child was comfortable with the parent being in an adjacent room. A common area of the home was selected by the parent for the interview. The various interviews took place in the family kitchen, living room, or den. Doors to the interview area remained open. A headset was worn by the child and by me allowing for enhanced recording acoustics while speaking at lower volumes. This spatial arrangement allowed children to share information about their experience confidentially.

### *The Interview Process*

The interview guide was designed with a progression of topics in mind. Questions #1 a-j were general questions about the experience of disabling asthma that were written to encourage children to express their thoughts openly with minimal structure. These questions were the principal topics of discussion during Interview #1. Question #1 k-Question 8 e were more specific to the things children likely used in their experience with asthma and the particular settings that were expected to constitute different contexts for the experience of disabling asthma. Those questions were generally topics of discussion during Interview #2. Questions 9-12 explored children's "intentionality and horizons" (Husserl, 1929/1975, p. 20) to ascertain the possibilities related to the experience of disabling asthma for each child; those questions were primarily covered in Interview #3.

Although certain questions were generally covered in particular interviews, I did not take control of the interview to force a linear progression through the questions. Instead the questions were used as reminders of potential sources of data that guided the interview process and brought continuity to probes using in the interview process. Children often determined alternative progression through the interview guide based on their spontaneous discussion of their experience. This was an appropriate occurrence.

I encouraged children to lead the interview by using open-ended questions and statements including “What was that like for you?” and “Tell me more about that.” Some questions were repeated to increase the reliability of data and to encourage children to expand their descriptions. Answers provided by a child during a previous interview might were sometimes reintroduced as probes to elicit further explanation or clarification. During the final interview a portion of the session was devoted to validation of key findings from previous interviews and presentation of phenomena described by other children or researchers. This intersubjective dialogue (Porter, 1998a) explored the validity of findings from this study and of other scientific conceptualizations about the children’s experience of asthma. It was not assumed that the children’s descriptions of respiratory aspects of disabling asthma would reflect the conventional medical model of symptoms. Yoos, Kitzman, McMullen, Sidora-Arcoleo, and Anson (2005) described unique ways children with asthma describe breathlessness.

#### *Data Recording and Management*

Interviews were recorded by a hand-held digital device and later transferred to a password-protected, University of Missouri computer maintained under institutional security guidelines. The workstation was secured in a private, locked office. The office

building was Dockery-Folk Hall and was accessible only by key, except during regular business hours. Digital recordings were stored on the hard drive and on a backup laptop computer for data protection. The laptop was also a University of Missouri device maintained in accordance with institutional security policies and accessible only by ID and password.

Digital recordings were stored in the computer and transcribed by voice recognition software and manual transcription processes. After analysis was completed, voice files were edited to remove unique identifiers in cases when a child inadvertently identified any person or specific location by name or other means in the course of the interviews. Once identifiers were removed, audio files were deemed appropriate for incorporation into professional presentations of data to communicate research findings. Interview transcripts in the form of text files were identified by name codes that did not reveal the actual name, home address, or school of any child. An index of code names for files and personal identifiers was maintained in a locked filing cabinet in the locked University office named above until completion of the study. The index of codes was shredded at the completion of the study. All related data files were stored as a single NVivo™ project folder for enhanced security and data management.

#### *Reliability and Validity of Interview Data*

*Reliability of data.* An important feature of the study design was the procedure for interviewing each child on three separate occasions at an interval of a week or two. Follow-up interviews made it possible to repeat questions that were central to the study, as well as questions that produced critical or unexpected results in previous interviews. Asking the question again paralleled a repeat measures design used to establish reliability

in other research designs (Brink, 1991). Obtaining audio recordings and use of verbatim transcripts also increased the reliability of the data. Research findings were linked to original audio recordings and transcripts, thereby affording greater reliability by making participants' statements available for critical review by others.

*Validity of the data.* A primary concern was that the data obtained described the phenomena of interest. Validity of the data in this study was enhanced by the sampling technique that carefully selected populations of rural children who were viewed by their school nurse as being at risk due to disabling asthma (Brink, 1991; Porter, 1999). Next, parents were asked to consider if their child experienced disabling asthma. Likelihood that appropriate children were recruited was increased by a screening procedure that used validated questions and an ordinal scale designed for parents of children 5 to 14 to rank their child's asthma disability (Usherwood, Scrimgeour, & Barber, 1990). In the course of the study, further validating data was obtained from parents by use of the Children's Health Survey for Asthma (Asmussen et al., 1999). These data appraised disease severity, impact of asthma on child and family functioning, and health care utilization factors from the parent's perspective. Use of condition-specific functional outcome measures will allow for comparison of demographic features of the illness experiences among future participants representing different populations (Sullivan & Olson, 1995).

Another dimension of validity in this study was the ability of the method and instruments to elicit data that were pertinent to the experience of interest. Use of a phenomenological framework that identified sources of data pertaining to the experience of disabling asthma increased the likelihood that valid data was obtained from the interviews (Porter, 1998a). Acknowledgement of my attributes as a researcher through

the bracketing procedure, that has been previously described, elucidated potential sources of personal bias. This information will assist others who judge the validity of the findings. Careful development of a semi-structured interview guide with review of content validity by a methodological expert, a clinical expert, and an expert qualitative researcher who has studied children's views of asthma increased the likelihood that the interviews were conducted in accordance with the aims of the study and produced valid data. Monitoring of the recruitment process and critical review of my analysis of the first three interviews by Porter reduced the likelihood that methodological error will be introduced into the study. Porter's expert guidance throughout analysis of phenomenological data in this study increased the validity of the findings.

#### Data Analysis

Each of the 8 participants was interviewed 3 times. With data from 24 interviews I obtained a rich and full description of the experience of disabling asthma among rural school children. Analysis of the 24 interviews followed Porter's (1994, 1998a) method described in Table 2 (Wongvatunyu, 2003). These methodological activities and research procedures initially described by Porter (1998a) were further clarified during research conducted by Wongvatunyu under Porter's guidance. The research procedures were adapted to my intended use of N Vivo qualitative software that supports coding text files, modeling to represent the taxonomy, and linking text files to audio files for quick access, analysis, and presentation of findings. Methodological steps included descriptive analysis, intersubjective dialogue, and filling out the phenomena (Porter, 1998a).

#### *Descriptive Analysis of the Contexts and the Experience*

Not all material in the interview transcripts and observations was relevant to the research questions. Two guiding principles were important to me as I sought to identify data that were relevant to either the context of the experience or children's intentions. The child was always at the center whenever relevant contextual information about the experience was disclosed. In addition, contextual data led back to the child's experience of disabling asthma and provided explanations for children's intentions.

The greatest challenge in the analysis was maintaining a distinction between what constituted contextual data and what constituted intentional data. I found it helpful to consider whether the item under examination conformed to Husserl's tripartite formula (Koestenbaum, 1975) previously described in Chapter 3 – "I" "act" object", meaning that any time the child as actor focused on a relevant aspect of disabling asthma, some part of the experience was disclosed. If these conditions were met the occurrence was viewed as intentional, in the sense that the child constituted her or his own reality. In contrast contextual data explained primarily what was imposed on the child by natural and human factors largely outside the child's control.

The determination of what constituted contextual data and what constituted intentional data drove much of the analytical process in this study. I developed simpler working definitions to facilitate the analysis. Borrowing terms from the theatre, I came to conceptualize context as data that was similar to the various sets, props, scenes, and actors around the protagonist. In contrast, intentions described the plot, that is, the child at work, shaping a personal experience of disabling asthma. However, hard lines of distinction did not always exist in the data. Children's perceptions were sometimes on the boundary between awareness and intention. Therefore, the

discussion of context and intention in Chapter 4 and 5 will at times be overlapping. This tension is consistent with a phenomenological approach that does not anticipate a final, rigid taxonomy. Experience is viewed as dynamic. It is necessary to constantly return to the descriptions of experience itself, rather than relying on abstractions to represent what it is like for people who are actually living the experience. The close relationship between

Table 2. *Methodological Activities*

<b>Methodological Step</b>	<b>Research Procedures</b>
5. Descriptive analysis	<ol style="list-style-type: none"> <li>1. Record each interview with a digital device</li> <li>2. Record observations after each interview</li> <li>3. Review audio file and transcribe the interview</li> <li>4. Review recording of interview observations</li> <li>5. Annotate transcript with observation notes</li> <li>6. Use descriptive phrases to categorize interview data</li> <li>7. Review descriptive phrases, eliminate redundancy</li> <li>8. Examine the relationships between categories</li> <li>9. Validate/revise coding by reviewing data with advisor</li> <li>10. Complete second interview to clarify &amp; expand data</li> <li>11. Repeat procedures 1 to 8</li> <li>12. Use model-building software to organize categories</li> <li>13. Review emerging coding structure with advisor</li> <li>14. Complete interview 3</li> </ol>
6. Intersubjective dialogue	<ol style="list-style-type: none"> <li>15. Describe findings to participant at last interview</li> <li>16. Record participant's response to findings</li> <li>17. Explain preliminary analysis to advisor</li> <li>18. Interview additional participants, repeating 1- 16</li> <li>18. Discuss changes in coding structure resulting from categorizing interviews from remaining participants</li> </ol>
7. Filling out the phenomena	<ol style="list-style-type: none"> <li>19. Compare and contrast participant interviews</li> <li>20. Decide if data supports closing the study</li> <li>22. Prepare a written description of phenomena</li> <li>23. Re-initiate interviews and analysis if validation is not successful</li> <li>24. Introduce the bracket into the analysis</li> <li>25. Describe the abutment of data and conceptualizations</li> </ol>

children's life-world and their intentions prompted me to present these data in an integrated fashion in Chapter 4, rather than in a dichotomous array of contextual (life-world) versus intentional findings. Children's intentions are listed in bold typeface in the taxonomy (Appendix I). Children's specific intentions are also discussed in detail in the findings found in Chapter 4.

#### *Intersubjective Dialogue and Filling out the Phenomena*

The goal of intersubjective dialogue according to Porter (1998a) is to provide opportunities for participants and other interested persons to reflect on the emerging phenomena and to provide comments. Participants were able to validate aspects of their experience in this way. They were also free to correct misunderstandings and to consider how other children had described their experience. These exchanges made it possible to compare and contrast children's experiences with more rigor. Conversations aimed at introducing the experience of other children occurred late in the last interview as part of a closure process. This timing avoided introducing external data that might have influenced the child's description of their own experience.

Intersubjective dialogue with school nurses, clinic nurses, public health administrators, and clinicians provided an opportunity to assess the impact of the data and to consider aspects of the children's experience that were unclear. Filling out the phenomena was facilitated by questions and concerns related to the meaning of children's experiences. In most cases questions could be readily answered by further explaining the context of the children's intentions. This finding encouraged me to provide the context in detail in Chapter 4 prior to discussions of children's intentions. Context often provided critical explanation as the reasons behind and significance of children's intentions. An

important attribute of the design of descriptive phenomenological research is the circulation of ideas that occurs between participants, researcher, and those who are roles related to the experience of interest. The resultant dialogue is intended to benefit conceptual clarity and prompt appropriate remedial action where warranted. Roberts (2000) stated: “There have always been people who have listened, sometimes there have been people who have heard, and perhaps less often, those who have acted wisely on what children have had to say” (p. 238).

*Conclusion: Data Analysis*

I used a descriptive phenomenological method to describe 8 rural children’s experience of disabling asthma. The method and analysis were based on Husserl’s (1929/1975) phenomenology and Porter’s (1994, 1998a) research method. The purpose of the analysis was to intuit and describe children’s intentions in context. The findings are presented in the next chapter.

## CHAPTER FOUR

### FINDINGS

The purpose of this chapter is to present the findings of a phenomenological analysis of 8 rural children's experience of disabling asthma. In the first section data pertaining to the experience will be presented to describe the context in which children lived their experience. I will provide a description of contextual features of life-world (Schutz & Luckmann, 1973) that were found to be close to the experience and specifically related to the children's intentions. Next, I will describe the phenomena of the experience with an emphasis on intentional analysis to reveal what the children were trying to do.

#### Introduction to the Children's Life-World and Intentions

Description of the findings will begin with the children's life-world (Schutz & Luckmann, 1973). I will proceed from broad to specific contextual levels in accordance with Porter's (1998a) method that suggested use of a hierarchical structure of nested concepts. In this description of the life-world I will use the terminology of features suggested by Spiegelberg (1975) and Porter (1995). The three terms features, descriptors and elements represent movement from general to specific contextual levels. The purpose of describing context is to encompass the range of observed experiences among the children rather than rendering them individually, case-by-case. These data are descriptive of the settings, circumstances, and relationships that were close to children's experiences of disabling asthma.

Use of the term life-world (Schutz & Luckmann, 1973) might seem obscure to the reader who is not immersed in descriptive phenomenology. However, the concept is very

relevant to any effort to understand human experience. I believe that the poet Ralph Waldo Emerson captured in verse the significance of the life-world when he described the uniquely human quest of shaping reality by redirecting consciousness in constructive ways.

Nature is not fixed but fluid. Spirit alters, moulds, makes it...

Every spirit builds itself a house; and beyond its house is a world;  
and beyond its world, a heaven. Know then that the world exists  
for you. For you is the phenomenon perfect. What we are, that only  
can we see. Build therefore your own world. (Emerson, 1836. p. 6)

The life-world of children in this study included four important features that explained the context in which they lived their experience of disabling asthma. These four features and the associated descriptors and elements will be described using the language of the children whenever feasible. Within the context to be described, children were trying to do a variety of things. I will describe their particular intentions, using quotations when appropriate.

An overview of life-world features will be presented first followed by a more detailed explanation of each descriptor and the supporting elements. The first feature was *discovering that asthma changes what I can do*. The second feature was *becoming the one who knows my asthma*. The third feature was *knowing how other people respond to my asthma*. The fourth and final feature was *coming to know more about asthma*.

I will first explain each of these four life-world features by listing descriptors that logically relate to and disclose the general idea behind the feature. These descriptors will be further illustrated in the following section when I present specific elements

revealed in the data of 8 children. The purpose of identifying features, descriptors, and elements is to make clear how children see their world as it relates to having asthma. As necessary I will present portions of the interviews to further clarify the data and disclose the specific nature of children's ideas.

#### *Discovering That Asthma Changes What I Can Do*

The first feature of children's life-world was *discovering that asthma changes what I can do*. Children described many activities that were changed because of their asthma-related breathing problems. Key descriptors included: (a) *being unable to run and play like other kids*, (b) *being unable to go outdoors at certain times*, (c) *being unable to enjoy pets and animals*, (d) *missing school*, (e) *getting sicker and staying ill longer than others*, (f) *finding it hard to sleep*, (g) *missing out on playtime with friends*, and (h) *spending time taking all my medicines*.

#### *Becoming the One Who Knows My Asthma*

The second feature of children's life-world was *becoming the one who knows my asthma*. A distinguishing term in the descriptive phrase for this feature is the word "my." The idea behind this feature stands apart from the notion of obtaining general knowledge about the disease of asthma. Data suggest that children were coming to own and assume responsibility for their asthma incrementally over time. This feature of the life-world reveals their progressive self awareness of their illness pattern and their dependence upon others. For the child this feature encompassed discovering that something was not right with her or his breathing, attempting to understand what was going wrong, and trying to prevent or stop the trouble. Key descriptors included: (a) *seeing the trouble asthma causes me*, (b) *knowing what makes my asthma worse*, (c) *wanting asthma to go away*,

(d) *knowing some things make my asthma better*, and (f) *remembering things about my asthma*.

#### *Knowing How Other People Respond to My Asthma*

A third feature of children's life-world was *knowing how other people respond to my asthma*. Data clearly demonstrate the children's awareness of a range of responses exhibited by others. This context shaped their intentions, especially as they considered who would likely help them and who would not. In certain circumstances these children demonstrated intentions that clearly anticipated and acted in concert with the expected responses of other key persons in their lives. Descriptors included: (a) *my asthma causes worry and concern*, (b) *sometimes I get special treatment*, (c) *knowing some people don't treat me like a normal person*, and (d) *knowing others help me with asthma*.

#### *Coming to Know More About Asthma*

A fourth feature of children's life-world was *coming to know more about asthma*. These eight children recognized that they lacked knowledge about many things, including their medications and basic facts about asthma. In the absence of accurate information the children imagined answers to common questions, feared the unknown, and sometimes hoped for a desired future. Key descriptors included (a) *realizing I don't know a lot about asthma*, (b) *knowing some people teach me about asthma*, (c) *knowing that others have asthma*, and (d) *realizing that asthma changes over time*. Related phenomena were (a) *asking for help to learn about asthma*, (b) *seeing that others have asthma*, (c) *making it better for kids who have asthma*, and (d) *thinking about having it the rest of my life*.

#### Discovering That Asthma Changes What I Can Do and Related Intentions

The eight children in this study gave many examples that illustrated their discovery that they were unable to do things that other children do. This feature of the life-world essentially describes disabling asthma from the children's point of view. Whereas some intentions emerge within this feature, much of the children's experience encompassed by this feature relates to being unable to be a normal child. The most commonly sighted element was *being unable to run and play like other children*. All eight children made multiple references to this problem.

#### *Being Unable to Run and Play Like Other Children*

One child commented that "I usually run or play with my friends. If they say, 'Let's have a relay race and see who wins.' I will be the one who loses most of the time." Another child said, "What's different is that sometimes at school when I do gym, I just can't do it. It crushes my feelings. My favorite thing is gym." One child reported that her inability to run and play like other children changed her role in games.

Most of the time we run or play hide and go seek. I'm always the seeker. Or we play jail tag and I'm always the one who has to do it. So I have to chase everyone and they can get out and come back. It's really, really hard for me.

I identified four descriptors that further explained this aspect of the life-world. These included: (a) *having trouble keeping up in physical education*, (b) *being unable to take part in active sports*, (c) *having trouble riding my bike*, and (d) *having trouble breathing in the pool*. One child graphically described the experience of difficult breathing during physical education class at school when rests were not allowed.

Three laps don't really get me. You just run out of air and your heart starts pumping. Then we get into the games. That's the difficult part, when you don't have air and like a minute later you still can't breathe and you can't stop.

Children reported giving up on participating in active sports that required vigorous physical activity. One child quit wrestling because the demanding practice routine consistently evoked breathing problems. A child reported wanting to play soccer, but chose cheerleading instead to avoid asthma problems that she believed would result from running too much.

Bike-riding was mentioned by an older child as an activity that challenged her and limited her ability to keep up with her friends. She reported asking her friends to be easy on her so that she could take part in bicycle races. “‘I'll race with you, but you have to be easy on me.’ And they didn't. So I went back and got my inhaler just in case I had an asthma attack.” She demonstrated the intention of being prepared for a likely exacerbation.

Two children identified problems with swimming. One child had to be rescued from the swimming pool one day when her asthma was flared-up. Whereas she was not certain whether her trouble came from being inexperienced as a swimmer or from her asthma, she described a worsening of her asthma on the morning of the swimming incident. A second child described her approach to managing her trouble breathing in the pool. She described taking a break for a dose of albuterol, resting for a time, and then returning to swim some more if she was breathing well.

### *Missing School*

Another important element was *missing school*. For most children this was a troubling part of having asthma. One child said, "It's never fun because I'm always sick and I miss so many days." When asked to give an example of a time when asthma kept him from doing something he wanted to do, another child quickly responded with a story about not being able to go to school because of a flare-up. Descriptors of missing school included: (a) missing out on fun things, (b) when I can't sleep I don't go to school, (c) what I do when I stay home from school, and (d) making up the work. Children described their efforts to get caught up with assignments and avoid consequences related to missing school and turning in late assignments.

#### *Finding it Hard to Sleep*

The children described sometimes *finding it hard to sleep* when having asthma symptoms. Sleep disturbance was related to two factors. For some children breathing was so difficult or coughing so persistent sleep was not possible. "At night when I'm sleeping and I'm having a hard time breathing, I wake up in the middle of the night." Treatments for asthma symptoms were not always effective at these times. "I had to wake up my mom and dad and they gave me that tube thing. And I couldn't fall asleep because I kept coughing and coughing. It didn't work." Another child described using albuterol and getting relief, but not being able to fall back to sleep. "I went to the couch and then my room and just keep napping in different places." She believed that the medicine kept her awake. "I'm not able to go back to sleep until the afternoon."

#### *Being Unable To Go Outdoors At Certain Times*

Children also often described *being unable to go outdoors at certain times* because of asthma. Temperature extremes, either too hot or too cold were most often

cited as reasons for this restriction. "I can't really go outside when it's really cold or hot." The significance of this limitation is illustrated by child who was asked what it would be like not to have asthma. "I could do anything I wanted. Go outside, have fun."

*Being Unable to Enjoy Pets and Animals*

*Being unable to enjoy pets and animals* was another important element that described children's discovery that asthma changed what they were able to do. Two children expressed in detail their love for animals and their disappointment in not being able to have pets. Children described intentions related to overcoming these restrictions. One child stated, "I really hope some day I can be around cats."

Another child related the belief that having a Chihuahua would be good for her asthma. She hoped that her mother would soon consent to her having this pet. When discussing the problems cats or dogs caused a child with asthma, she interjected, "Chihuahuas don't. My mom said that if I get a Chihuahua that it would help me stop having an asthma attack." Remarkably, the child held a very strong belief that exposure to pets could have serious consequences for someone with asthma. "I know already this. If a kid has asthma and you get a little kitty or a dog, then they can die [the child]."

Another child described a unique and unanticipated aspect of being around animals. He sensed that animals were afraid of him and he attributed this to fear to the belief that they did not want to catch his asthma. "It's pretty hard to go around pets. Sometimes, sometimes when animals look at me and all that, sometimes they feel kind of scared because they probably just don't want to catch it. I guess I always thought that you can't, you can't pass the asthma to other people or the other animals." It is possible

that his wheezing or labored breathing startled animals at times, prompting his thoughts about why animals feared him.

#### *Getting Sicker More Often And Staying Ill Longer Than Others*

Children also saw themselves as *getting sicker more often and staying ill longer than others*. This perception was an important part of several children's experience.

My sister doesn't have asthma, but all the time it's like if my family gets the croup, I get a worse croup the next day. And then one day I had to go to the doctor, when the whole family did and I had the best throat. My dad had the worst throat and my sister was the second-worst. The next day my sister got better. The next week after that they were done with it and so was my dad. I had it for two weeks more and I missed that week of school.

One child also noted that medicines worked for her family, but not for her, so she often had to "go back for a new kind, taking it again and again." Another child described what it was like to always be sick when the rest of the family felt good. Children also lamented times when they were unable to be with their friends because they were sick.

#### *Spending Time Taking All My Medications*

These 8 children expressed strong, negative feeling about *spending time taking all my medications* when other children were playing and doing normal things. Children described medicine-taking as a burden that limited what they were able to do. "All the puffers, they kind of ruin half of your life." This child described the routine of taking daily medications as one that interfered with and had changed her life permanently. When asked what three things they wished for in relation to having asthma, most children readily listed not having to take medications.

One child described some pleasure in being able to use her hands in learning to use inhalers. She described enjoying manipulating the devices to make the medicine come out. However she still named medicine-taking as the worst part of having asthma. A related element of *spending time taking my medicines* was *missing out on playtime with friends*. Children resented being indoors taking medications while other children enjoyed free-time at play.

#### Becoming the One Who Knows My Asthma and Related Intentions

The eight children described coming to recognize how asthma affected their well-being and learning to live with and reduce the effects of their disease. Key elements of this feature included: (a) *seeing the trouble asthma causes*, (b) *knowing what makes my asthma worse*, (c) *wanting asthma to go away*, and (d) *knowing some things make my asthma better*, and (e) *remembering things about my asthma*. Many intentions were apparent in this context as children tried to shape their experience of asthma.

#### *Seeing the Trouble Asthma Causes Me*

*Seeing the trouble asthma causes me* involved each child recognizing the unique ways in which their disease manifested. Key descriptors included: (a) *coughing more*, (b) *breathing hard*, (c) *wheezing*, (d) *having trouble talking*, (e) *having a sore throat*, (f) *waking up because it's hard to breathe*, (g) *being unable to walk*, (h) *having trouble eating*, (i) *feeling my chest hurting*, (j) *feeling tired*, (k) *feeling stuff going down there*, (l) *not knowing it's about to happen*, (m) *not remembering what happened last time*, and (n) *having good days when it's not so active*. Two important, opposing intentions were associated with this element. Children were either choosing to notice and to respond to their symptoms or to ignore the trouble.

*Seeing the trouble asthma causes* involved a complex array of symptom patterns and probable co-morbidities. Children's descriptions of their breathing problems usually included more than one symptom. One child stated, "Whenever I'm in a bad shape, it's like I'm not breathing well and I'm coughing really bad." Even the youngest and most developmentally immature of the eight children described her breathing problems in very specific terms.

I can't hardly talk, and I can't hardly breathe, but I can really breathe out of my nose good. I can't breathe out of my mouth. It is like [she holds her chest and tries to breathe out], I can't breathe anything out.

When asked if she knew when asthma was getting worse she responded affirmatively with a dramatization of labored exhalation (typical of air-trapping associated with asthma exacerbations) and with a description of the sensation of either gastroesophageal reflux or excess mucus production in the airways.

Uh-huh, I know. [She demonstrates an exaggerated effort to exhale.] I feel stuff going down here, and then it hits my chest. Then I say, "Mommy, I'm having a hard time breathing." And she says, "OK, we'll get your breathing treatment."

Attending and responding to asthma symptoms was a choice that children did not always exercise. Children described ways they found to ignore their breathing trouble. One child revealed, "When the T.V. goes on my thinking goes off. So it [the T.V.] annoys me, and I can just ignore the asthma." Another child described an episode that might explain why one might sometimes choose to ignore asthma. "When we were almost done I was having trouble breathing. But then it stopped. I just kept on playing.

Then it was really hard trouble for me to breathe.” The intermittent symptom pattern described by this young child might lead one to ignore breathing problems for a time.

Choosing to ignore asthma symptoms might also be related to the variable chronic pattern of illness reported by the children. An important element of *seeing the trouble asthma causes me* was *having good days when asthma is not so active*. All children enjoyed periods of relative well-being when breathing was untroubled. One child stated, “In a way, when you have asthma, you can do anything that another person can do, when it gets not real active and all that.” Another child remembered, “ ’Cause like Friday was track and field day, and I wasn’t coughing at all.” However, some children noted that even on good days they would not be free of symptoms if they ran hard or got near an environmental trigger.

Two additional elements further explained the challenges of *seeing the trouble asthma causes me*. Some children reported *not knowing it’s about to happen*. Their breathing problems occurred abruptly without warning. They had no milder, early symptoms to alert them of coming trouble. A possibly related element was *not remembering what happened last time*. Some children had surprising difficulty remembering previous episodes of even severe asthma exacerbations involving urgent care in medical settings. *Not remembering what happened last time* might impair protective responses that help children learn to avoid similar flare-ups in the future.

#### *Knowing What Makes My Asthma Worse*

Another descriptor of *becoming the one who knows my asthma* was *knowing what makes my asthma worse*. Elements associated with *knowing what makes my asthma worse* included: (a) *running, working, or playing hard*; (b) *breathing certain kinds of air*

*can make asthma worse, (c) believing that my allergies and my breathing are connected, (d) catching a cold or getting sick, (e) having problems with my stomach, (f) having problems with my nose, (g) having croup with my asthma, (h) coughing and vomiting, (i) lying on the carpet, (j) talking too much, (k) having a fever or flu, (l) knowing that my asthma is worse at night, and (m) not knowing what started the trouble.*

When asked, “What makes asthma worse for you?” one child responded, “Playing too rough and running all the time - outside at school and on the playground, running.” Children described several activities that were too physically demanding for their asthma, including jumping too high on a trampoline, racing uphill on a bicycle, running too much in chase games, and sports involving a lot of running. Children also recognized many factors that were mediated through the air including temperature and weather change, odors, animal dander, smoke from fires, chemicals, and tobacco smoke. Sensitivity to room temperature and weather change were frequent elements in descriptions of factors that made their asthma worse.

...it’s better when the seasons aren’t changing because the weather change makes my breathing get worse or better. In the summertime if it stays a certain... if it doesn’t go over a lot, like one day it went from 32 degrees to 55 degrees and that made me cough a lot.

Some children described an association between being close to things to which they were allergic and experiencing worsening asthma. However, a relationship between environmental triggers and asthma symptoms was not always identified by the children. One child described an asthma attack that resulted in an emergency room visit. The child believed that the episode happened because she ran too much. She did not associate her

breathing trouble with an exposure to cats earlier in the day that had caused her to sneeze and wheeze.

Another child described his experience of having trouble breathing at the zoo.

Last year when I went to the zoo, certain places had certain kind of air. Like the penguins, it's too cold, so sometimes I had to wear my heavy jacket. When I walked near the elephants, around there, sometimes the hair and all that bothers my asthma.

He associated the trouble he experienced when being around animals with other possible allergic responses. “Don't know if I really mentioned this, but sometimes animals and all that make my asthma worse, just like my blanket does.”

Children also associated strong odors with worsening asthma, including the smell of certain foods, perfumes, and the rank smell of a dirty hamster cage. One child described intentions related to avoiding an unusual disturbing odor. “Sometimes at lunch, people eat with their mouth open and I just lay my head down on the table.” He described the cafeteria as a hard place to breathe due to food odors and cold air wafting into the room from the loading dock. He waited anxiously for the bell to ring so he could leave the cafeteria.

Some of the 8 children named unexpected things that made their asthma worse including “certain kinds of cat litter”, the “little white powder stuff they put on the ground” at school, and a detergent used to clean blacktop at school. Exposure to tobacco smoke was a problem for some children. “I have a grandmother that smokes. She comes here sometimes. That makes my asthma worse here.” Outdoor smoke from the burning of agricultural fields before spring planting was a problem for at least one child.

Some children identified and listed allergies among the things that made their asthma worse. One child expressed a thoughtful grasp of the relationship between allergic responses and asthma symptoms. “Because my allergies and my breathing connect together, so if I don't take my tablet [Singulair™] I either get sick easier or stop breathing.” Other children did not see this connection. One child described his trouble with cats as allergic, but saw no connection with asthma. When asked if being around cats could make his asthma worse, he responded “It's just my allergies.” However, most children identified things that could make their asthma worse, including carpet, cats, “my blanket”, furniture, and spring pollen. Children recognized that these objects did not always have the same effect on their asthma. “Trigger my asthma? Sometimes my blanket does.”

Colds and infections were common problems children identified that made their asthma worse. One child described relative levels of disease activity for flu, fever, and asthma. She noted that when all three problems were bad she almost had to go to the hospital.

I had the flu and a fever and asthma, all of them were high at the same time and I almost had to go to the hospital. But somebody changed it and I just had to go to the doctor. And I was really nervous when I heard that I had to go to the hospital. She also described how asthma medications seemed to stop working at these times. Other children did not understand the concept of having a cold or see a link to asthma.

Children also mentioned a number of less common things that made their asthma worse. One child reported having taken stomach medicine for a time. He believed that this helped his asthma. Another child noted that on certain days his nose was stuffy and

this made his asthma worse. He noted that a nose spray helped at these times. Another child associated nighttime with a worsening of her cough. One child believed that talking too much made her asthma worse.

One of the eight child described croup as a major source of trouble. She had difficulty distinguishing between croup and asthma at times. She saw the two as different but related problems. When asked what croup was like for her she replied with a detailed explanation that provided insight into why she missed so many days of school.

Coughing, throwing up a lot, usually. Just a few weeks ago I had to stay home for a week. Because it was so bad... it's all because of my asthma because it acts up when the air changes and all that. It's never fun because I'm always sick and I miss so many days.

She also described vomiting as a result of coughing so much. "Like one day I was in my bed and I sat up. I was coughing so much that I ran to the bathroom and threw up. I went into my parent's bedroom and said, 'I'm throwing up. I'm throwing up. Help!'"

Whereas children often described what they believed had caused their asthma trouble, there were also many times when they could provide no explanation. One child stated, "Sometimes I get trouble, and sometimes I don't." When asked why asthma comes and goes, another child responded "I don't really know." Uncertainty was a common problem they faced. In many instances the children simply lived with *not knowing what started the trouble*. A related intention was *watching for what makes my asthma worse*. Vigilance concerning factors that made asthma worse was associated with actions or intentions to make asthma better. These will be described later in this section.

#### *Wanting Asthma To Go Away*

Another descriptor of *becoming the one who knows my asthma* was *wanting asthma to go away*. Children recognized the bad effects of having asthma and longed to be free of the illness. The desire to have it go away was linked to the losses experienced. The burden of having asthma was evident in the words of one child who said “I’d be a regular boy. I might actually kind of feel like a regular little boy.” He further described in explicit terms what it would be like if he did not have asthma.

I wouldn’t have to miss my recess. Then I wouldn’t have to miss a whole bunch of days. I would be able to go to my classroom. I wouldn’t miss out on good things that happen when I’m at home. I wouldn’t miss being at my friend’s house. Not going as much to the hospital and the clinic and the drug store and all the things I have to take – my medicines.

Other specific elements associated with *wanting asthma to go away* included: (a) *forgetting about asthma*, (b) *hoping I will outgrow it*, and (c) *believing it will get better*, and (d) *fearing my asthma might get worse*. One child talked about how going shopping made it easy to forget about her asthma. Another child hoped to outgrow his asthma. “When I turn about, I think 16, I might grow out of my asthma. It feels like it. We’ve been in the hospital. We think my asthma might disappear. Probably even sooner than that.” Now all children had a hopeful view of their asthma. One child held deep fears about her asthma getting worse. “If you don’t outgrow it, it’ll be there for the rest of your life. It would keep getting worse for me, harder. My question is what if you get a really bad disease with asthma? What would happen?”

*Knowing Some things Make My Asthma Better*

Another important descriptor of *becoming the one who knows my asthma* was *knowing some things make my asthma better*. A related element *finding what helps me breathe better* was further described by these 8 children as (a) *knowing some kinds of air make breathing easier*, (b) *staying well helps my asthma*, (c) *believing certain foods are good for asthma*, and (d) *finding breathing is easier with quiet activities*. Children described intentions associated with *finding what helps me breathe better*. Each of the eight children described specific ways she or he was *making my asthma better*.

Children described several intentions and actions pertaining to *knowing some kinds of air make breathing easier*. One child stated, “I need air. Fresh air.” She went on to explain that this need was greater than for other people who do not have asthma. As an example she described her efforts to avoid the ill effects of hot, humid air in the bathroom when her sister was showering. She opened the bathroom door to let in fresh air. For short trips into the humid air of the bathroom, she reported, “I figured out a way. If it takes too long, I hold my breath. I figured out a way to not breathe in there.”

Another child who lived on a farm noted that she took her albuterol inhaler and wore a bandana over her mouth to avoid breathing cold air directly when she went out to play in the snow. She also reported trading chores with her brother so she would not have to go the barn in cold weather to feed the calf. One child was particularly sensitive to the wind. She described how she found a way to stay outdoors and play when the wind was blowing too hard, instead of going in to the nurse for a breathing treatment. However, she only had access to this sanctuary on days when her class was allowed access to a particular part of the playground.

I could go to the nurse and take my inhaler or there's this warm place where barely any air can get in on the playground. But if we're just allowed to stay up at the top playground, then I have to go to the nurse or the office. [The clubhouse] has a little top on it all the way and there's only doors about that big that you can go in and there's just little bitty lines on that that blow in and you have to lean against that. Or you can just lean on the two doors.

Most children commented on the merits of air-conditioning and wished for classrooms where the temperature was just right. When I asked one child what he would change at school to help his asthma he answered, "I want Miss D.'s room just right. It's always hot in there."

Children also described some things they believed would help them breathe better that were not directly related to breathing. One child described washing her hands to keep from getting sick and having a lot of coughing. Another child thought that getting shots for the cat might help. Three children mentioned foods as having a role in breathing better. One child observed that, "Certain food makes your asthma better, like chicken noodle soup." Another child produced a list of foods that would help her asthma. "Carrots, bananas, apples, oranges, fruits, vegetables. Not a lot of junk food."

A third child had no faith in the value of particular foods. "None of them make anything happen. Some of them make me feel better, but it doesn't do anything." However, her belief that eating or drinking was beneficial became clearer when she offered suggestions for the ideal place she would want to be if asthma was troubling her.

Have a soda fountain in every single room and get up whenever we wanted and a buffet whenever we wanted to eat and drink. And that would help me because my

throat wouldn't hurt. And I would stop coughing sometimes. Anytime I could eat and drink. No matter what. Everybody could in every room. And there would be macaroni and cheese, because I love macaroni and cheese. It is something that makes me happy. It's cheesy.

Most of the children described *finding that breathing is easier with quiet activities*. This discovery was related to intentions such as sitting down to rest more often and choosing activities that did not involve much running. "Well, if I've been running and everything, if I said, it helps it. I'll sit for a minute." When I asked this child why he sat down for a minute, he responded "Because I'm coughing just a tiny tad." He explained that taking short breaks allowed him to breathe better, avoid coughing, and keep being part of the activity. "Then I have to sit down for a little minute then I get back up and play." One child described how she modified basketball to avoid breathing problems. "Like basketball. It's really low [the goal]. I don't really run. I just dribble really, really slow and then make the basket. Because ours, we can pull down [the goal]. I make it the lowest, so I can cheat."

*Finding ways to stop my breathing problems* was an important sister element related to *finding what helps me breathe better*. However, a contextual distinction was apparent in the data. Children described more urgent and focused behaviors in the context of *finding ways to stop my breathing problems*. The intention *stopping my breathing trouble* describes many of the children's reported actions in this study, including (a) *waiting for asthma to go away*, (b) *using my medications*, (c) *choosing quieter activities*, (d) *drinking or eating*, (e) *getting fresh air*, (f) *forgetting about my asthma*, and (g) *seeking comfort*. Whereas, *finding what helps me breathe better* was revealed by children

in relation to the experience of being relatively well, *finding ways to stop my breathing problems* related to strategies the children discovered to be effective at times when their asthma was exacerbated.

The children did not always take medications when they recognized that they were having breathing problems. *Waiting for it to go away* was an intention that children exhibited when they did not have access to their medication, when they did not want to stop to take a medication, and when they thought the asthma might go away on its own. One child revealed, “Finally, I stopped wheezing. If I wait too long, like 30 minutes, it stops. But I didn't want to wheeze that long. And so I was trying to find my inhaler, but I couldn't find it.”

Another child described his usual way of dealing with breathing problems on the playground. “I just sit down for a minute and it starts getting better.” Some children described waiting and not knowing if the asthma would get better without medicine. Other children reported taking medication immediately and not bothering to wait because they knew it would only get worse. “I always have to stop and take medicine, before it gets worse.”

*Using my medications* encompassed many intentions described by the children. The contextual element *knowing medicines can help my asthma* was further described as *knowing my routine* and *knowing about my medicines*. These data were the most complex set encountered in this study. Analysis required up to 8 levels of classification to adequately describe the context and intentions. I will represent the structures of experience in context, shifting to a narrative form rather than holding to the hierarchical

framework used thus far in the discussion. However, the taxonomy on page 348 presents all levels of the analysis hierarchically.

The 8 children described *knowing my routine* for taking medications. These routines involved (a) *knowing how you are supposed to take the medicine*, (b) *knowing when and why I take it*, (c) *remembering to take them*, and (d) *not knowing what I took*. Problems associated with taking medicines included running out of medications and not knowing where the medicine how the medicine was supposed to be taken.

*Knowing how you are supposed to take the medicine* encompassed several critical intentions including (a) *breathing in my medicine in a special way*, (b) *taking a regular breath*, (c) *choosing to take it the wrong way*, (d) *forgetting to take my medicines*, (e) *getting the nebulizer ready*, (f) *taking this medicine every day*, and (g) *brushing my teeth after this medicine*. Only two children described *breathing my medicine in a special way*. One child demonstrated deep breathing when explaining how she took albuterol by nebulizer. She also described her effort verbally as taking “deep breaths”. A second child noted that when taking albuterol by nebulizer with the mask he had a unique way of breathing the medicine. “You are supposed to breathe it in and out, slowly. I usually use my nose to breathe it in. I’m not like other people who use their mouth.” None of the 8 children described or demonstrated correct inhalation technique for either metered dose inhalers (MDI) or nebulizers. Several children had valved holding chambers for their MDI, but reported that they usually did not use this important device.

When questioned about how they took their medicines most of the children reported *taking a regular breath* when breathing their inhaled medication. The most common term the children used to describe the type of breath they used for inhaling

medications was “a regular breath”. No child described an appropriate effort to exhale before breathing their inhaled medication into the lungs. No child described breath-holding at the end of inhalation to try to increase the amount of medicine that remained in their lungs.

Most children were not sure where into their bodies their inhaled medication was going. Only two children mentioned the lungs. Some children named the heart or stomach as the place where the medicine was supposed to go. One child believed that it was important to breathe deliberately into the nebulizer mouthpiece to avoid getting too much medication into the mouth. She did not know where in her body the medicine was going. Another child described seeing the mist cloud rising from the opposite end of his spacer, indicating loss of large amounts of the medication. Most of the children reported watching TV as part of their medication-taking routine, particularly when taking medications by nebulizer. “I just watch TV while it’s running.”

When talking about their medications two children specifically described *choosing to take it the wrong way*. One child remembered taking albuterol concentrate designed for use in the nebulizer and squirting it into his mouth. “It tasted bad. Sometimes I still do it.” He also reported smashing medications and throwing some into the garbage to avoid having to take them. A second child recited from memory a manufacturer’s directions for use of a medication, then added, “but I don’t listen to the instructions.” He went on to describe using the medication in a way that would not be expected to provide much benefit. These examples demonstrated that knowledge and behavior were not always congruent in the taking of medication.

Children also described the intention of *taking this medicine every day*. However, they often gave examples of forgetting to take these or choosing to take their daily medication only at certain times. Two children recounted times when they ran out of medications. Some children reported taking their daily medications because they believed doing so would help make their breathing better. One child believed taking her daily medication was very important, and she included “brushing my teeth after this medication” as an important part of her daily routine (for taking inhaled steroids). Another child concluded that her daily medications were “not so important”, because she did not feel differently after taking them. One child described *knowing you have to take I* giving insight into his actual use of the medicine. He stated “My purple inhaler, you’re supposed to take it every day. When it gets to a certain point, you have to take it.”

Several children volunteered very specific information about *getting the nebulizer ready*. The level of detail in their accounts suggested that children prepared their own medications and administered their own treatments.

I pour this little medicine into my little container; it’s a circle. And I screw the mask back on. And I just put [the mask] on [my face]. Then I touch a button and it just starts going. It goes up. There’s like air from the machine that goes up to the medicine, then goes up to the mask and there is like white smoke up in the air.

Children experienced difficulty with medication concepts related to *knowing when and why I take it*. “Yeah, uh, sometimes, sometimes when I get new medicines I don’t even know what it does, but when I take it I feel a lot more better. I don’t even know what it’s called.” Children were more familiar with medications they took at

special times for breathing problems than with those medicines that were prescribed for daily use to control asthma.

Several children described their dependence upon a parent to tell them about new medications. After a sick visit to the doctor, one child commented, “They tell my mom and she shows me.” Lack of understanding of the purpose of specific medications was apparent in children’s experience of *not knowing what I took*. “I have no clue what it’s called. I just drink it.”

Children also struggled with *remembering to take my medication*. Several children described ways they shared responsibility for remembering their medications with family members and friends. One child reported that a friend watched the specific placement of his inhaler on a dresser so he could monitor its use. I took this as evidence that he was checking to see if it had been moved. “When he goes into the living room and looks up on the dresser where my inhaler is at and says, ‘Jerry, did you take your medicine?’” Another child described how sometimes he would remember and at other times his mother would remember that it was time to take his medication. Responsibility for remembering some medications fell entirely to the parent, such as allergy injections that had to be given in a nearby town.

Children also described being too busy or distracted to remember to take their medication. One child pointed out that when he felt good it was harder to remember to take medication. “Sometimes me and my dad forget and I go a whole week without them. I still feel good.” This same child described two ambulance rides to the emergency room for very severe asthma exacerbations. A few weeks after making the above statement he required emergency transport by helicopter for another asthma exacerbation.

Children described much more participation and control in the use of quick relief medications than in the use of daily controller medications. Among all 8 children *deciding to take a treatment* was an important component phenomenon. Intentions included: (a) *getting to my medicines*, (b) *choosing how to take it*, and (c) *judging if the treatment is helping*. At least three children *dealing with unwanted effects of my medicines*.

Children described many experiences related to *getting to my medications*. The context included *depending on someone else to get to get my medicine* and *knowing where my medicine is supposed to be*. *Getting to my medications* involved a variety of significant challenges for all 8 children in this study. Children reported a number of difficulties encountered when they had to suddenly stop what they were doing in order to retrieve their albuterol. “I said, ‘stop the game, stop the game. I’m not in it any more if you guys won’t let me stop.’ So finally they let me stop and get my inhaler.”

*Depending on someone else to get my medicine* encompassed several aspects of the experience. At school children had to usually had to obtain permission from their coaches, teachers, and other adults in authority over them. Access to medication for some children was relatively easy. “I either tell the coach or tell someone and they either get my inhaler, or I get it myself.” However, most children described a more structured procedure for getting their medication.

I tell her [the teacher] I need to take my inhaler. She will send me up to the nurse and she will call the nurse and let her know I’m coming. And just in case my breathing is getting worse, somebody comes with me. One of the classmates walks me.

At home children also relied on others to get their medication. When troubled by breathing problems, one child often depended on her parents and her younger sister to locate and retrieve her albuterol. She described a sort of relay team approach by which she was *depending on someone else to get my medicine*. “If I need it real fast they will give it to my sister and make her run over to me.” Another child reported sending friends to find his father with a message to bring his albuterol quickly.

Children also described instances when their albuterol could not be located when they needed it quickly. The problem of *not being able to find my medicine* was frightening for several children. Others reported having never been without ready access to their quick relief medication.

One time I was jumping on the trampoline. My sister she came in here [into the house]. She couldn't find my inhaler and that made me really scared and I'm like, “What if I stop breathing, what if I stop breathing, what if I do, what if I do?” She said, “I don't know; ask Mom.”

Another child was unable to locate his albuterol inhaler during my interview with him. “Here is one of them, I think... nope it's not in here. My dad must have picked it up.” Six of the 8 children also described their thoughts involved in *choosing how to take my quick reliever medicine*. These children had albuterol in two forms – inhaler and in a form that required a nebulizer to administer a treatment. One child described a step-wise approach. “When I go to the nurse first she says to take my inhaler. I wait for a couple of minutes. If that doesn't work I take my nebulizer.” Other children based the selection of a nebulizer treatment on the belief that it was stronger and more effective.

I only take this [albuterol by nebulizer] if I can't breathe real well or if I'm sick.

Three times a day. If I don't want to take this [MDI], I take the nebulizer three times a day, instead of the inhaler because the nebulizer gets into my system quicker.

Children also described choosing to take albuterol by nebulizer rather than inhaler when the level of symptoms was unusually high. "When I am really sick." "If I get up and I cough a lot..." However, several children complained that nebulizer treatment take too long. One child pointed out the merits of a quick treatment when he compared his albuterol inhaler to a nebulizer treatment. "It's one hundred times faster than that."

The time required to prepare and take a nebulizer treatment was problematic for several children. One child reported no longer taking her daily inhaled steroid because the treatments took too long and kept her from playing with her friends. She further explained that she told her mother that the medicine was not helping her. The length of time required by the nebulizer treatment and the lack of an immediate, discernable effect of inhaled steroids led the child to judge the medicine to be of no value.

Children described *judging if the treatment is helping*. They were aware that improvement after taking quick relief medicines was not immediate. "Um, when I take my inhaler and it gets all the way through my system, I can breathe as well, well... I can breathe good and I can breathe like a normal person." Seven of the 8 children gave examples of times they were *waiting to see if the medicine will help*. One child quantified this waiting time. "Sometimes five minutes, nine. Sometimes it's half an hour or hour or something."

Some children also distinguished various levels of response to the treatment including: (a) *feeling that the medicine is helping*, (b) *being a little better, but not back to*

*normal*, and (c) *finding the medicine did not help*. Children also described *going back for another treatment* when asthma symptoms returned. The ability of the children to judge the degree of relief experienced when taking albuterol was evident in their remarks. One child described the experience of returning to normal breathing after a treatment in this way. “It feels good. I smell fresh air.” Another child reported that his quick relief medicine “Helps me a little bit. Less coughing.”

Most children described times when their asthma medicine did not seem to work. One 7 year old astutely surmised, “If I have a fever or flu, even a small fever takes over the medicine. And then it couldn’t help. It like takes over the asthma control.” Children also described days when more than one nebulizer treatment was needed at school. “One time I had to go twice a day, I was so bad. My teacher sends a note at the end of the day that I had to go back to the nurse. She always sends that if I have to go back to the nurse.”

*Finding the medicine did not help* was associated with *calling mom and going home* or *going to the doctor*. One child described having breathing problems at school that often did not respond to albuterol treatments. She related a common sequence of events involving having trouble breathing at school, going to the nurse for a treatment, then being picked up by her mother to be taken to the doctor’s office in a nearby town. “We call in. I’ll get picked up early at school and then we’ll head on there.” Another child described dependence on office visits when asthma was not well controlled. “If I’m sick I go to the doctor immediately. If I start coughing I go to the doctor immediately.” Three children made such trips to their doctor for poorly controlled asthma while they were participating in the study.

Three children described rather severe albuterol side effects. These children described *having problems after taking my albuterol* that included *shaking uncontrollably, being unable to stand still, and being unable to fall asleep*. *Shaking uncontrollably* was a troublesome problem for some of the children that was associated with *having trouble writing* and *having trouble drinking at the fountain*. Two children described having to redo their cursive writing work due to hand tremor associated with taking albuterol.

I feel really, really shaky. It makes you really, really shaky. And when you have to go back to class and write it's really hard. One day we were doing cursive and I had to redo the paper – it was all messy.

A child described a time when her whole body was shaking so much after taking albuterol that she could not drink from the water fountain without getting wet. Her friends nicknamed her “shaky”. She was very troubled by her classmates’ assertion that she was deliberately shaking. “It [albuterol] makes me shaky and one day it almost made me fall over because I was that shaky. And whenever I do it, everyone says, “stop shaking, stop shaking.” She also described very strong emotions related to her classmates accusing her of intentionally not standing still.

I was out at recess and I was running too much because we had to run 5 laps around the playground and our playground is really big. When we got done I had to go up to the nurse [for an albuterol treatment]. After I went to the nurse, I came back to the classroom. As I was walking back to the classroom I was moving a lot and I couldn't really stand still. People say I'm joking - that I was doing it myself and I'm saying, “No I'm not doing that myself. You need to believe that.”

Another child described her difficulty falling asleep after taking albuterol at night. “[Yawn] I can’t fall asleep when I take my asthma medicine. Then I have to go to bed. Sometimes I just play in bed. Sometimes I don’t go to sleep and then in the morning I don’t get up.” When questioned about the type of albuterol treatment that caused side effects, none of the children reported one form worse than another (nebulized vs MDI). One child described choosing to not take albuterol in order to avoid unwanted side effects. “Some days I’m like, well, I want to run faster, but I don’t want to be using my inhaler a lot. So I tell myself to stop or slow down.”

A final element associated with *using my medications* was *knowing about my medicines*. Children described *knowing the cost is high* and *knowing what the medicine does*. Two children shared specific concerns related to *knowing the cost is high*.

If I need my medicine for a breathing treatment medicine, they will go to Wal-Mart and buy it. Just so I can have a breathing treatment. A breathing treatment with the medicine that costs a lot and all the stuff that goes with it, which is the tube, the mouthpiece, the tubing that connect to the mouthpiece, the lid and the thing that holds all the medicine. The medicine costs a lot.

It was apparent that this child felt guilty about imposing a financial burden on her family. She demonstrated an awareness of economic consequences when she said:

They cost a lot, and we would probably have more money to buy more stuff, like more food, ice cream and toys. ’Cause the inhaler and all that stuff they cost a lot of money. And I say, “Why does it have to be me? It’s not fair.”

The high cost of medications was associated with missing doses of the daily control medication by another child. When he explained why he sometimes ran out of medicine

he stated: “Certain of these medicines cost my Dad a lot. Like the purple one costs a couple hundred dollars just for another one.”

Most of the children described either vague concepts or uncertainty related to *knowing what the medicine does*. When asked what a particular asthma medicine did, a child responded, “They make me feel a lot better and they make me go to sleep at night.” Another child responded to the same question saying, “Helps me get better.” Other children reported forgetting or having never known what various medications were supposed to do. “I forgot. It’s so long ago.” “I don’t know.” Another common response to questions about the purpose of medications was “for my asthma.”

Another component phenomena related to *stopping my breathing* trouble that I discerned from all 8 children’s descriptions was *choosing quieter activities*. Associated intentions included (a) *slowing down the pace*, (b) *taking a nap*, (c) *lying down*, and (d) *avoiding noise and people who bug me*. Children described various ways they were *slowing down the pace* including (a) *taking a break from the activity*, (b) *going at a nice steady pace (the NSP)*, (c) *lining up to stop the activity early*, and (d) *cooling down*. “Some days I’m like, well, I want to run faster, but I don’t want to be using my inhaler a lot. So I tell myself to stop or slow down.” Another child described more severe activity limitations due to asthma symptoms. He described the need to slow the pace as simply: “Stop running and walk.”

Four children described *taking a break from the activity* in order to stop their breathing trouble. Breaks allowed them to return to physical activity in a short time. One child carefully explained how, if allowed, he would arrange physical education class to

include a break in the middle, then return to active play. Another child described using a break to be able to continue jumping on the trampoline.

Most of the time everyone goes on the trampoline, and 'cause they like to do flips on it. Sometimes I have to stop. "You guys can keep on jumping and I'll just sit and wait until my asthma slows down." Then I get back up and try to jump and then I do that again. Then finally I just get off, if it's too bad.

A unique and apparently successful approach to reducing breathing problems associated with running was described by one child. She used an acronym to describe her careful approach to pacing herself during prolonged runs. In her account she also implied that her friends are the more inactive kids at school. Her approach was well articulated.

Well, me and my friends, they don't like to run, but I tell them that they can run because they don't have asthma. And I said, "I'm going to do the NSP, nice steady pace." I didn't really win the first place and usually I don't. They get tired after the second one, and we have to run four in fourth grade. So I did the nice steady pace, and I did not come in last.

Breaks from activity were sometimes unwanted. Several of the children in this study reported being required by adults to stop fun activities due to their breathing problems. Their frustration and disappointment were readily apparent in descriptions of being on the side line. "So they are out running and playing and you're sitting on the bench and that makes you mad. Because I don't get to run and play."

An unexpected intention related by three children was *lining up early to stop running*. "It was almost time to go to my room. I couldn't wait. The teacher said if we walked [instead on running], we had to get back in line. So I started walking to get back

in line, so I could catch my air.” Another child described a similar intention. “My mom told me not to run, but I walked over to this one hill close by where we line up and I was looking for four-leaf clovers.” These children anticipated the end of running activities and attempted to use “lining up” as a way to stop their breathing problems. “I was hoping it was time to line up and quit playing and stuff.” Children also described *cooling down* as an approach to reducing breathing problems.

Other intentions related to *stopping my breathing trouble by choosing quieter activities* included (a) *taking a nap*, (b) *lying down*, and (c) *avoiding noise and people who bug me*. Four children described the benefits of naps or sleeping when they were troubled by serious breathing problems. “Well, one night, I mean one morning, I couldn't breathe. I had to take a treatment. I felt real, real good. Then I started feeling bad again. After I took a nap, then I felt good.” Another child explained that when her asthma was bad she liked to be in bed. “Because I get a lot of sleep. That helps a lot.”

Another child described the benefit of lying down on couch at home or on the cot in the nurse's office at school when his asthma was troubling him. He stated that he felt “glad because I can lay down and stuff and rest.” A unique aspect of *choosing quieter activities* was described by one child as *avoiding noise and people who bug me*. She described having difficulty trying to find a quiet place where she would not be disturbed when she was having trouble breathing at school. “There's not really a place that you can be by yourself with nobody's bugging you. The bathroom always has somebody in it, that starts to jabber, just by itself, or constantly somebody talking.”

Most children described *drinking or eating* as an intention related to *stopping my breathing trouble*. “Because one time I coughed and I drank something and ate some

string cheese and I felt better.” The most common associated behavior was simply *drinking water*. “Drinking a lot of water. Drinking water helps a little. It helps you not wheeze as bad.” Getting a drink of water might be related to more than just the act of swallowing water. The same child explained that getting a drink also provided a break from the physical activity and a moment of sanctuary from unkind peers.

I either just get really, really teary, but no one knows about it. They either don’t notice or they don’t like me or they are just mean to me. Because some of the kids are just plain mean to me. I usually say, “Can I go get a drink, please? My asthma is really acting up. And if I don’t get a drink, I’ll probably stop breathing. Please let me go get a drink.”

Children described the merits of drinking water in terms of helping their throat and stomach, as well as their breathing. These descriptions were suggestive that gastroesophageal reflux or pharyngitis might have been a component of their difficulty.

Sometimes my throat starts hurting and I don’t have any water in my mouth and I can’t breathe very well and I run over and ask my coach if I can walk. Sometimes he says yes and sometimes he says no.

Another child commented that drinking water helps “just a bit, for a second.” “Because I stop coughing and my throat doesn’t feel damaged any more.” When asked whether the water helped his throat, stomach, or lungs, a third child remarked, “That’s a hard question. Sometimes when I am running I get a cramp in my stomach. When I keep running, I hold my stomach so I won’t hurt no more.”

Children noted and sometimes complained that adults instructed them to get a drink when they were having breathing problems. “My mom always gives me a drink of

her water [when I'm coughing]." Another child noted that the coach often denied her request for go to the nurse for albuterol and had her get a drink of water instead.

"Sometimes he thinks I'm faking it, because most of the time when I'm running he either tells me to get a drink or calm down. If it doesn't work, he still won't let me go to the nurse."

Two children extolled the merits of *eating chicken soup* when they were troubled by asthma symptoms. "When I am sick, one time when I was sick my friend was staying all night with me. I had to eat chicken noodle soup and drink Seven-up. Then I started to feel better." Another child stated: "Sometimes just by cooking something it helps my asthma... Some people don't know that chicken noodle soup is actually a medicine." He also believed eating tomato soup was helpful when his asthma was flared up. Another child, previously mentioned, found eating or drinking anything was helpful for stopping her coughing.

Children described other ways they were *stopping my breathing* trouble, including (a) *getting fresh air*, (b) *forgetting about my asthma*, and (c) *seeking comfort*. Several children explained that *getting fresh air* helped them to stop their asthma symptoms. One child described outdoor air as easier to breathe than the air in her house. "I go outside and I start playing. The fresh air starts going down in my throat and then I feel better." Another child described waiting anxiously to leave the cafeteria so he could return to the hallway and his classroom where he could breathe fresh air. "And I just can't wait until I get out of the lunchroom so I can get some air. Then I can just forget about it."

Other children also described attempts at *forgetting about my asthma*. Their descriptions suggest an effort to escape unpleasant feelings and thoughts associated with

their breathing problems through distraction by watching television, eating, or using their imagination to think of pleasant things. When asked what she thought about when having trouble breathing, she responded “Nothing. My mind goes blank.” Another child stated: “It just helps me concentrate more when I can chew on something.” In another instance a child described imagining a “kitty cat world” when she was having trouble breathing.

I love them. They are my favorite things in the world. All the flowers were blooming, and little cats were there. The man was a cat and everything that I liked was there. All the cats liked me and I was cat woman because I love cats.

A final intention pertaining to the component phenomena *stopping my breathing trouble* was related to *seeking comfort*. One child found consolation in a hand-made blanket. He described having this blanket through the years as he moved from the city where he lived with his mother to the country where he lived with his father. He told of holding onto the blanket during a frightening ambulance ride when he had a severe asthma attack. Even though he believed he was allergic to something in the blanket he treasured it as a familiar object of comfort.

When I’m basically in a situation where I can’t breathe and all that... I don’t know, it’s like my blanket is like a good luck charm. When I curl up into it, it makes me feel better. I rest on it. It makes me fall asleep. It’s real comfy, like a good luck charm.

An intention related to *making my asthma better* was *wondering why I am having trouble*. This element encompassed children’s ongoing efforts to understand what they could do to avoid the trouble asthma caused. This element reflects unexplained flare-ups of asthma. Children described their thoughts about what might be causing them to have

trouble with asthma. “Maybe it’s because of my allergies. Umm. Maybe it’s the stuff they put on the ground. Sometimes before we go out there, they clean the blacktop.” One child gave a graphic image of what this experience was like for him.

Sometimes I just stand outside and just do nothing, just stand by the wall. And I start breathing real hard, real hard. I don't know if that's why. I guess I'm not doing something right. Or I just don't need to go out.

A final descriptor associated with *becoming the one who know my asthma* was *remembering things about my asthma*. Whereas children remembered many things about their experience of asthma, they also struggled to recall some details. Several children described *being unable to remember the last trouble I had* with asthma. One child told about having trouble breathing at karate class. She reported using her albuterol after arriving home, however she could not remember whether she used an inhaler or a nebulizer.

Time-related recall was particularly difficult for the children. Several children had difficulty remembering the last time a medicine was taken when the interval was more than a day or two. One child who had been out of school only a few days commented “Umm. See now that I’m out of school, I can’t remember anything about school.” She had a whimsical explanation for her inability to recall certain facts. Referring to imaginary animals in her head that were responsible for retrieving information from her memory she said, “I think they are supposed to remember, but they didn’t label all the files. They labeled some of them, but not all of them. When I do math it took them 20 minutes to figure it out. I don’t think they labeled it.”

A distinguishing element among the children was whether or not each child could recall how asthma began. Most children had difficulty *remembering how asthma began* because their asthma started when they were infants or toddlers. Others recounted a time when they were able to breathe normally or memory of a distinct beginning of asthma. “When I was little I did not have any asthma trouble.” “We didn't really know whenever I just first got asthma. It was a week later after I learned I got asthma. I started coughing real bad, wasn't breathing real good.” Children who did not remember a time without asthma had more difficulty describing what asthma was like for them.

#### Knowing How Other People Respond to My Asthma and Related Intentions

A third feature of the experience of asthma for these 8 children's was *knowing how other people respond to my asthma*. The children demonstrated an awareness of a wide range of responses exhibited by others. They considered who would be likely to help them and who would be less likely to help. Their intentions suggested that they appraised, anticipated, and acted in concert with expected responses of persons in their lives. Descriptors included: (a) *knowing that my asthma causes worry and concern*, (b) *realizing I sometimes get special treatment*, (c) *knowing some people don't treat me like a normal person*, and (d) *knowing others help me with asthma*.

One child's description of other people's responses to his asthma illustrated a spectrum of responses that children experienced. He described his perception that certain people around him were concerned about him because he had asthma. “It makes people worry about you.” He felt cared for and valued when people worried about him. However, he also commented that other people were concerned because they were afraid of catching his asthma.

I think, I think people are scared of me now, because since I got asthma... and that's my best buddy in my class. His mom, when I start coughing, his mom said, "Oh, I don't want your asthma." I don't really think you can pass asthma to somebody else.

Even though he did not believe asthma was a contagious disease, he felt disturbed by the remarks made by his friend's mother. "I'd like to say to her, 'You can't catch asthma. It basically stays with the person that has it. It's not like a disease. It's just something that you got born with.'"

Among his peers, the same child found that some classmates were jealous of the special treatment he received, whereas others looked up him at times because of his knowledge of asthma.

They get kind of jealous of me because I get to do special things. They say, "Oh, that's not fair." Sometimes I just get a sticker because I got asthma. The other kids are saying, "Hey, I want one." I can sit in the room and read. The other kids say, "Why did he get to read?" Or I get M&Ms and they say "Why did he get candy?"

Another kind of special treatment brought pride to this child. When a peer had an asthma attack, this child was regarded as an asthma expert by his friends. They looked to him for advice on how to help the boy who was having breathing trouble.

Some children in the study described *knowing some people don't treat me like a normal person*. The desire to be like others was best illustrated by a girl who reported often being called names and teased because of her asthma.

They treat other people, let's say, one of my friends, she doesn't have asthma and they don't make fun of her. Sometimes I say, "Why can't you not call me names? I'm just like a normal person except I have asthma. That doesn't make me really, really different than any other person. That doesn't make me a freak or something like that."

Other children did not experience being treated differently by others. However, these children still reported many ways in which their lives were limited by asthma.

A particularly important descriptor of *knowing how people respond to my asthma* was *knowing others help me with asthma*. Important contextual elements included *knowing some people know more about asthma* and *going to the doctor*. Related intentions included *getting someone to help me*, and *showing others my asthma*.

Children appraised the asthma knowledge of others in their world and they sought help *knowing some people know more about asthma*. One child said "My parents know a little bit about it. My nurse knows a lot. My nurse has been telling my parents about it."

Most children relied largely on their parents' knowledge of asthma. "Yeah, he knows a lot about asthma. Sometimes when I need to go the doctor's office, he kind of asks about my asthma and they give him more stuff. And my dad knows about it and all that." However, one child noted that parents do not always know about asthma. "She don't know that much about asthma, but her son has asthma." Another child identified his baby sitter as knowledgeable. He supported this belief citing as evidence (a) her understanding of his medication regimen, (b) her ability to manage his asthma flare-ups, and (c) her familiarity with his allergies.

A phenomena associated with *knowing others help me with asthma* was *getting someone to help me*. Component phenomena included *going to the school nurse* and *telling my teacher or coach*. Intentions associated with the component phenomena *going to the school nurse* included (a) *waiting to see what happens*, (b) *getting the coach to let me go to the nurse*, (c) *walking to the nurse*, (d) *finding my class after my treatment*, (e) *getting help when the nurse is not there*, and (f) *deciding not to go to the nurse*.

All 8 children described experiences related to *going to the school nurse*. Children determined when it was necessary to go to the school nurse by *waiting to see what happens*. One child explained “well before I go to the nurse I kind of wait and see what happens and then I go to the nurse.” Several children described their experiences related to *getting the coach to let me go to the nurse*. Some children had ready access to the nurse by simply telling their coach that they needed their medication. Two children reported difficulty convincing their coach that they were having breathing problems.

Sometimes my throat starts hurting and I don't have any water in my mouth and I can't breathe very well, and I run over and ask my coach if I can walk.

Sometimes he says yes and sometimes he says no.

Another child described her realization that her wheezing had to be really bad to convince the coach that she needed to go to the nurse.

If I'm not really wheezing a lot but if I'm just wheezing a little, he says “It is going to be OK, just try to breathe in and out”. But if I'm like wheezing real bad, he lets me go to the nurse.

Children described a variety of experience related to *walking to the nurse* that raised concerns about their safety. Whereas some children reported being escorted by a

classmate from the classroom to the nurse's office, other children described walking alone. One child told about arriving at the school nurse's office and finding that no one was there. "I just go back to my classroom and wait in there. She will tell me to go lay down in the nurse's room. You have to wait like 15 or 20 or 5 or 10 minutes and then she will be there." The child described lying down on the cot to try to catch his breath while he waited alone. Most children described a having to go alone a short distance from the classroom to the nurse's office.

Safe asthma practice was exemplified in one child's description of going to the school nurse. "She will send me up to the nurse and she will call the nurse and let her know I'm coming. And just in case my breathing is getting worse, somebody comes with me. One of the classmates walks me." However, other children's descriptions raised concerns about their safety. One child's description of a desired future included "So I won't be going into the office and saying 'I need my inhaler or my nebulizer'. I won't be walking down a long hall." Several other child in this study described how they walked to the nurse's office "by myself."

Another child described his experience after returning to school from a doctor's visit. He had to leave school due to breathing problems. After receiving albuterol by nebulizer at his doctor's office, he was sent back to school for the rest of the day. After returning to school he went alone from the office to try to find and rejoin his class.

They weren't there. I was trying to look for them. I thought Mrs. Smith's class was in music. I saw [Jane] and she went out, so I thought Mrs. Smith's class was in music. Then Mrs. Jones [school nurse] saw me looking for my class because I didn't know where they were.

His school nurse finally helped him locate and rejoin his class.

Children also described *getting help when the nurse is not there*. One child described going to the office to take albuterol when the nurse was not available. She described being given the inhaler and having no one to watch her take the medicine or coach her to take in the correct way. When asked who helped him with asthma at school another child named his principal. He then described going to the office and depending on the principal or other office staff to give him his inhaler.

Sometimes, when there is nobody in the office, in the nurses office, sometimes she [the principal] goes in there and gets my medicine. Or like the other people where you have to check in and all that, they got the computers, they get my medicine.

Not all of the 8 children decided to go to the school nurse. One child described going to the nurse in the first grade, but not in the second grade. She reported not telling her teacher or friends that she had asthma. “They might have told the teacher and she would say, ‘Where’s Whitney, where’s Whitney? Come on. Let’s go to the office and take your treatment or whatever’s up there.’” This was the same child who described dreading taking nebulizer treatments and deciding she did not need her daily inhaled control medication. Despite her decision to not seek help at school, she described deep fears about asthma. However, she quickly shifted her attention to her immediate good health, rather than changing her mind about telling others about her asthma. “It feels scary and it makes me think I’m going to die. [Silence.] Like today at recess I wasn’t even having a hard time breathing. We didn’t even get to go outside either.”

Children described other experiences related to *telling my teacher or coach*. Some children described an orderly way their asthma problems were managed in the classroom. One child explained a sort of step wise approach in the classroom that handled the range of asthma symptoms she experienced during the school year. These steps involved (a) simply telling the teacher that she needed a treatment, (b) being sent to the school nurse, (c) coughing so much that the teacher sends her back to the nurse, (d) being kept inside by her teacher during recess on bad asthma days, and (e) her teacher sending a note home on days when she required more than one albuterol treatment. “My teacher sends a note at the end of the day that I had to go back to the nurse. She always sends that if I have to go back to the nurse.”

Another descriptor of *knowing how people respond to my asthma was going to see the doctor*. Children described *getting a check up* and *seeking help when I’m sick*. Only two children described going to the doctor for their asthma when they were well. One child reported having spirometry performed during their doctor visits. This same child was the only one of the eight children who described having a peak flow meter and recording their asthma symptoms using a symptom diary. This child saw a specialist for her asthma. The two children who had well checks for asthma described having people listen to their breathing with a stethoscope. However, neither child knew what the doctor was listening for or what was heard.

All 8 children talked about being seen by a doctor when their asthma was worsening. A pattern of episodic, sick care prevailed among the children. “If I’m sick I go to the doctor immediately. If I start coughing, I go to the doctor immediately. And I’ve had to go to the doctor a lot this year.” This child was on no daily inhaled corticosteroid.

Whereas 4 of the 8 children had inhaled corticosteroids, only one reported long periods of uninterrupted daily use.

Children identified “getting medications” as the primary reason for their doctor visits. “Sometimes if these medicines aren’t helping they will give me a new one. Like when I have a fever or something they will give me new medicine.” Several children commented that the nurses and doctors explained new medications to their parents and then their parents later explained the medicines to them. “They tell my mom and she shows me.” One child believed that her throat was an important part of her asthma trouble and a way the doctor knew how she was doing. “They look at my throat and they say if I need to take my breathing treatment more often or I need to get medicine or something like that.”

Another rich and complex phenomenon associated with *knowing others help me with asthma* was *showing others my asthma*. Children in the study described their experiences related to making others aware of their asthma. Some children found that their parents, friends, teachers, or coaches readily saw their breathing problems. “She just knows that if you don’t run and play that your asthma is giving you trouble?” Other children described their efforts to help others see their trouble. One child recounted, “Once we had to run until the teacher got there. I went up to my gym teacher and I was crying because I couldn't breathe.” Another child provided a more analytical description of the challenge of helping others to see her breathing problems. “I start breathing in and out really, really, really deep and I tell him it’s hard, and I can hardly breathe anymore.”

Contextual descriptors associated with *showing others my asthma* included (a) *not being asked*, (b) *knowing they don’t believe me*, (c) *knowing doctors and nurses could*

*help them know, and (d) knowing they sometimes see my asthma first. Related intentions included (a) answering their questions, (b) using a smiley face scale to tell them about my trouble breathing, (c) bringing a note from home, (d) waking up my mom or dad, (e) moving to the couch closer to my parent's bedroom, (f) telling my parents, and (g) deciding not to tell them.*

Several children described *not being asked* directly about their asthma by doctors and nurses. “Sometimes when I need to go the doctor’s office, he kind of asks dad about my asthma and they give him more stuff. And my dad knows about it and all that.” Children’s descriptions of their clinic visits involved the parent answering questions about the child’s breathing problems. Two children specifically stated that no one asks them questions when they go to the doctor.

Some of the children were troubled *knowing they don’t believe me*. One child remarked, “Sometimes I’m basically nervous because people don't believe me.” Another child described an incident when she began having trouble breathing during rough play with her sibling. “One time my brother was starting to play with me. I said, ‘Get off, get off, I can't breathe.’ He wouldn't listen. Then I said, ‘Get off!’ Then he did and I went to tell my Momma.” Children reported telling their parents about times when adults ignored the child’s efforts to describe their trouble breathing. One child struggled to convince her coach that sometimes it was very hard to breathe and she needed to get her albuterol.

If I’m not really wheezing a lot, but if I’m just wheezing a little, he says “it is going to be OK, just try to breathe in and out”. But if I’m like wheezing real bad he lets me go to the nurse.

She realized that her coach was judging her asthma based solely on her wheezing and labored breathing. After being denied permission to go to the nurse on several occasions when she felt short of breath, she exaggerated her breathing trouble when she felt that she really needed a treatment.

So I go [she makes wheezing sounds and labored breathing sounds] so I could just go to the nurse because I know when I have to get my inhaler because the nurse taught me. She said you know when you need it so just tell whoever is by you or tell your teacher or someone. They will let you come up here and let you have your inhaler. That's happened two times already that my coach won't let me go take my inhaler.

Children described many instances when they were *answering their questions*. "When we got to the doctor's office she asked me, 'Where is it hard to breathe at?' I pointed right at my chest." Another child explained with uncanny insight the reason behind his father's obtuse questions in the hospital.

And when my dad comes into the room he asks me a couple questions, like, "Are you feeling better?" Or "Do you want to like go to Wal-Mart?" Sometimes I say "yes" and sometimes I say "no". Yeah, he just wants to see if I feel better.

One child recalled the line of questioning he faced after admission to the hospital.

Sometimes it's actually at the emergency room when they ask me these questions. "Have you been feeling well?" "Have you been active?". "Have you been sleeping well?" I guess it's like when I first get up, it's like I can't really answer that question.

Another child described her fear of facing questions at the hospital.

I had the flu and a fever and asthma, all of them were high at the same time and I almost had to go to the hospital. But somebody changed it, and I just had to go to the doctor. And I was really nervous when I heard that I had to go to the hospital. I was thinking: “What were they going to ask me and what would happen to me?”

Another intention associated with *showing other people my asthma* was *bringing a note from home*. One child described having to bring a note from her parents to be allowed to slow the pace in physical education class when her asthma was giving her trouble. She explained that when recovering from asthma flare-ups she could return to school sooner if allowed to opt out of more vigorous physical activities. “Yeah, like not having to run around the playground. Like PE. That makes my asthma go up as fast as I could. Sometimes I have to bring notes saying I can’t run because of my asthma.”

A unique aspect of *showing other people my asthma* was the problem of other children not knowing enough about asthma. One child who was disturbed by the fact that her peers doubted that she really had asthma.

One of the kids in my class said, “No, you don’t have asthma. I bet you a hundred bucks you don’t.” And they didn’t find out, so they didn’t owe me a hundred bucks, and I didn’t owe them any money.

She described *knowing doctors and nurses could help them know*. One way she believed health professionals could help is “by sitting them down and saying, ‘This is what I have noticed about asthma. This is what you can do to help asthma.’ And all that stuff.”

Another intention related to *showing other people my asthma* was *waking up my mom or dad* when having trouble breathing in the middle of the night. One child described having to get his parents to help him during a bad coughing episode. “I had to

wake up my mom and dad and they gave me that tube thing. And I couldn't fall asleep because I kept coughing and coughing. It didn't work." Another child described her experience of awakening her parents and then *moving to the couch to be closer to my parent's bedroom*. "I have to go wake up my mom or my dad. [I take a breathing treatment.] She says, 'Go get your cover and your pillow and lay on the couch'. That's what my mom says." She explained that her bedroom was too far from her parent's room, so they moved her to the couch to be able to better monitor her asthma.

Children described many instances when they were *telling my parents* about their breathing problems. This was an important intention related to *showing other people my asthma*. However, several children in the study described a higher level of asthma symptoms during the interviews than was reported by their parents in the recruitment process. This finding suggests that children do not always tell their parents about their asthma symptoms. One child, whose mother indicated in the recruitment process that he had seldom experienced asthma symptoms in recent weeks, provided a very different description. He explained that whenever he ran too much he coughed. When asked if there were days when he could run without coughing he responded flatly, "Nope."

Additional evidence that children did not to fully disclose their asthma symptoms was apparent in the intention *deciding not to tell them I have asthma*. "Sometimes when I'm playing with my friends and I start having an asthma attack, then I don't tell nobody. I don't even tell my friends and I feel scared. I think I shouldn't tell them." When asked why she did not tell others about her asthma, she replied "I don't know." In a later interview she described *hiding her asthma* because of *not wanting to miss recess*.

When I am having asthma, sometimes it makes me know that I need to tell the teacher. But I don't want to. I don't want to miss recess, but I need to, so I won't have a heart attack or something.

Children also described *knowing that others sometimes see my trouble first*. One child said that her parents notice her wheezing and remind her to take albuterol and Atrovent. “My mom and dad, if I come in from outside, and I’m really wheezy, they say ‘Go take your inhalers’”. One child described always depending on her mother to know if she was having trouble and needed a breathing treatment. She named her mother her “asthma sidekick” in recognition of the primary role her mother played.

My mommy seems like a sidekick when it comes to my asthma. Pretty much!

She knows everything that I need and tells me something. Sometimes, she talking to me and my brain is going. I don’t know, and sometimes I don’t even hear.

Another child described *knowing that they sometimes see my trouble first*. This child noted that his grandmother had asthma and could see when he was starting to have trouble. He described times when she intervened to bring him albuterol or she pulled him out of physical activity when she noticed his labored breathing. “She’s a nurse and she has asthma. She knows when I am getting ready to have an asthma attack.” In another instance he described his classmates recognizing his breathing trouble and alerting the teacher. “After PE people saw me, that I was having trouble breathing. Then they told the teacher.”

This child, who relied heavily on others for recognizing his breathing problems, reported using a novel approach to describe his breathing problems. When at the doctor’s office during an asthma exacerbation, he was given a smiley-face scale to rate his asthma.

And the doctors gave me this little sign to see which one I was having. It was the one right before the last one. It was smiley faces. The first one was like real happy, then it was getting worsser, and worsser. Then at the last it was really bad. It [his asthma] was like this [he demonstrates a very sad face]. The one right before the really bad one.

After an albuterol treatment he used the scale again to estimate the amount of improvement in his breathing. This simple analog scale seemed to provide him with an effective way to describe his asthma symptoms.

Another important descriptor of *knowing how other people respond to my asthma* was *knowing my family helps me*. Children described three related contextual elements including (a) *knowing they help me with my asthma medicine*, (b) *knowing they will get me to the doctor*, and (c) *knowing they remember things about my asthma*. Several intentions were related to the context of *knowing they help me with my asthma medicine*, including (a) *asking family members to bring me my medicine*, (b) *expecting my family to remind me to take my medicine*, and (c) *depending on my family to give me medicine*.

Children gave many examples of times when family members helped them with medications. Whereas a particular parent (mothers more often than fathers) usually provided most direct care related to asthma, children also described help received from their extended families. One child articulated deep appreciation for a network of caring family members. When asked who helped her with her asthma she responded:

My whole huge family. My grandma has about 20 grandkids, and some of them, like one of the little ones, one time I said, "Can you go get my inhaler, please?"

Can you go ask my mom for it?” He ran and ran, and he said, “Ok, I’ll go do it.”

He finally got my inhaler for me. They [the extended family] really help me a lot.

A final descriptor of *knowing how other people respond to my asthma* was *seeing that some people stick up for me*. Three children described times when their friends stepped in to help them when they were experiencing breathing problems. Beyond the obvious benefit of having someone to alert an adult, children might experience strong psychological support from knowing friends are there to care for them. One child said, “Sometimes when I get sick people stick up for me. They go to the teacher. I feel real special because I have asthma.” He knew from experience that people do not always support a person who has asthma.

Yes, people help me when I’m in a real, real bad situation. People help me.

Sometimes, sometimes when I play tag with my other friends they say “Jerry, are you having an asthma attack?” They start running and saying “what do we do?” I get frustrated and say “Don’t panic, go to the teacher.” Yeah. I can respect my friends around here. Then again, where I used to live you can’t respect nobody around that neighborhood.

#### Coming to Know More About Asthma and Related Intentions

The children in this study recognized that they lacked basic knowledge about asthma and about their medications. *Coming to know more about asthma* was an important feature of their experience. Key descriptors included (a) *realizing I don’t know a lot about asthma*, (b) *knowing some people teach me about asthma*, (c) *knowing that others have asthma*, and (d) *realizing that asthma changes over time*. Whereas, some children described learning about asthma in informal ways, their accounts largely

underscored the lack of education provided to them. Their desire to learn more was apparent.

*Realizing I Don't Know a Lot About Asthma*

All children in the study described *realizing I don't know a lot about asthma*. One child appraised her lack of knowledge stating "I don't know a lot about asthma because I'm just a little kid. I'm only 10 years old. And I don't know a lot about it." Many basic questions about asthma were challenging to the children. When asked, "Do you think asthma could keep a kid from playing a sport they wanted to play like basketball or soccer or running track?" One child revealed her uncertainly. "No, not a lot, but maybe." When asked "Can you give asthma to other people?" A child answered, "No, I don't think." Lack of knowledge about asthma for some children related to not having anyone to teach them. When asked if anyone had taught them about asthma several children responded flatly, "No."

Two elements related to *not knowing about asthma* were *not knowing how I'll learn about asthma when I'm older* and *wondering what causes asthma*. One child explained her concerns about gaining knowledge in relation to growing older and being responsible for more of her own care. "Not knowing a lot about it is really scary because if I don't know a lot about how will I learn about it when I'm older?" She went on to describe her fear that she would have a bad asthma attack when her family was not around to help her.

*Wondering what causes asthma* was associated with an array of beliefs among the children in this study. The question of what causes asthma was on the minds of several children. One child stated simply, "Don't know." When asked if he wondered why he had

asthma he responded, “Sometimes.” Some child in the study had only very basic concepts about the etiology of asthma. “It’s a disease.” Two children described *believing you are just born with asthma*. One stated, “Some people are born with asthma.” Another said, “I don’t know. It’s a special thing that you are born with.” One child described *believing some medicines cause asthma*.

Another child had a more sophisticated idea about the cause of asthma. She believed *bad coughing from germs and not taking care of yourself* caused her asthma? “I think because of really bad coughing.” When asked what she thought made her cough a lot she responded, “Not washing your hands or something. Not taking care of yourself.” Another child described *believing that running and playing cause asthma*. He had no explanation why running and playing would cause him to have asthma, but might not cause the same effect in another child. One child described *believing that sometimes smoke causes asthma*. Another explained *believing problems with my throat cause asthma*. When asked why he thought having a sore throat caused asthma he explained, “Because it gets sore and I think that’s what makes me cough.” He went on to explain that this was not due to having a cold. “No, just me coughing.” A final child described *believing dogs, and cats, and fur cause asthma*.

#### *Knowing Some People Teach Me About Asthma*

The 8 children described receiving a little informal education about asthma or none at all. When asked how she learned about asthma one child replied, “I really don’t. The nurse tells me a little about it.” Several children responded to the same question saying no one taught them about asthma. However, one child described learning about

asthma in the general curriculum at school. She expressed excitement about being able to share what she knew about asthma with her reading class.

We are learning about, in our reading class, we are learning about in this book where this kid has asthma. And we had to look up the word asthma. And tomorrow I think I told the teacher I would bring in my inhaler, because in the book they said that he had bad asthma. I know how he feels.

Another child elaborated on what he had been told about asthma while at the doctor's office. "They like tell me about it. How it works... If things don't get better... I might outgrow it... and everything." When asked how he learned these things, he responded "They talk to me." When asked how he would like to learn about asthma he answered, "Read books."

#### *Knowing That Others Have Asthma*

All 8 children told about *knowing that others have asthma*. This knowledge was an important source of information about the illness. Children compared their own experience of asthma to the experience of others. Some children reported having family members who had asthma. "And me and my cousin and a few other of my cousins have asthma. So some of my family has asthma and my mom has asthma." However, some children had no friends or family members with asthma. Two children reported only seeing another person with asthma at school. Yet, these two children had never talked to their peer who had asthma. In contrast children with a friend or family member who had asthma described positive aspects of being able to share their experiences.

### *Realizing That Asthma Changes Over Time*

Most children related an awareness that asthma changes over time. This understanding arose from their own experience of having days when they experienced little or no trouble breathing. At other times the children had been troubled by serious breathing problems that brought suffering and restriction to their lives. Whereas, some children described circumstances that would likely cause a return of their asthma symptoms, most children were uncertain about the future. The context of *realizing that asthma changes over time* was especially apparent in the intention *thinking about having asthma the rest of my life*.

#### Phenomenological Analysis of Children's Intentions in Context

Having presented the contextual features, descriptors, and elements, I will now summarize the structure of the experience using a hierarchical framework of phenomena, component phenomena, and intentions according to Porter's (1995) method. Discussion of the structures of experience will be organized around the four major contextual features (a) *discovering that asthma changes what I can do*, (b) *becoming the one who knows my asthma*, (c) *knowing how other people respond to my asthma*, and (d) *coming to know more about asthma*.

#### *A Phenomenon Associated with Discovering that Asthma Changes What I Can Do Making the Best of Things*

Within the context of *discovering that asthma changes what I can do* children in this study were *making the best of things*. The children often described their efforts to carry on normal activities as best they could. "Most of the time we run or play hide and go seek. I'm always the seeker. Or we play jail tag and I'm always the one who has to do

it. So I have to chase everyone and they can get out and come back in. It's really, really hard for me." This phenomenon of the experience was further described by two component phenomena *accepting with my limitations* and *hoping things can be normal for me*.

*Accepting my limitations.* One child found that she could not meet the exertional demands placed on her in team wrestling.

I was in wrestling. He had us run around the thing for a long time and he wouldn't let me stop. Because he said you have to do the whole thing. If you fall, trip, or stop you'll have to do 50 push ups. So that's why I quit.

One child described her acceptance of not being able to sleep due to breathing problems. "It is like I just don't want to get up. I just want to go to sleep and then I'm having a hard time breathing and breathing. So I just get up." Another child described wanting to play soccer, but accepting the fact that his asthma made it impossible. "It's pretty difficult because I can't really go outside when it's really cold or hot. And I wanna play soccer but sometimes I can't breathe and I have to go to the nurse."

*Making life normal for me.* All 8 children described efforts related to *making life normal for me*. This component phenomenon was apparent often as they talked about trying to return to play after resting from a flare-up of asthma, skipping treatments to be able to play with friends, and requesting their peers to modify physically active games so that they would be able to participate. Related intentions were evident in throughout the experience of disabling asthma. These were linked more closely other phenomena and will be described in detail in the following discussion.

Some of the children looked to a distant time in the future when things might be different for them. Children hoped for relief from limitations that asthma imposed on their lives. For example, several children expressed their hopes of being able to have a pet soon. “I really hope someday I can be around cats.” Children also hoped for a time when they would be free from the need to take medications. “Before I knew I had asthma, about two summers ago. I was fine. I didn’t have to do anything before I brushed my teeth, and I didn’t have to take any pills unless I was sick.” These “horizontal” intentions were associated with actions in the present aimed at *making life normal for me*.

#### *Phenomena Associated with Becoming the One Who Knows My Asthma*

##### *Noticing When My Asthma is Getting Worse*

In the context of *becoming the one who knows my asthma* children experience revealed two phenomena *noticing when my asthma is getting worse* and *making my breathing better*. The 8 children in this study were not always aware of their own breathing problems. Several children described episodes when other people noticed first that they were having trouble breathing. These data support the importance of the emergent phenomenon *noticing when my asthma is getting worse*. This phenomenon was a precursor to the child becoming an active force in shaping their experience of asthma. A related component phenomenon was *seeing what makes my asthma worse*.

One child described his dependence on his grandmother for recognizing his breathing problems. “She’s a nurse and she has asthma. She knows when I am getting ready to have an asthma attack.” Another child described her mother as knowing all about her asthma and letting her know when she needed a treatment. These two children

who were very dependent on others to recognize signs of asthma. They described few actions aimed at making their breathing better.

In contrast, other children described in detail their awareness of a wide range of changes in their breathing that told them their asthma was getting worse. These descriptions were often linked directly to children's comments about recognizing what was causing their breathing trouble. After identifying what made their asthma worse, children often described actions that they took to reduce their trouble. One child described the discovery that exposure to carpet made her asthma worse. She recounted the experience of rolling herself up in a carpet remnant and then having trouble with her allergy and asthma. She then described avoiding lying or playing on the carpet so that her asthma would not get worse.

Her intention to stay off the carpet was related to the component phenomenon of *seeing what makes my asthma worse*. It is interesting that she also demonstrated an acute awareness of how asthma affected her breathing. Her description of *noticing when asthma is getting worse* was a strikingly accurate experiential account of air-trapping. Air-trapping is a physiologic change resulting in labored expiration and dyspnea commonly associated with asthma exacerbations. "I can't hardly talk and I can't hardly breathe. I can really breathe out of my nose good, but I can't breathe out of my mouth. It is like [she holds her chest and tries to breathe out]. I can't breathe anything out."

#### *Making My Breathing Better*

*Making my breathing better* was associated with two component phenomena *helping my breathing* and *stopping my breathing trouble*. Children described many things they did to improve their breathing. These activities were related to advice from others,

the children's beliefs, and their past experiences. *Helping my breathing* encompassed such diverse intentions as (a) *eating soup*, (b) *opening the bathroom door*, (c) *getting shots for the cat*, (d) *finding a place to play out of the wind*, (e) *wearing a scarf over my mouth, holding my breath to keep from breathing that air*, (f) *staying indoors when it's too hot or too cold*, (g) *washing my hands so I stay well*, (h) *spending time in places where I breathe better*, and (i) *choosing physical activities that allow time to rest*.

*Stopping my breathing trouble*. Children also described many intentions related to seeking relief from troublesome symptoms. Whereas, *using my medicines* was one important way children sought relief from their asthma symptoms, there were numerous other approaches, too. Related intentions included: (a) *choosing quieter activities*, (b) *drinking or eating*, (c) *forgetting about my asthma*, (d) *getting fresh air*, (e) *seeking comfort*, (f) *waiting for my asthma to go away*, and (g) *wondering why I am having trouble breathing*. Children often described *choosing quieter activities* when they were experiencing trouble breathing. The adjective *quieter* applied to several dimensions. Children described (a) *avoiding noise and people who bother me*, (b) *lying down or taking a nap*, and (c) *slowing down the pace of physical activity*.

*Drinking or eating* was also common activity reported by children. Some children reported being instructed by an adult to get a drink when they were experiencing trouble breathing. Other children described drinking or eating as a means they had discovered to bring some relief. Children's descriptions of *drinking or eating* were sometimes strongly suggestive of concomitant gastroesophageal reflux. In her imaginative description of an ideal world for asthma by one child captured the perceived benefit of ingesting food or drink.

Have a soda fountain in every single room and get up whenever we wanted and a buffet whenever we wanted to eat and drink. And that would help me because my throat wouldn't hurt. And I would stop coughing sometimes.

Several children described the intention of waiting to see if their asthma would get better. *Waiting for asthma to go away* was described in association with watching the progression of symptoms after taking quick reliever medications and when no medicine was taken. A high degree of uncertainty about the imminent course of asthma was apparent in their descriptions. A related intention was *wondering why I am having trouble breathing*. Child described their reflections about the trouble they were having as they waited to find out what course their asthma symptoms would take.

The intention *using my medications* was complex and deeply nested in children's experience. Subsidiary intentions included (a) *deciding to take a treatment*, (b) *getting to my medicines*, (c) *choosing between a nebulizer and an inhaler*, and (d) *deciding if the treatment is helping*. More deeply nested contingent intentions for *using my medications* included (a) *going back for another treatment*, (b) *calling for help when the medicines do not work* and (c) *dealing with problems after taking my albuterol*.

#### *Phenomena Associated with Knowing How Other People Respond to My Asthma Getting Someone to Help Me*

Within the context of *knowing how other people respond to my asthma* children in this study described (a) *getting someone to help me*, (b) *showing other people my asthma*, and (c) *wanting to be treated like a normal person*. The phenomenon *getting someone to help me* was associated with three component phenomena (a) *getting my family to help me*, (b) *telling my teacher or coach*, and (c) *going to the school nurse*. Intentions

associated with *getting my family to help* included (a) *waking up my parents*, (b) *sending them to get my quick reliever medicine*, (c) *counting on them to get me to the doctor*, and (d) *telling them when I need help*.

#### *Showing Other People My Asthma*

*Answering their questions.* The phenomenon *showing other people my asthma* was associated with three component phenomena (a) *answering their questions*, (b) *helping them see my breathing trouble*, and (c) *deciding not to tell them*. Intentions associated with *answering their questions* included *thinking about what they are going to ask* and *remembering how it was*. Two children described anticipating and worrying about the questions they would be asked in the hospital. One child who had several hospital visits for asthma distinguished between hard and easy questions. He described his frustration with difficult questions posed to him when someone was obtaining a clinical history.

Several children demonstrated or described their efforts at trying to remember details about their asthma. Remembering certain details was difficult for most children, especially when the time frame was more than a few days. However, the children demonstrated vivid recall other aspects of their asthma experience. The intention *remembering how it was* encompassed both the successful recall of illustrative data pertaining to children's experience of asthma, as well as other data types that children had difficulty remembering. Questions related to when things had happened were particularly challenging for the children.

*Helping them see my breathing trouble.* The component phenomenon *helping them see my breathing trouble* encompassed several unique intentions, including (a) *making*

*my breathing even harder, (b) using a smiley face scale to rate my trouble breathing, (c), bringing a note from home about my asthma, and (d) moving to the couch at night so they can hear me better.* One child described exaggerating her wheezing to convince an unbelieving coach that she needed her albuterol. Another child described in detail how he was able to rate his breathing difficulty before and after a breathing treatment at a clinic by using a smiley face scale provided to him by a nurse.

Children also explained the benefits of having a note from home when trying to convince a teacher or coach that their asthma was flared up and that physical activity might need to be limited. The note provided evidence that the child was not just claiming to be having difficulty breathing. Another child described the night-time routine of moving from her bedroom in the back of the house to the couch in the living room to be closer to her parents. She explained that the move to the couch made it easier for her parents to wake up and help her when she was troubled by worsening asthma symptoms.

*Deciding Not to Tell Them.* The component phenomenon *deciding not to tell them* encompassed several problematic intentions for one child. With the start of a new school year she decided to keep her asthma a secret. She described hiding the fact that she had asthma from her friends, her teacher, and the school nurse. She stated that she did not want to miss recess, so she chose not to tell her teacher when she had troubled breathing on the playground. She also described knowing that her friends should know about her asthma in case they needed to help her. However, she remained silent and hoped that she would breathe well.

### *Asking To Be Treated Like a Normal Person*

The phenomenon *asking to be treated like a normal person* was described by two children in the context of unkind teasing by peers. These children described wanting to be seen as a normal child with an illness, rather than as a diseased person or a “freak”. One child drew a parallel between wearing glasses and having asthma, urging for kind treatment for persons with health conditions. She explained being normal as the experience of being accepted for one’s individual differences. Other children did not feel that they were treated differently because of having asthma.

### *Phenomena Associated with Coming to Know More About Asthma*

In the context of *coming to know more about asthma* the children described ways they had learned about asthma, as well as ways they wished to learn about asthma. An important, indirect source of knowledge about asthma was other people around the children who had asthma. The children also thought about having asthma in the future and they described ways they would make it better for other kids with asthma. Some children considered living with asthma the rest of their lives. Phenomena included (a) *learning about asthma*, (b) *making it better for kids who have asthma*, and (c) *thinking about having asthma the rest of my life*.

### *Learning About Asthma*

The phenomenon *learning about asthma* was further described by 2 component phenomena *asking for help to learn more about asthma* and *seeing that others have asthma*. *Asking for help to learn more about asthma* was described by *discovering what I need to know about asthma* and *thinking about how I want to learn*. Children appraised their own lack of knowledge about asthma and imagined ways they could fill this gap.

Several children stated that no one taught them about asthma. Some children lacked a correct anatomical view of their breathing and asthma. Children expressed intentions related to what, why, how, and where they wanted to learn about asthma. When asked what he was thinking about doing that might change his asthma, one child responded, “Learning more about it.” Several children described books as an important and preferred way to learn about asthma. One child asked for a specific asthma book during this study.

The component phenomenon *seeing that others have asthma* was described by several intentions, including (a) *seeing other people having trouble breathing*, (b) *grading their asthma*, (c) *watching them use asthma medicines*, and (d) *having asthma together*. Three children described *seeing other people having trouble breathing*. One child described a peer’s trouble breathing. “She can’t breathe too hot air, too cold air, she can’t do all that stuff.” Another child retold his observation of a peer who was wheezing. “Coming from art, this one guy had asthma and he ran up the ramp and a minute later he was like [he makes the sound of labored breathing and wheezing]. He couldn’t breathe.”

One child judged the severity of asthma among his peers by *grading their asthma*. He first described someone with mild asthma. “Got’s a little bit of asthma, but not a whole bunch.” Later, he also described more serious asthma in a peer and related that degree of asthma to himself. “He was going on the way there but he took one step and said ‘Oh, I can’t breathe.’ And he has major asthma too.”

Children also described *watching them use asthma medicines*. One child described observing her karate coach stopping to take albuterol too often. Another child related a subsidiary intention of *seeing them hide their asthma medicine*. He reflected on why his friend tried to conceal use of albuterol when he was having trouble breathing.

Sometimes when we're running, he like... I can hear him wheezing a little bit. Then he goes over to his mom. He likes to lie to us. He says "Oh guys I'm just going to go to the restroom." When he went to the bathroom, I used to look at him. And he was in there taking his inhaler. I think he is real nervous, 'cause if everyone knows they might laugh at him. But everybody knows in my class that I got asthma.

Several children stated that they had no friends who had asthma. However, the benefits of having a friend who has asthma were apparent in the remarks of two children. One child identified with a peer who had trouble breathing. "We are kinda the same just she doesn't have to take all these medicines. She even has an emergency inhaler. She has it in her coat pocket, but she is not allowed to take it at school." Another child provided a poignant description of her experience of *having asthma together* with a friend.

I have a friend that walks slow because she has asthma. And she knows about it. And me and her talk about it because me and her go play on the playground together since we have asthma. And me and her are the only ones who have asthma in this grade. And she told me. We spend a lot of time together because we have asthma together.

Children in the study had creative and sensible ideas about *making it better for kids who have asthma*. One child imagined how those with asthma could take part fully in physical education class without getting into trouble due to too much running.

We could change it so if people got asthma the first half they would run, then the second half they could do fun things, too. When you can't run you can like play

freeze tag. The people who don't have asthma could stay on the other side and play all the games they want.

He continued to describe what "asthma games" would entail, offering two strategies for breaking up the running. "First we run, then we might have to walk backwards or something." His second strategy involved a game that incorporated learning and some intermittent running. "Yeah and you actually learn stuff in the game."

When it lands on a certain number our teacher starts giving us these certain parts that we have in our body. When it lands on that number we have to start guessing. Boys would be on one side and girls on the other. If the girls get it right they have to chase us. If the boys get it right we have to chase them.

Children in the study proposed several other ways for *making it better for kids with asthma*. One child suggested reading books about asthma to children while they take their nebulizer treatments. Another child thought an asthma club would help kids learn about asthma and have a good time too. A final child advocated making good-tasting asthma medicines in the shape of kitties.

Some children hoped their asthma would get better, however other children were *thinking about having asthma the rest of my life*. "If you don't outgrow it, it'll be there for the rest of your life. I feel really worried. If I'm going to have it the rest of my life or not." When asked what she worried about, she replied "It would keep getting worse for me, harder." Other children expressed uncertainty about what having asthma would be like for them in the future.

## Summary: The Children's Experience and the Context

I have described the children's life-world and the structures of their experience using Porter's (1998) method of descriptive phenomenology. Four features of the experience emerged as descriptive of the life-world. Children's intentions were organized around these features and the related descriptors and elements that described what it was like to be a rural child with disabling asthma (a) *discovering that asthma changes what I can do*, (b) *becoming the one who knows my asthma*, (c) *knowing how other people respond to my asthma*, and (d) *coming to know more about asthma*.

First, in the context of *discovering that asthma changes what I can do* the children's experience revealed the phenomenon *making the best of things*. The children's experience was characterized by two component phenomena *accepting my limitations* and *making life normal for me*. Some children described *giving up on active sports*, *making up missed school work*, and various ways of dealing with disturbed sleep. The children recognized and described many ways in which asthma limited their lives.

Next, in the context of *becoming the one who knows my asthma* the children's experience revealed two phenomena *noticing when my asthma is getting worse* and *making my breathing better*. Two opposing component phenomena were associated with *noticing when my asthma is getting worse*, including *seeing what makes my asthma worse* and *ignoring my asthma*. The phenomenon *making my breathing better* was associated with two important component phenomena, *helping my breathing* and *stopping my breathing trouble*. Children described many things that they were doing to try to help them breathe better or to stop their asthma symptoms.

In the context of *knowing how other people respond to my asthma* I identified three phenomena including *getting someone to help me, showing others my asthma, and asking to be treated like a normal person*. Component phenomena associated with *getting someone to help me* included *deciding to go to the school nurse, telling my teacher or coach, and getting my family to help me*. Component phenomena associated with *showing others my asthma* included *answering their questions, helping them see my breathing trouble, and deciding not to tell them*. A component phenomenon associated with *asking to be treated like a normal person* included *asking them why they call me names*.

## CHAPTER FIVE

### CONTRIBUTION, SIGNIFICANCE, AND LIMITATIONS

I have described the framework of the study, relevant scientific literature, the research method, and findings of this descriptive, phenomenological study of the experience of disabling asthma among eight rural school-age children. In this chapter I will first present a synopsis of findings to answer the first two research questions. Next, I will reintroduce the bracketed literature to describe how the findings from this study contribute to current knowledge. Next, I will summarize the significance of these findings, considering implications for public health, clinical practice, nursing science, and future research. Finally, I will present the limitations of this study.

#### Understanding 8 Rural Children's Experience of Disabling Asthma

This section has two parts. The first section will consist of a synopsis of the findings that address the first research aim - to describe children's intentions related to asthma. The second section will address the second aim of the study - to examine the varied contexts of their experiences at home, at school, in their community, and in the places where they receive health care services.

#### *Children's Intentions Related to the Experience of Disabling Asthma*

The structures of experience were described in detail in Chapter 4, first in context and then in hierarchical order, using Porter's (1998) method of descriptive phenomenology. Four features of the experience emerged as descriptive of the life-world. Eight phenomena were discerned and are illustrated in Figure 9. Children's intentions were recognized as relevant to specific features, descriptors, and elements that described

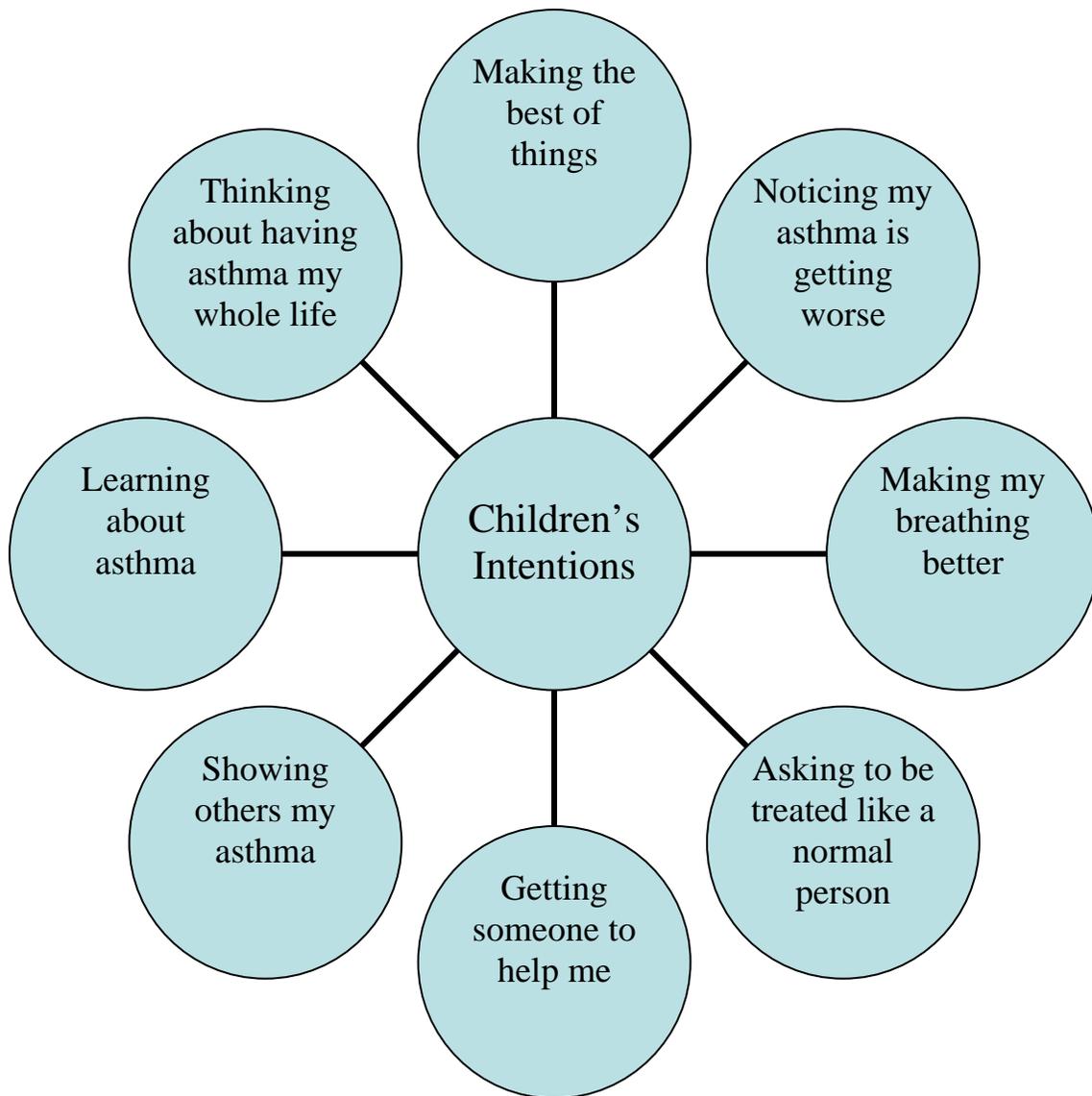


Figure 9. Phenomena of the Experience of Disabling Asthma

what it was like to be a child with disabling asthma. The features included (a) *discovering that asthma changes what I can do*, (b) *becoming the one who knows my asthma*, (c) *knowing how other people respond to my asthma*, and (d) *coming to know more about asthma*.

First, in the context of *discovering that asthma changes what I can do* the children's experience revealed the phenomenon *making the best of things*. The children's experience was characterized by two component phenomena *accepting my limitations* and *making life normal for me*. Some children described *giving up on active sports*, *making up missed school work*, and various ways of dealing with disturbed sleep. The children recognized and described many ways in which asthma limited their lives.

Next, in the context of *becoming the one who knows my asthma* the children's experience revealed two phenomena *noticing when my asthma is getting worse* and *making my breathing better*. Two opposing component phenomena were associated with *noticing when my asthma is getting worse*, including *seeing what makes my asthma worse* and *ignoring my asthma*. The phenomenon *making my breathing better* was associated with two important component phenomena, *helping my breathing* and *stopping my breathing trouble*. Children described many things that they were doing to try to help them breathe better or stop their asthma symptoms.

In the context of *knowing how other people respond to my asthma* I identified three phenomena including *getting someone to help me*, *showing others my asthma*, and *asking to be treated like a normal person*. Component phenomena associated with *getting someone to help me* included *deciding to go to the school nurse*, *telling my teacher or coach*, and *getting my family to help me*. Component phenomena associated with *showing others my asthma* included *answering their questions*, *helping them see my breathing trouble*, and *deciding not to tell them*. A component phenomenon associated with *asking to be treated like a normal person* included *asking them why they call me names*.

In the context of *coming to know more about asthma* I identified two phenomena including *learning about asthma* and *thinking about having asthma my whole life*.

Component phenomena associated with *learning about asthma* included *asking for help to learn more about asthma* and *learning what it is like for others who have asthma*.

Component phenomena associated with *thinking about having asthma my whole life* included *thinking my asthma might get worse* and *thinking my asthma will go away*.

### *The Contextual Features*

A detailed description of the life-world of the 8 children was presented in Chapter 4. This section will briefly summarize the findings to address the second aim of the study - to examine the varied contexts of their experiences at home, at school, in their community, and in the places where they receive health care services. Features, descriptors, and elements close to the experience of disabling asthma among these rural children will be briefly summarized. This discussion will be organized around the four major features of the children's life-world (a) *discovering that asthma changes what I can do*, (b) *becoming the one who knows my asthma*, (c) *knowing how other people respond to my asthma*, and (d) *coming to know more about asthma*.

#### *Discovering That Asthma Changes What I Can Do*

The first feature of the children's life-world was *discovering that asthma changes what I can do*. Children described in detail the limitations on their activities that were imposed by their asthma-related breathing problems. These descriptions do not mirror clinical concepts about childhood asthma. Key descriptors included: (a) *being unable to run and play like other kids*, (b) *being unable to go outdoors at certain times*, (c) *being unable to enjoy pets and animals*, (d) *missing school*, (e) *getting sicker and staying ill*

longer than others, (f) finding it hard to sleep, (g) missing out on playtime with friends, and (h) spending time taking all my medicines. The children's descriptions suggest that the current asthma literature has not adequately represented the experience of disability.

#### *Becoming the One Who Knows My Asthma*

The second feature of the children's life-world was *becoming the one who knows my asthma*. The feature revealed the children's awareness of what was not right with their breathing and their recognition that specific circumstances or conditions were related to their breathing problems. Children described their desire to be normal and their awareness that asthma was not as much of a problem at times. Children remembered some past events and forgot others related to having asthma. Memories shaped their experience. Key descriptors included: (a) *seeing the trouble asthma causes me*, (b) *knowing what makes my asthma worse*, (c) *wanting asthma to go away*, (d) *knowing some things make my asthma better*, and (f) *remembering things about my asthma*. The children's descriptions provided rich data for evaluating the validity of existing conceptualizations about how children who have asthma care for themselves.

#### *Knowing How Other People Respond to My Asthma*

A third feature of the children's life-world was *knowing how other people respond to my asthma*. Children described other people around them who impacted their experience of asthma. They distinguished between those who were knowledgeable and those who did not understand asthma. Children appraised the likelihood that people around them would be helpful. Children experienced gratitude, frustration, anger, and fear related to how their peers and influential adults responded to their asthma. Descriptors included: (a) *my asthma causes worry and concern*, (b) *sometimes I get*

*special treatment, (c) knowing some people don't treat me like a normal person, and (d) knowing others help me with asthma.* Children valued the professional care they received, however their descriptions point to serious deficiencies. These compelling data should influence efforts to improve social support and health care approaches.

#### *Coming to Know More About Asthma*

A fourth feature of the children's life-world was *coming to know more about asthma*. The eight children revealed their lack of knowledge about asthma. They described thoughtful consideration of aspects of asthma that they did not understand. Some children described thoughts about the future and conceptualizations related to the possible course of their illness. Key descriptors included (a) *realizing I don't know a lot about asthma*, (b) *knowing some people teach me about asthma*, (c) *knowing that others have asthma*, and (d) *realizing that asthma changes over time*. Implicit in their descriptions was a glaring lack of educational exposure and opportunities.

#### Relationship of the Findings to Bracketed Literature

The third aim of this study was to compare and contrast the phenomena of children's experience of disabling asthma with pertinent findings, concepts, constructs, and theoretical frameworks found in scientific literature and in expert clinical practice guidelines. This discussion will include (a) conclusions based on a comparison of the findings to related qualitative studies, (b) detailed comparison of selected contextual and intentional findings with the remaining literature, (c) conclusions pertaining to the construct of asthma self-management, and (d) reintroduction of my personal bracket.

#### Conclusions Based on an Overview of the Findings and Relevant Literature

Significant prior qualitative work pertaining to children's experience of disabling asthma will be reintroduced in this section. Global aspects of prior qualitative inquiry, including methodological concerns and specific findings, will be considered as in relation to children and asthma. The contribution of findings from my study will be discussed in light of prior work.

#### *Ability of Young Children to Describe Their Asthma-Related Experience*

An important general question related to designing and conducting qualitative research with young children is the age at which children are capable of describing their experience. Yoos and McMullen (1996) reported that school-aged children had clear ideas about their experience of asthma and were able to convey these to adults in a manner readily understandable by multiple observers. Other qualitative researchers reported meaningful findings obtained through semi-structured interviews with children ages 6 to 18 (Ireland, 1997; Pradel, Hartzema, and Bush, 2001; and Rydstrom, Englund, and Sandman, 1999).

The findings from my study also illustrate the ability of young children ages 7 to 10 to provide very detailed and insightful explanations of their asthma-related experiences. Pradel et al. (2001) found that 7 year-old children sometimes provided short answers to questions and did not describe certain aspects of asthma that were readily described by 12 year-old children. Two 7 year-old children in this study seemed to initially have difficulty participating in the interview. However, over the course of three interviews, both children provided rich, relevant data. This finding suggests that a series of interviews with the same interviewer might be required to obtain detailed data from young school-aged children.

### *Perceptions and Intentions of Young School-aged Children*

Pradel et al. (2001) interviewed 32 children, including a group of younger children age 7 and a group of older children age 12. Pradel et al. reported specific differences between younger and older children. Comparing younger to older children, the researchers characterized younger children as not providing a comprehensive list of environmental causes for their attacks. They also found that 7 year-old children often responded to breathing difficulty by telling their mothers, by resting, and by just not knowing what to do. In contrast older children reported various environmental factors causing their asthma attacks and they used relaxation and breathing techniques and taking medications to manage their attacks (Pradel et al.).

The mean age of children in my study was 7.5 years. Figure 10 illustrates the 8 children's descriptions related to *knowing what makes my asthma worse*. These findings challenge the premise that young children are not aware of various environmental factors related to their worsening pattern of asthma. Figure 11 illustrates the children's descriptions of *making my breathing better*. The various perceptions and intentions represented in this figure also challenge the claim that young children enact a limited range of responses to their breathing problems Pradel et al. (2001). Pradel et al. found that younger and older children shared some things in common. They reported that physical exertion was reported most often as the cause of an asthma attack. I found that the 8 children made 3 times more references to physical exertion as a cause of asthma symptoms than to any other factor. These data agree with the findings of Pradel et al. They found the most common symptom mentioned with an asthma attack

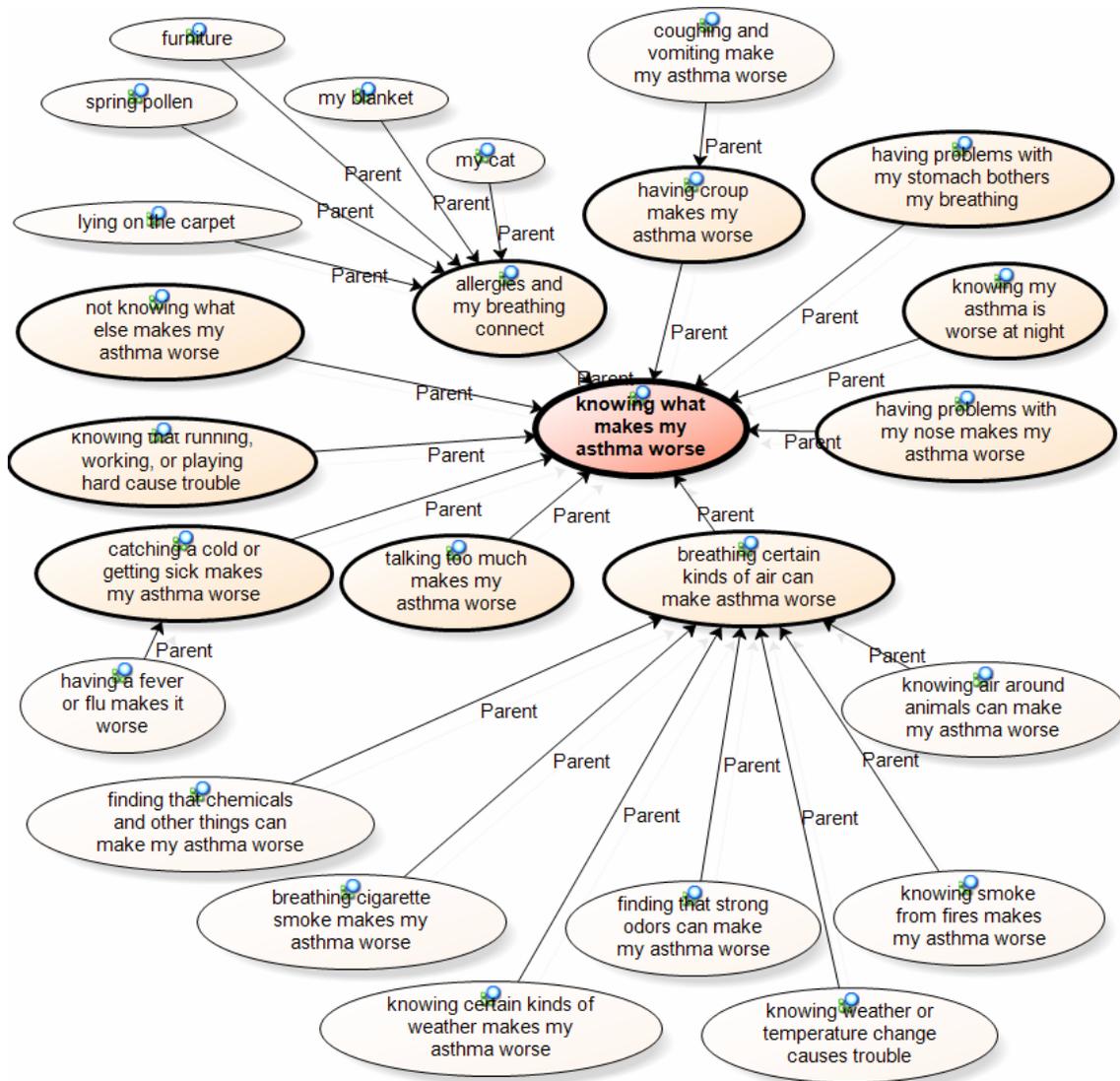


Figure 10. Knowing What Makes My Asthma Worse

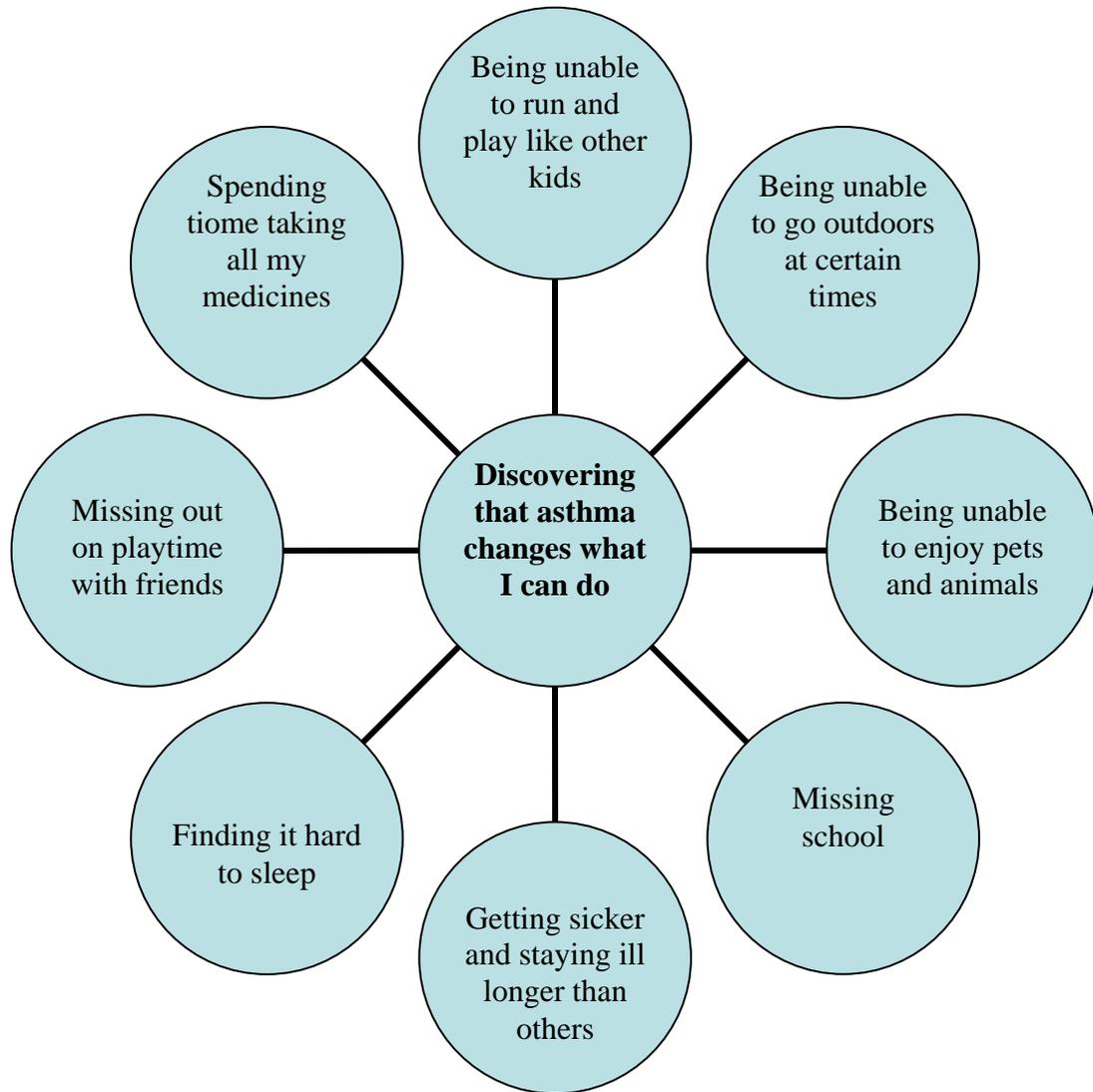
was difficulty breathing, rather than coughing, wheezing, or shortness of breath. However, coughing and hard breathing were described with similar frequency by the 8 children in this study. Wheezing was much less frequently reported.

*Comparison of the Findings with Prior Descriptive Studies*

*Semi-Structured Interviews with Urban Children*

In a descriptive study of asthma among 28 urban children ages 6 to 18 years, Yoos and McMullen (1996) used open-ended, semi-structured interviews to identify five dominant themes in children's narratives (a) "I can't", (b) restrictions, (c) symptoms and treatments, (d) death and (e) adaptation. Whereas there are similarities between my findings and the findings of Yoos and McMullen, their thematic summary does not display the variety and richness of experience that is evident in the descriptions of the 8 rural children. Thematic profiling of children's experience fell short of the researcher's goal to describe children's experience of asthma. This conclusion was supported by the comments of Yoos and McMullen, when they identified the need modify future studies to give children a chance to "clarify, critique, and challenge" (p. 290) investigators' interpretations of their illness narratives. The taxonomy of findings from this study suggests that much greater complexity and detail are required to adequately describe children's experience of asthma.

Yoos and McMullen (1996) found that children's experience of asthma did not reflect the optimistic expectation of disease control advocated by national guidelines and health care professionals. Instead, they found that a larger than expected burden of disease was apparent both in the illness themes and by use of an analog scale that rated children's worry and the perceived impact of asthma on their lives. Yoos and McMullen's findings were supported by the descriptions of the 8 children. Figure 11 represents the children's descriptions of the life-world feature *discovering asthma*



*Figure 11. Discovering that Asthma Changes What I Can Do*

*changes what I can do.* Data suggest that the 8 rural children’s experience of disabling asthma involved many limitations in their day-to-day lives.

*A Study Employing Grounded Theory Methodology*

To explore beliefs, attitudes, and perceptions, Ireland (1997) interviewed 10 school-aged children ages 9 to 12 in a qualitative study. Using grounded theory

methodology, Ireland noted at the outset that the intent was to produce a model or theory about the experience (children's perception of asthma). However, in her conclusions, Ireland suggested that a descriptive, qualitative method would be more appropriate at this stage of research into children's experience of asthma. "It is hoped that the key themes will assist in understanding children's experience of having asthma. This research provides a description of the children's reality, rather than an integrated theory" (Ireland, p. 1064). A number of findings from Ireland's study are relevant to this study.

According to Ireland (1997), analysis utilizing the constant comparative technique revealed the core variable to be "normal for me" (p. 1062). The author suggested that the desire to establish normality sometimes led to compromise and sub-optimal control of asthma. These findings are related to the phenomenon *making the best of things* that described children's intentions *accepting my limitations* and *making life normal for me*. Ireland's "core variable" is also related to *ignoring my asthma, deciding not to take a treatment*, and *deciding not to tell them*. Whereas "normal for me" is related to these intentions, its designation as a core variable is not consistent with data obtained from the 8 children. Instead, the children were usually responding in adaptive ways to avoid breathing problems and so that they could enjoy all that their peers enjoyed. The term "normal" was rarely used by the 8 children; therefore "normality" might be a researcher-derived abstraction, rather than a core variable related to children's experience.

Ireland (1997) identified three other important categories that described children's perceptions of asthma: (a) "discontinuity," (b) "paying attention," and (c) "leaving asthma behind" (p. 1062). Discontinuity was the experience of recognizing something is wrong as asthma disrupts daily activities. Paying attention had to do with self-monitoring

changes in breathing in response to treatments. Leaving asthma behind was described as choosing to go on with one's life knowing that one cannot be normal while you're stopping to deal with asthma. These findings bear similarities to aspects of the structures of experience described by the 8 children. However the three concepts as presented by Ireland are isolated and asymmetrical as presented.

Discontinuity (Ireland, 1997) resembles the feature of experience *discovering that asthma changes what I can do*. However, the 8 children also described *becoming the one who knows my asthma, knowing how other people respond to my asthma, and coming to know more about asthma*. Again “discontinuity” is a complex, abstract label rather than a descriptor of the essence of the experiences. “Paying attention” is a descriptive phrase that is similar to *noticing when my asthma is getting worse*. However, the phrase lacks the context and specificity of the phenomenological descriptor discerned in this study.

The component phenomena *seeing what makes my asthma worse* and *ignoring my asthma* describe what the children were doing, both when they attended to their asthma and when they ignored it. Ireland's (1997) category “leaving asthma behind” relates to *ignoring my asthma*. However, this is only one of two possible responses within a larger intentional class that Ireland did not identify. In this study I identified the component phenomenon *seeing what makes my asthma worse* resulting in a more balanced description of children's experience of asthma.

Ireland (1997) believed that tension between deciding to pay attention to asthma and choosing to leave asthma behind had to do with empowerment issues. Ireland held that children who were permitted to exercise responsibility over their asthma were more inclined to pay attention and take appropriate action. These concepts are related to

*becoming the one who knows my asthma.* However, the data from this study are not adequate to support or to refute Ireland's suggestion that empowerment is a relevant construct. Ireland hypothesized that children who had few opportunities to change their disease experience, as in the case of those attending schools with restrictive policies hampering access to asthma medications, were more likely to choose to leave the asthma behind, ignoring warning signs and failing to take action. The phenomenon *showing other people my asthma* provides evidence that children were trying to make others aware of the problems asthma caused them. The component phenomena *answering their questions* and *helping them see my breathing trouble* point to the children's efforts to get the help they needed.

#### *A Study Employing a Phenomenologic-Hermeneutic Method*

Rydstrom, Englund, and Sandman (1999) used a phenomenologic-hermeneutic method to describe what it is like being a child with asthma. "The aim of this method is to uncover the meaning of lived experiences through interpretation" (Rydstrom et al., p. 590). Fourteen children between the ages of 6 and 16 years of age with moderate or severe asthma and normal cognitive development were interviewed. However, the authors elected to use the children's own words to report "meaning units" (p. 594). They found that hermeneutic interpretation was not necessary or appropriate. Their findings suggested that a descriptive approach was more appropriate for investigating what it is like for children to have asthma. The detailed taxonomy of findings (page 348) from interviews with these 8 rural children supports the appropriateness of a descriptive (rather than interpretive) approach for exploring children's experience of asthma.

Rydstrom et al. (1999) concluded that the experience of asthma was largely described by children's efforts to live normal lives. I found that the 8 children were *making the best of things by making life normal for me*. However, this aspect of the experience represents only one phenomenon among many. Therefore, the experience can not be adequately characterized by the concept “wanting to live normal lives.” The researchers identified two sub-themes that they believed to exist in opposition to one another: “feeling that they participate in everyday life” and “feeling like outsiders in everyday life.” Data from this study did not support these themes as central to the experience of the 8 children.

Conflicting emotions about having asthma were identified by Rystrom et al (1999). The researchers identified “feeling confident in other people’s wish to help” and “feeling guilty” as descriptive of how children felt about their asthma (p. 594). I found that a related contextual feature of the children’s experience *knowing how other people respond to my asthma* was complex. Whereas, the associated descriptors *knowing others help me with asthma* and *knowing my asthma causes worry and concern* were related to the findings of Rydstrom et al., a phenomenological analysis revealed a nexus of related contextual and intentional factors. More complete descriptions than those offered by Rystrom et al. are required to adequately represent this aspect of children’s experiences.

#### *Conclusions Related to the Utility of Porter’s Method*

In summary, comparison to findings from prior qualitative studies of children’s asthma, suggests that Porter’s descriptive phenomenological method (1994, 1998a) is a more productive and appropriate approach. This conclusion is based on richer, more complete data sets that were yielded by Porter’s (1998a) method, compared to three other

qualitative approaches that have been reviewed in this section. Data from the study of 8 rural children have confirmed some prior findings obtained by researchers who used other qualitative methods. Other findings reported in prior work have not been supported by this study. The taxonomy and graphic representations of the 8 children's experiences are important products of this study, and are useful tools for comparing and critiquing results from other studies.

#### Comparison of the Literature and Selected Contextual and Intentional Findings

In this section I will discuss selected aspects of the taxonomy (page 348) to reintroduce selected concepts from the literature that are relevant to the findings. Section headings will mirror the taxonomy of the experience.

##### *Discovering That Asthma Changes What I Can Do*

##### *Being Unable to Run and Play Like Other Kids*

Kieckhefer (1988) found physical activity to be the most important criterion of good health among 71 children, ages 9 to 11, with chronic asthma. All 8 children described ways in which asthma limited their ability to run and play. This finding supports contention of Kieckhefer that absence of asthma symptoms might not be the best criterion of good health for children who have asthma. These data suggest that health professionals and parents should focus more on children's perceptions of being unable keep up a level of physical activity comparable to their peers. Recall of these experiences might be facilitated by non-traditional clinical interviews and novel approaches to help children record and articulate their thoughts (Rich, Lamola, Gordon, & Chalfen, 2000).

### *Finding it Hard to Sleep*

Sleep disturbance was associated with missing school in the children's descriptions. This finding correlates with published reports that nocturnal awakening was related to school absence and parental work days missed, independent of other disease severity measures (Diette et al., 2000). A key descriptor was *knowing when I can't sleep I don't go to school*. This finding suggests that efforts to eliminate sleep disturbance are critical to reducing absenteeism and related asthma disability. School-age children with asthma were found to be 7.8 times as likely to experience sleep disturbance (Yeatts & Shy, 2001). The scope of this problem is likely greater than previously understood based on the finding that up to one-third of children with mild to moderate asthma experienced sleep disruption during periods of relative stability (Strunk, Sternberg, Bacharier, & Szeffler, 2002).

Data suggest that the effect of disturbed sleep and school absenteeism might amplify disability among children with relatively mild disease when medication is the cause of sleeplessness. An important finding in my study that related to this problem was the intention *getting up and giving up on sleep*. This intention was related to two divergent elements *being unable to breathe well enough to sleep* and *being unable to fall asleep again after a breathing treatment when my breathing is okay*. The second contextual element relates to a medication side effect that leads to sleep loss and missed school. This finding suggests a different strategy for reducing sleep loss, missed days of school, and disability. Elimination of medications that interfere with sleep could reduce school absenteeism and related academic and social difficulties.

### *Spending Time Taking All My Medications*

Children in the study described their dissatisfaction with the time and effort required to take medications. Some children reported skipping or stopping medications that took too long to take, especially those delivered by nebulizers. Buston and Wood (2000) described children's self-reported reasons for not taking asthma medication. Reasons included forgetfulness, embarrassment, believing medications to be ineffective, difficulty using inhalers, inconvenience, fear of side effects, laziness, and denial. The children's experience revealed that the time required to take medications sometimes constituted an dreaded interruption of daily life routines. The contextual element *finding taking medicines ruins half my life* illustrates the strong feeling some children had about their medicine routines. This finding supports Ireland's (1997) conclusion that recommended self-care actions impose demands on children and can interfere with day-to-day life.

#### *Making the Best of Things*

Analysis of cross-sectional data from the 1988 National Health Interview on Child Health revealed that children 5 to 17 with severe asthma were three times as likely as normal children to have severe behavior problems (Bussing, Halfon, Benjamin, & Wells, 1995). The phenomenon *making the best of things* characterized the 8 children's experience and challenges long-standing images of children with severe or disabling asthma as likely to exhibit behavioral problems. Rather, their intentions demonstrated highly adaptive responses to chronic, troublesome breathing problems. The component phenomena *accepting my limitations* and *making life normal for me* underscore this finding and urge continued efforts to support and assist children who have asthma.

### *Becoming the One Who Knows My Asthma*

The various contextual and intentional components associated with this feature of the children's life-world add to a growing body of evidence that argues for adults to listen to children. The data urge parents, clinicians, and other adults who are responsible for school-age children to acknowledge children's capacity for being the critical voice in discussions of their asthma. Guyatt et al. (1997) concluded that by age 11 the clinical history could be derived from the child's report alone. He held that prior to age 11, parental report is likely to add to the clinician's assessment of disease in the child (Guyatt et al.). The taxonomy and findings of my study illustrate clearly that children at a much younger age (the mean age of these 8 children was 7.5 years) have already developed ability to observe, describe, and respond to many of the things that are relevant to their asthma. The level of detail in the children's descriptions is a sobering indictment against failing to ask them questions, refusing to believe their reports, and deferring to parents' or caregivers' reports. Unfortunately, children explicitly described each of these circumstances occurring in their day-to-day lives.

### *Knowing the Trouble Asthma Causes Me*

The children's descriptions of symptoms associated with their breathing trouble were strongly suggestive of asthma, as well as common comorbid conditions linked with asthma. Various diseases have been reported to co-exist with and contribute to childhood asthma, include allergy (Sicherer, Noone, & Munoz-Furlong, 2001), gastroesophageal reflux disease (Gilger, 2003), and sinusitis (Dykewicz & Fineman, 1998). The children's descriptions of *knowing the trouble asthma causes me* were particularly suggestive of gastroesophageal reflux as a comorbid with asthma. Contextual elements associated with

this finding included (a) *having trouble talking*, (b) *finding my voice hurts*, (c) *having a sore throat*, (d) *feeling my chest hurts*, (e) *having problems with my stomach bothers my breathing*, and (e) *feeling stuff going down there*.

#### *Seeing What Makes My Asthma Worse*

Children described specific environmental exposures that they believed worsened their asthma and allergy symptoms. Awareness of a link between being exposed to something in the environment and having asthma or allergy symptoms was sometimes associated with specific intentions to avoid the triggering event. Tobacco smoke exposure at home was apparent for one child during the study. Exposure was reported to occur on occasion by a second child, when a relative who smoked visited his home. Evidence of outdoor smoking was apparent at a third home, without signs of indoor smoking.

The quality of housing has closely been linked to childhood asthma morbidity (Saegert et al., 2003). The homes of the seven children who participated in this study had no apparent environmental risk factors. One child's home presented multiple exposures likely to worsening asthma, including cats, carpet, mold, and cigarette smoke. He was the same child who reported skipping his inhaled steroid for days at a time, and who required air transport to an intensive care unit in the weeks following participation in the study. The occurrence of ambulance rides to the emergency room for severe asthma had not resulted in remediation of household asthma triggers. This finding is consistent with a report of adverse factors in home environments of children with asthma being unabated after routine clinical care and counseling (Finkelstein et al., 2002).

Mold exposure at school was found to be associated with increased risk of viral respiratory infections and asthma exacerbations (Taskinen et al., 1999). Rhinovirus was

found to be the most common of several respiratory viruses that were found to be associated with 80-85% of asthma exacerbations in school children ages 9 to 11 years (Johnston et al., 1995). Exposure to peers who owned pets was also shown to correlate with a much higher rate of asthma exacerbations among sensitized children (Almqvist et al., 2001). The 8 children did not describe indoor exposures at school that they believed affected their asthma. However, there were outdoor exposures that the children identified as troublesome, including chemicals used around the school for care of the property and weather-related factors.

### *Knowing Some Things Make My Asthma Better*

Coping behaviors identified among 39 school-age children with asthma who were experiencing dyspnea included: taking medications, changing positions, drinking fluids, relaxation, distraction, and seeking support from others (Carrieri, Kieckhefer, Janson-Bjerklie, & Souza, 1991). My findings suggest that children exhibit many other intentions aimed at both preventing breathing problems and reducing the difficulty they experienced during times when asthma symptoms were increased. The phenomenon *making my breathing better* and two component phenomena described these intentions *helping my breathing* (Figure 12) and *stopping my breathing trouble* (Figure 13). The structures of experience demonstrate a wide range of responses. Use of the term “coping” to describe all of these intentions would be inadequate. Children enacted intentions based on their assessment of environmental factors, previous experience trying to avoid the effects of asthma, and their immediate needs and desires. These circumstances are best



*Figure 12.* Helping My Breathing

understood and described by considering the context and intentions that constituted children's experience.

Dietary factors related to asthma morbidity have been reported in the literature.

Consumption of fresh fruit was associated with lower rates of wheezing among children



Figure 13. Stopping my Breathing Trouble

(Forastiere et al., 2000). A diet high in omega-3 fatty acids and low in omega-6 fatty acids was found to be protective against asthma morbidity (Covington, 2004; Oddy, de Klerk, Kendall, Mihrshahi, & Peat, 2004). Some of the children were aware that certain foods might help their breathing. The contextual element *believing certain foods are good for asthma* and the intention *eating soup* described the children’s food-related

experience. These findings suggest children's capacity to consider and adapt dietary patterns that would be favorable to decreased asthma burden. Support and assistance for children in relation to diet is warranted.

#### *Knowing My (Medication) Routine*

Non-adherence was found to be a common and serious problem in the care of children with asthma (McQuaid et al., 2003). Payne and Balfour-Lynn (2001) suggested that explanations for worsening asthma morbidity trends, in the face of more potent medications, might exist within the day-to-day experiences of children and their families who are living with disabling asthma. In-depth interviews with adolescents with asthma revealed a need to carefully examine individual reasons for non-adherence and to address personal barriers individuals face in their efforts to care for themselves (Buston & Wood, 2000). My findings suggest similar problems occurred among the 8 school-aged children. A number of explanations were revealed for why the children did not take their medications as prescribed. The data disclosed two primary factors – reasons why the medication was not taken and factors related to technique that limited the effectiveness of inhaled medicines. These two factors will be briefly discussed.

#### *Taking This Medicine Every Day*

Whereas, daily use of controller medications is necessary for optimal management, adherence has been shown to vary widely (Zuckerman et al., 2000). Non-adherence in the daily use of and inhaled corticosteroid was found to be a common and serious problem in the care of children with asthma (McQuaid et al., 2003). Explanations for missed doses among the 8 children included (a) *choosing to take it only at certain times*, (b) *knowing when you really have to take it*, (c) *forgetting to take them*, (d) *not*

*knowing what I took*, and (e) *running out of medications*. Episodic use of inhaled corticosteroids, long-acting beta agonists, and leukotriene modifiers was reported by children. The contextual element *knowing when you really have to take it* offered one explanation for omitted doses. This factor was described as realizing one's asthma worsening, so all medications are taken. During periods of relative wellness daily use of controller medications was not enforced or perceived by the child to be important.

Various reasons have been reported in the literature for discontinuation of inhaled corticosteroids (IC). Parental discontinuation of medications was reported by more than two-thirds of families for a variety of reasons, including: (a) fears of unknown side effects (53%) and addiction (18%), (b) belief that a medication was no longer effective (18%), and (c) feeling that the child was on too many medicines (23%) (Handelman et al., 2004). I found that another reason for discontinuation of IC was the child's assessment that the treatment had no effect. The intention stopping *the medicine because it does not help* applied to a nebulized IC. The child explained further that her mother trusted her to know what helped and what did not help. The data suggest that the child made the decision to stop use IC. This finding points to the need for education of children and their parents regarding the value and effects of IC. Lack of immediate changes in the experience of breathing posed a serious barrier to adherence for this child.

In relation to daily medications children also reported *forgetting to take them*. Children described needing and responding to reminders by friends or family members. These data support findings from other studies. In a qualitative study researchers also found that children reported benefit from parental reminders and rewards for remembering to take medications (Penza-Clyve, Mansell, & McQuaid, 2004). Children

also described *not knowing what I took*, implying that they did not remember which medications they last used. Complex treatment regimens might contribute to this confusion. Reminders and easy record-keeping systems might help children improve adherence to their medication routines. Guidance for parents to improve their skills in assisting children is warranted. Children were dependent upon their parents for a regular supply of their medications. *Running out of medicine* was an aspect of the children's experience. These data suggest that parents need additional support and guidance to assist them in efforts to maintain the necessary supply of medications.

#### *Knowing How You Are Supposed to Take Asthma Medicine*

Effective use of inhaled medications requires not only regular use, but correct inhalation technique. Training for inhalation has been shown to improve technique, markedly increase deposition of medication into the lungs of children, and reduce asthma morbidity (Amirav et al., 2005). The 8 children revealed little understanding of correct inhalation technique. Two specific intentions indicated poor technical skills *taking a regular breath* and *choosing to take it in the wrong way*. An intention compatible with appropriate technique was described by only one child who explained how she was *breathing my medicine in a special way*. Two children described *choosing to take it in the wrong way*. Examples provided by the children included (a) swallowing albuterol concentrate that was intended for inhalation by a nebulizer, (b) deciding not to use a valved-holding chamber for inhaled corticosteroids taken by metered dose inhaler, (c) and disregarding instructions for correct use of a nasal spray. These findings suggest the need for improved education and training regarding inhaled medication and increased parental supervision.

### *Knowing How Other People Respond to My Asthma*

The importance of other people who interact with the child who has asthma is well-known. My findings contribute further to an understanding of how children view and respond to the influence of other people. Researchers described a community where the population had a very low level of awareness of asthma, held a number of erroneous beliefs about asthma, and exhibited non-supportive behaviors toward children with asthma (Hazir, Das, Piracha, Waheed, & Azam, 2002). Hazir et al. reported that these factors were related to poor asthma outcomes among children in the study. One of the 8 children in this study specifically contrasted the experience of living in a neighborhood where he perceived that people cared about him and helped him with the experience of living where no one cared. The 8 children described in detail their experience ways in which other people were responding to their asthma. Findings point to both positive and negative effects on the children's experience of asthma.

Negative emotions, including anxiety were associated with adverse effects. Children with asthma who had higher levels of anxiety had lower asthma quality of life scores (Annett et al., 2001). Another study comparing scores on the State Trait Anxiety Inventory for Children between 92 children with asthma and normal controls found anxiety disorders to be significantly more frequent among children with moderate to severe asthma (Vila et al., 1999). The experience of the 8 children suggests that anxiety was related at least in part to the treatment received at the hands of other people. Data suggest that anxiety might be readily reduced with more effective medications and kinder, more appropriate treatment by others.

The contextual descriptor *knowing some people don't treat me like a normal person* was related to very negative emotions for children in my study. This aspect of the experience was one of several that revealed children struggled for fair treatment. Positive events in the life of children who had asthma were found to mitigate the effects of acute and chronic stress (Sandberg et al., 2002). The descriptors *knowing I get special treatment* and *knowing some people look up to me* support the value of positive events in the children's lives. These data suggest opportunities for increasing children's experience of positive events related to asthma and reducing their level of anxiety.

#### *Deciding to Go to the School Nurse*

Many children (71.8%) cited having breathing problems at school as particularly troublesome. Most primary school children reported having trouble getting their medication when they needed it at school (Chadwick, 1996). Data from my study support this finding. Children described numerous experiences related to asthma at school. Many of these experiences centered around interaction with school nurses. However, not all children sought help from a school nurse as evidenced by the intention *deciding not to go to the school nurse*.

A survey of 550 school nurses identified three commonly cited problematic aspects of practice (a) delegation of responsibility for administering medications, (b) communications to build partnership with parents, and (c) lack of school policies supportive of asthma care at school (Calabrese, 1999). The 8 children described aspects of their experiences that contribute to knowledge about the problems cited by Calabrese. Restricted access to the school nurse was apparent in the intention *getting the coach to let me go to the nurse*. Safety concerns emerged from the data in the context of *walking to*

*the school nurse's office.* Children described instances of arriving to find no one present in the health room and, in one case, lying alone on a cot trying to breathe better. Safety concerns were also raised by children descriptions of *finding my class as after a treatment.* In other circumstances children described careful procedures that were executed by their teachers and nurses to ensure their safety.

Among the other pressing issues evident in the literature was teacher and school staff readiness to provide care for children (Fillmore, Jones, & Blankson, 1997). The children described *getting help when the school nurse is not there.* Children described receiving their medications from school administrators, teachers, and clerical staff. These data support the findings of Fillmore et al. rearguing the need to promote teacher and staff readiness for a role in caring for school children who have asthma.

#### *Knowing My Family Helps Me*

Researchers reported that the care for many children who have asthma might be complicated by the presence of multiple caregivers. Among 789 children aged 6 to 9 more than one-third of children received asthma care from four or more caregivers (Wade et al., 1999). The 8 children did not describe conflicts or confusion between multiple caregivers. However, none of the 8 children reported living between 2 or more homes. Therefore, the data would not be expected to reflect on that aspect of the experience. Children described numerous ways that they depended on their families including *knowing they help me with my medicines and counting on them to take me to the doctor when I am sick.*

#### *Showing Others My Asthma*

The 8 children described important ways that they were trying to explain what it was like for them to have asthma. Their efforts were determined and sustained against serious barriers to communication. The descriptors *not being asked* and *knowing they don't believe me* represent two important barriers. These experiences were a source of frustration and negative emotions for the children. These findings echo concerns reported by other researchers. Clinicians exhibited poor communication patterns when caring for children with asthma (Wissow et al., 1998). Ostergaard (1998) described specific problems in doctor-patient communication including: “differences in the conceptual vocabulary; the doctor's reluctance to consider the patient's story, relying instead on auscultation; as well as pursuit of unexpected, odd differential diagnoses” (p. 156). In another qualitative study, children often commented that clinicians directed questions towards their parents and ignored them. Some children felt intimidated and left out by this communication style. They felt valued when the discussion included their opinions and personal reports of symptoms and treatments (Dixon-Woods et al., 2002).

Children described specific strategies for *showing others my asthma*. Children's descriptions of *answering their questions* demonstrates that they understood the importance of communicating specific facts about their asthma to others. Anxiety about being able to answer questions at the hospital, described by two children, underscored their concerns. The children's concerns are well founded. Clinician behaviors had special bearing on children with disabling asthma, particularly those experiencing an unusually high burden of disease (Bender, 2002; Dolan et al., 2004; Halterman et al., 2003). Children in my study described helpful actions by clinicians and school nurses. These

data support the use of effective strategies by professionals who care for children who have asthma.

The contextual element *knowing they care* described a child's experience at a clinic. This finding was consistent with conclusions by other qualitative researchers. An important component of quality of care identified by children was sensitivity to their feelings and communication skills (Dixon-Woods et al., 2002). The value of specific competencies enacted by health professionals was also evident in the children's experience. One child's description of *using a smiley face scale to tell them how much breathing trouble I'm having* illustrated use of an appropriate tool that facilitated communication between the child and clinician. Another child described reduced side effects and marked increase in therapeutic effect after her school nurse gave her a spacer. These findings emphasize the potential for reducing asthma burden for other children.

#### *Coming to Know More About Asthma*

It is clear that the trend of increasing asthma disability among children is not merely a result of a lack of adherence to medical treatment plans as suggested by some researchers (Hogan & Wilson, 2003). Evidence suggests children who learn about asthma through formal educational experience improve sleep patterns, reduced school absences, decreased need for urgent health care services, and reduced number of episodes for difficulty breathing (Krishna et al., 2003; Wolf et al., 2003). The children's experience demonstrated many intentions related to *learning about asthma*. Several children preferred books as a means of learning about asthma over other modalities.

Most of the 8 children described *wondering what causes asthma*. However, their descriptions did not correlate with the report of Handelman, et al. (2004) that, "Among

children, contagion was the primary explanatory model for asthma etiology (53%).”

Children in this study spoke about their explanations. I discerned these as: (a) *believing you are just born with asthma*; (b) *believing some medicines cause asthma*; (c) *believing that running and playing cause asthma*; (d) *believing problems with my throat cause asthma*; and (e) *believing dogs, and cats, and fur cause asthma*. This finding suggests the existence of greater diversity in children’s beliefs about etiology than suggested by Handelman et al. The children’s explanations point to the need for asthma education concerning the causes of asthma.

A contextual descriptor of the children’s experience of asthma was *realizing asthma changes over time*. One child described *thinking my asthma might get worse*. Another child described *worrying I might die*. These data suggest that these rural children considered the possibility that their asthma would become increasingly severe. These data might correlate with reported findings concerning rural parent’s fears. Parents of children with asthma living in rural communities were far more likely than urban parents to report fear that their child would die of asthma (Green, Greenblatt, Plit, Jones, & Adam, 2001). These findings point to the need for reassurance and education for rural children, as well as their parents.

Wilkerson (2002), in a commentary on study by Rydstrom, Englund, and Sandman (1999), concluded that an important implication of the findings was that children needed re-education about asthma as they grew older since their concerns and experiences change. Children in my study described *thinking about having asthma the rest of my life*. One child described worrying I won’t be able to care for my self when I’m older. She explained her concern as being afraid of having trouble breathing when her

parents might not be there to help as *having an asthma attack when they aren't there*.

These data support the concept that children's need to know about asthma changes and should be assessed individually. Educational programs should be adapted to meet the needs of children over time with the understanding that as their experience of asthma changes and their readiness to learn new things will likely change as well.

### Conclusions Pertaining to the Construct of Asthma Self-Management

Findings pertinent to the construct of self-management will be presented in this section. Scholars, educators, and clinical experts have widely advocated self-management education to improve children's ability to engage in therapeutic behaviors and to reduce asthma-related illness (Creer & Burns, 1979; Guevara et al., 2003; Velsor-Friedrich & Srof, 2000). I presented a critical review of the validity of self-management as a construct previously. In this section I will review specific findings that address four conceptual problems identified in Chapter 2: (a) philosophical bias and methodological errors; (b) conceptual blurring of children's and parent's roles; (c) failure to observe children in natural settings; and (d) neglect of children's perspectives in preference for the point-of-view of clinicians.

#### *Philosophical Bias and Methodological Errors*

The origin of self-management as a construct related to childhood asthma is found in the medical literature in an article by Creer & Burns (1979). Creer (1979) posited that children's clinical progress was associated with use of an educational intervention based loosely on social learning theory. I found no evidence to support the rationale that social learning theory affords specific insight into the needs and experience of children who have disabling asthma. My findings suggest that children's experience of disabling

asthma is complex and is composed of a wide range of phenomena. Without direct analysis of these experiences, self-management evolved as a construct without adequately understanding children's intentions and the context in which they live day-to-day.

Methodological errors in the development of the construct included sampling error and neglect of validation steps that would have allowed children to confirm the data. The operational definition of asthma used by Clark et al. (1980) for selection of child participants was only wheezing. This restricted the sample to a clinical subset of children who have asthma (Kelly et al., 1996). The data underline the fact that among children who are experiencing significant disability due to asthma, wheezing was only one of many relevant symptoms. Failure to collect data from the natural setting eliminated a critical source of knowledge about children's daily experience in the setting where most asthma care takes place. These errors made it impossible to adequately conceptualize what children who have asthma are trying to do in their experience. This problem has likely contributed to the development of inadequate interventions and increased disability among children who have asthma.

#### *Conceptual Blurring of Children's and Parent's Roles*

My findings also bring into focus the problem of conceptual blurring of children's and parent's roles. Early researchers explicitly described collapsing children's interview data into parent data in the development of the concept of asthma self-management. This step was deemed expedient and warranted "since the responses from caretakers and children were combined to provide a qualitative description of positive family actions and their obstacles" (Clark et. al, 1980, p. 284). However, the authors' assertion children are not capable of adequately describing their own experience of asthma stands in

contradiction to the taxonomy of findings (page 348). Other evidence from this study supports data that cast doubt on the adequacy of parental reports of children's asthma symptoms (Guyatt, 1997; Lewis, 1977; Odigwe, 2004). Children's detailed descriptions of *knowing the trouble asthma causes me* and *knowing what makes my asthma worse* are unlikely to be known and adequately described by parents.

#### *Failure to Observe Children in Natural Settings*

Data derived from a descriptive phenomenological study of children involving three interviews in their homes is substantially more complete than data obtained in a single interview conducted in a clinical setting. Many relevant sources of information were readily accessible in the homes, including environmental triggers, medications and supplies used in daily routines, and the context for the child's description of day-to-day life in relation to asthma. Findings support the position that development of self-management construct in the absence of observational data in natural settings would not adequately reflect the challenges children face as they care for themselves and seek help from others.

#### *Neglect of Children's Perspectives in Preference for the Point-of-view of Clinicians.*

Clark et al. (1980) described the framework for development of self-management as an approach for addressing children's asthma. Data were obtained through interviews with both children and adults in hospital clinics. However, an index for measuring self-management was derived explicitly "from the clinical perspective of health-care providers" (Clark et al., p. 282). Children's responses to closed questions and their open-ended comments were incorporated to a very limited extent, in preference for parental input and clinician interpretation of the relevance of the data.

The 8 children demonstrated a unique and compelling perspective that did not correlate with clinician's views of childhood asthma. Their intentions revealed very particular efforts to manage their illness, including noticing when they were not breathing well, identifying what made their asthma worse, acting to improve their breathing, taking steps to stop their breathing trouble, and seeking help from others. These data are more relevant to efforts to promote effective self-care among children than are the perspectives of researchers and clinicians.

In summary, the advancement of asthma self-management as a construct and an approach to care has proceeded with very little direct knowledge about how children actually view and experience their illness. Reasons for failure to achieve hoped-for reductions in the burden of asthma through self-management approaches (Scarfone, Zorc, & Capraro, 2001) are likely related at least problems described above. My findings indicate that additional descriptive, observational studies are needed to ascertain and incorporate children's perspectives into more-effective, evidence-based approaches aimed at reducing the burden of asthma.

These findings suggest that self-management might not be a suitable construct around which health care services for children with asthma should be designed. Other conceptual frameworks for understanding children's needs and behaviors should be considered. My findings suggest that knowledge of children's actual experiences would better prepare health care professionals for building partnerships with children to improve asthma outcomes than the current, researcher-derived construct of self-management. Further investigation of children's experience of disabling asthma is warranted to try to answer these questions. Porter's (1998) nursing research approach based on Husserl's

phenomenology (Husserl, 1913/1962) was well suited for describing asthma-related experiences and for examining the validity of related constructs (Porter, 1995b, 2000).

#### Reintroduction of My Personal Bracket for this Study

Next, I will reintroduce two theoretical frameworks that were included in my personal bracket – Self Care Deficit Nursing Theory and Chronic Illness Trajectory Framework. Finally, findings pertaining to expert clinical guidelines for asthma and the national asthma public health agenda will be discussed.

#### *Self-Care Deficit Nursing Theory and the Children's Experience of Asthma*

The findings of this study are relevant to many aspects of Orem's Self-Care Deficit Nursing Theory (SCDNT) (Orem, 1995). However, the children's experience entailed much more than "self-care." The 8 children described ways in which they were discovering and coming to exercise mastery over some aspects of their asthma. I will comment on a few selected findings of interest. The Theory of Self-Care proposes that humans have an ability to take deliberate action for regulating life, health, and well-being. The Theory of Self-Care Deficit proposes that to maintain life, health, and well-being, each person must take many self-care actions in an adequate and timely manner throughout the course of each day (Orem). The phenomena, component phenomena, and intentions that structure the 8 children's experience of disabling asthma describe and explain many self-care actions. Children demonstrated varying levels of participation and proficiency in these activities.

Orem (1995) stated that a self-care deficit exists when a person's ability to perform the required actions is inadequate to meet all or part of the total need for self-care action. The children's descriptions suggested some serious self-care deficits. Orem

(1995) identified a number self-regulatory needs including lack of knowledge, skill, or psychological readiness to perform self-care actions. Orem pointed out that these needs are accentuated when actions involve multiple steps that must be performed continuously over a long time, when actions are technically complex, and when actions require informed judgments and decision-making at several steps of execution. Self-regulation is also challenging when it requires attention to both internal, bodily conditions and external, environmental conditions that are in flux. Each of these conditions correlated with aspects of the experience of disabling asthma among the 8 children. The level of complexity noted in the phenomenon *stopping my breathing trouble* demonstrates the empirical complexity of an important intention that has attributes of self-regulatory activity. These findings point to the importance of examining the experience fully, to avoid reducing phenomena into simplistic, abstract representations.

Orem (1995) emphasized that the regulatory requirements of self-care change over time for children with growth, development, decreasing dependency upon others, and variations in general state of health. These factors were apparent in the findings. Orem (1995) also pointed out that self-care actions are dictated by the specific technologies available to aid regulation of functioning for a particular disease. This effect was evident for the children as they sought to use various inhalation and monitoring devices for asthma. Orem (1995) stated that time, energy, money, supplies, and motivation are necessary to sustain the work of self-regulation. Whereas basic aspects of these challenges to self-care were evident, the children's experiences demonstrated complexity and richness not anticipated by the theory.

Orem (1995) defined a dependent-care agent as a caregiver who takes action on behalf of an individual who does not have the capacity or ability to take required self-care action, as in the case of young children. The children were dependent upon others for various aspects of their day-to-day asthma care. This fact was illustrated in detail by the contextual descriptor *knowing others help me with asthma* and by the phenomenon *getting someone to help me*. The children sought help from parent, school nurses, teachers, principals, coaches and others. Again the empirical findings demonstrated far more complexity than suggested by self care deficit theory. Children described very specific intentions that were associated with their appraisal of how others would likely respond to their asthma. These data point to the need to focus more carefully on the experience of seeking help from others to understand related context and intentions.

In The Theory of Nursing System Orem proposed that properly educated and experienced nurses are needed to identify and design a plan of care for individuals whose demands for self-care exceed their ability to perform required actions. Thus, a nursing system is the design and implementation of a plan that bridges the identified gap between the action requirements necessary for the regulation of life, health, and well being and the individual's ability to accomplish those required actions (Orem, 1995). The experience of these 8 children suggests the need for improved nursing care that is based on their actual needs and intentions. School nurses, as well as nurses in clinics and hospitals where the children received care demonstrated some components of Orem's theoretical nursing system. However, most children failed to receive an adequate level of care and support from their nurses. This finding points to the need for further training and systems changes

to improve nursing care for children who have asthma. The specific context and intentions of the children's experience describe many opportunities for improving care.

Orem (1995) identified the supportive-educative system (SES) as a component of a nursing system. Orem also described particular nursing roles that are relevant to a SES, including provision of support and guidance, fostering an appropriate developmental environment, and teaching. Support and guidance address the regulatory requirement of fostering the child's psychological preparedness and ability for problem solving to sustain the work of self-care. Specific aspects of support include counseling a child who encounters barriers to self-care at home or school, aiding the child in setting and achieving realistic goals, and strengthening the child's ability to communicate effectively with adults and peers who impact their efforts at self-care (Orem, 2001). The value of these nursing roles was apparent in the experience of the 8 children. Relevant objectives of a support dimension of a SES have been described as a result of this study of the experience disabling asthma. The findings strongly support the importance of including in training efforts to equip peers, caregivers, and adults who impact the care of children who have asthma.

In summary, the findings offer data relevant to key concepts of SCDNT. More detailed analysis of the adequacy of Orem's theory is warranted. Whereas the theory conceptualized some relevant aspects of rural children's experience of disabling asthma, many aspects were not anticipated. Empirical study of children's experience has provided data to guide the improvement of nursing care of children in clinical and school settings. Whereas the findings describe some specific things that children were regulating (Orem, 1998), the structures of experience relate to many other dimensions other than self-care

and self-regulation. These findings confirm the need to study the experience, rather than rely on theory alone to characterize what children are doing in their experience. An empirical approach has identified more clearly, in context, what children are doing. These data describe ways nurses can assist the child in their efforts to reduce the effects of asthma and to live normal lives.

#### *Chronic Illness Trajectory Framework and the Children's Experience of Asthma*

My findings support the relevance and validity of some aspects of chronic illness trajectory framework (Corbin & Strauss, 1991). However, the conceptual fit was not as close as SCDNT. The children's experience exemplified a core attribute of chronic illness trajectory framework (CITF) - the view that some diseases manifest as a changeable illness course that extends over a long period of time with no absolute point of cure. The 8 children's descriptions of asthma reflected phases of expressed illness as predicted by CITF. The course of asthma for children was usually unpredictable. Their descriptions of illness episodes also supported the general statement: "Much depends upon the individual, the action taken to shape that course, and the turn of events that occur" (Corbin & Strauss, 1992, p.16).

In CITF Corbin and Strauss (1992) proposed the existence of major phases of chronic illnesses including (a) pretrajectory (before signs and symptoms appear), (b) onset, (c) crisis, (d) acute, (e) stable, (f) unstable, (g) downward, and (h) dying. They suggested that diseases differ in phase patterns. The accounts of the 8 children reflected the first 7 phases described by Corbin and Strauss (1992). However, my findings suggest that CITF provides a framework for analysis and academic instruction, rather than an explanatory model of the experience disabling asthma among rural school age children.

My findings suggest that CITF has greatest utility in aiding the health professional who needs to understand where a child is in this hypothesized pathway. However, use of the framework should not replace exploration of the child's lived experience. Categorization of children's asthma according to the framework would not adequately represent the experience of the 8 children or facilitate optimal support and partnering with the child. However, CITF raised appropriate questions for the professional seeking to aid the child. For example Corbin and Strauss (1992) pointed out that in addition to major illness phases there can also be short-term fluctuations or "sub-phases" during which the illness moves in a direction contrary to the overall phase. One of the children with unstable asthma stated, "In a way, when you have asthma, you can do anything that another person can do, when it gets not real active and all that."

My findings suggest that asking a child "How is your asthma today?" would probably not reveal the more important overall illness phase. Six of the 8 children described specifically times when they were not troubled at all by asthma. Therefore, even in the presence of significant disability, there were times when children's short-term illness pattern did not reveal serious chronic illness. The two patterns must be carefully distinguished. Therefore, the children's experience of chronic illness supported the relevance and validity of phase changes (Corbin & Strauss, 1992).

CITF also suggests that people who are experiencing a long term disease hold a personal vision of how the illness course will likely progress in the future (Corbin & Strauss, 1991). This vision or disease outlook is influenced by various factors, including the person's biography or larger life events, the severity and frequency of symptoms previously experienced, meaning and significance ascribed by the individual to the

illness, and family and community interactions. Corbin and Strauss (1992) termed this vision of the illness course “the trajectory projection” (p. 16). Several of the children provided descriptions of how they imagined asthma would be for them in the future.

Some of the children described *realizing that asthma changes over time*. In this context the phenomenon *thinking about having asthma the rest of my life* encompassed two opposing component phenomena, *worrying that my asthma might get worse* and *thinking my asthma will go away*. These data support Corbin’s (1998) suggestion that persons hold unique views of chronic illness. The data also supported the concept advanced by Corbin (1998) that ideas held by a person about how a disease will impact their life shapes a person’s intentions and behavior. One child who believed he would outgrow his asthma described going for weeks without taking his control medication. He also described knowing when *feeling good when I don’t take my medicine* and *knowing I’m supposed to take it every day*, but *knowing when I really have to take it*. His description strongly supported the fact that he restarted his maintenance medicine only when his asthma was out of control.

Data also supported the CITF hypothesis that illness projection poses the possibility that a person's expectations about the course of an illness might not match the actual severity and risks of the disease. Health care providers should be concerned that similar behaviors might be rooted in very different projections about an illness. The child mentioned above, who believed that he would outgrow his asthma, required emergency transportation by helicopter for a severe asthma exacerbation a few weeks after the participating in the study. His ill-conceived optimism appeared to contribute to his failure to engage in critical self-care behaviors.

The concept of intentionality is specifically addressed in the CITF (Corbin & Strauss, 1992). Corbin and Strauss (1991) advanced the idea that chronicity evokes a long-term plan for dealing with continuing illness. “Trajectory scheme refers to the plan designed to: (a) shape the overall illness course, (b) control any immediate symptoms, and (c) handle disability” (Corbin & Strauss, 1992, p. 17). My findings support all three components of “trajectory scheme.” Children were shaping their illness course in the context of *becoming the one who knows my asthma*. Related phenomena included *making life normal for me* and *making my breathing better*. Children were trying to control immediate asthma symptoms by *stopping my breathing trouble*. Children were handling their disability in the context of (a) *discovering asthma changes what I can do*, (b) *knowing others help me with asthma*, and (c) *coming to know more about asthma*. They described many intentions related to (a) *making the best of things*, (b) *accepting my limitations*, (c) *getting someone to help me*, and (d) *asking to be treated like a normal person*.

Corbin and Strauss (1991) suggested that the trajectory scheme includes much more than the medical plan of care. They people adapt technology to their way of life in an attempt go on with living despite the disruptions brought on by illness. The children’s experience reflects frustration and inconsistency in the use of asthma-related technologies. One child avoided taking a control medication that required a nebulizer, reasoning that the treatment took too long and did not make her breathe better. Other children had spacers to aid inhalation of medicines delivered from metered dose inhalers (MDI), but chose not to use these important devices. No child described proper technique for use of their MDI. At least one child had a peak flow meter, but did not use this device.

These findings suggest that children struggled to adapt technology to their lives in effective ways.

Corbin and Strauss (1991) pointed out that trajectory scheme encompassed more than a medical plan of care and related technologies. Within CITF persons incorporate other responses into their long-term plan, including rituals, diversions, meditation, prayer, special nutritional practices, use of vitamins, supplements, and minerals, and other forms of alternative therapy might play an important part in a person's strategy for managing illness. Scholars have reported that children and families widely use additional strategies to manage asthma (Madsen et al., 2003). The 8 children demonstrated many responses to their illness that fell outside the realm of traditional medical regimens. Related intentions included, (a) *eating soup*, (b) *finding a place to play out of the wind*, (c) *choosing quieter activities*, and (d) *seeking comfort*. These data support the notion of a trajectory scheme.

CITF advances a view that individuals are engaged with the larger concerns of living one's life while trying to reduce the burden of illness. This point of view places living, rather than managing the illness, at the center (Corbin & Strauss, 1992). The phenomenon *making the best of things* and the component phenomenon *making life normal for me* supports the assertion that living one's life, rather than managing illness might be a person's central concern. These data carry implications for health care professionals who would build stronger and more effectual partnerships with children who experience disabling asthma. This objective would likely be better served by endeavoring to provide health care in the larger context of how a child seeks to live her or his life. Children's intentions reveal what they are trying to do and provide a basis for a partnership built on the mutual objectives of controlling disease and living a normal life.

## Significance of the Findings

In this section I will summarize the significance and major implications of this study for public health, clinical practice, nursing science, and future research. In preparation for the proposed study, I found no published investigations of the experience of disabling asthma among children in general or rural children in particular. Description of phenomena associated with 8 rural children's experience of asthma has contributed new knowledge. This knowledge informs efforts to reduce asthma disability. The widening gap between what is technologically possible in the treatment of asthma and what is actually being achieved in the care of children has been explained in part by the data from this study.

The results of this descriptive phenomenological study hold special significance for several disciplines and audiences. Future research should be based in part on questions that arise through dialogue with these diverse groups, who have special interest in the findings. In the following section I will briefly raise issues that are pertinent to (a) efforts to reduce the public health burden of childhood asthma, (b) inclusion of children as participants in research, (c) clinical care of children who have asthma, (d) development of school policy and improvement of school services for children who have asthma, and (e) interventions and research related to asthma among rural children.

### *The Significance for Public Health Initiatives*

The disabling asthma survey conducted in the sampling procedure of this study provides specific and compelling benchmark data that document the scope of disabling asthma among school children in Missouri. These data are consistent with national data reporting asthma as the single most common cause of disability in childhood (Msall et al.,

2003). The significant impact on rural Missouri children was established with a mean rate of disabling asthma of 2.1% (Francisco & Konig, 2005), compared to the national rate of 1.4% for urban and rural children (Newacheck & Halfon, 2000). Geographic disparity in the distribution of over 3200 rural children with disabling asthma was established with zip-code census tract mapping in the sampling procedure for this study. These data identify schools where interventions to reduce the burden of asthma are needed.

Qualitative data derived from use of a descriptive phenomenological approach involving 8 rural children from 8 of the original 20 schools selected in the sampling procedure identified the need to (a) improve school policies and services to protect and aid children who have asthma, (b) more effectively address children's needs in clinical settings, (c) meet the asthma-related educational needs of children, and (d) better inform and prepare parents and others for supportive roles that will assist these children.

Instruments developed or adapted for use in this study might aid public health efforts to address disabling asthma among children, including the (a) Disabling Asthma Survey for School Nurses (Francisco, 2005), (b) semi-structured interview guide, and (c) Disabling Asthma Screening Form for Parents (Usherwood, Scrimgeour, & Barber, 1990), adapted with permission (T. P. Usherwood, personal communication, October 17, 2005)

The response rates I encountered with contacts during the conduct of this study indicate that school-based public health approaches to asthma are likely to be effectual. The response rate to the Disabling Asthma Survey for School Nurses was 83% with more than 1000 Missouri school nurses responding. Permission was received from 19 of 20 superintendents to request school nurses to assist in recruitment of child participants for

the study. The specific findings of the study also support the value of school-based efforts for addressing the growing public health problem of disabling asthma.

### *The Significance for School Policy and Services*

Findings have particular significance for school policy and services. I will highlight four areas with reference to related evidence from the literature that reveals the implications. The four areas will include (a) children's rights to seek professional care at school, (b) asthma competencies for school staff, (c) safety of children who are experiencing asthma symptoms, and (d) asthma education services for children who have asthma. Children's rights to seek professional care at school should be protected.

Children described being denied access to the school nurse during times when asthma symptoms were troubling them. School personnel should be advised that judgements regarding asthma should be reserved for individuals with specific expertise. School staff should not block access to a nurse or parent when a child asks for help. The child's right to access supportive care should be protected by a policy that simply states that no child will be denied access to special care by a school nurse, an individual with specific and substantial training related to childhood asthma, or the child's parent, during times when the child reports persistent coughing or difficulty breathing.

Children's descriptions revealed that asthma medications and supportive care were provided by school personnel other than school nurses. Teachers, coaches, and others were involved in other aspects of care for children who experienced asthma symptoms at school. These data point to the need for training pertaining to the recognition of signs of asthma and supportive care be provided to all school staff. Specific personnel who will supervise the use of asthma medications in the absence of a

school nurse should participate in additional training to ensure they have specific competencies required to assess the child and facilitate correct inhalation technique. School nurses should have specific training to prepare them for the care of children who have asthma. The children's experience suggests that critical aspects of the nurse's role include (a) assessment of the child's breathing status, (b) support and counseling related to interactions with peers and school staff, (c) education of school personnel, and (d) promotion of optimal inhalation technique.

The children's experience suggested safety risks, as well as best practices for schools. Children who are experiencing difficulty breathing should not walk alone to the point of care, whether that is a nurse's office or some other location. A system for alerting the school nurse should be utilized to provide advance warning that a child is having difficulty breathing and needs assistance. This procedure facilitates readiness on the part of the school nurse to care for the child. A line of vision policy, whereby the child is always within view of a responsible adult or, if necessary, a peer, could safeguard children from the occurrence of life-threatening events at times when their breathing is unstable. Children should also be escorted back to their teacher after receiving breathing treatments or returning to school after receiving treatment off-site.

Children with asthma might not be able to complete rigorous physical activity on days when their asthma is poorly controlled. Adults who are responsible for physical education activities should allow periods of rest. They should also report these episodes to parents and school nurses for further evaluation. The recruitment procedure used in this study demonstrated that school nurses were effective in identifying children who experienced disability due to asthma. If school staff reported their observations to the

nurse, interventions to address the child's asthma-related health could be managed according to established protocols (Missouri School Asthma Manual, 2005). Doubts held by school staff about the validity of a child's reports of having breathing problems should be set aside in preference of the view that children want to be well, actively playing alongside their peers. Children who withdraw from physical activity should be asked by coaches and teachers if they are having trouble breathing. Findings should then be communicated with the school nurse and parent.

All 8 children described lacking essential knowledge and wanting to learn more about asthma. In Healthy People 2010 (DHHS 2001) it was pointed out that only 6.4% of persons with asthma received formal patient education in 1998. Healthy People 2010 objectives target an increase to 30%. None of the 8 children reported having participated in formal asthma education. Books were highly valued as a means of asthma education among the children. Inclusion of asthma-related literature in the general curriculum was described with enthusiasm by one child as a way to share with peers what it is like to have asthma. The effectiveness and value of asthma education has been demonstrated (Guevara, 2003; Krishna, et al, 2003; Wolf et al., 2003). Schools should provide formal asthma education to reduce asthma disability and to eliminate unnecessary absenteeism and loss of revenue (Missouri Department of Health and Senior Services, 2006).

#### *The Significance for Nurses and Clinicians*

The children appreciated compassionate care they received from health-care workers. They also valued knowledge gained from people who provided their clinical care. However, the children described aspects of their experience that point to the need for improved clinical care. Clinical staff should value the insights and experience of

children. The description of *not being asked about my asthma* was particularly disturbing. Parent's reports underestimate important aspects of children's asthma (Schulman, Ronca, & Bucuvalas, 2004). Information about children's asthma should come first from the child who is living with the disease. The findings demonstrate that young school age children have much to say about their asthma. By age 11 children's reports correlate better with objective measures of asthma than do parental reports (Guyatt et al, 1997). Before age 11, parents' reports contribute to, but do not replace, children's reports. The findings of this study suggest that clinical histories should probe children's experience of asthma with open-ended questions, such as, (a) "What is it like for you when you run or play hard?" (b) "What is the worst part of having asthma for you?" and (c) "What is it like for you having asthma at school?" When posed by nurses and other clinicians, these types of questions would anticipate and encourage meaningful input from children.

Only one child described regular check-ups for asthma. Other children described visits to the doctor only in the context of being ill and seeking relief from asthma symptoms. Other researchers have reported inadequate numbers of encounters with clinicians among rural children who had asthma (Horner & Fouladi, 2003). The children's descriptions raise this possibility, as well. Except in the single case mentioned, clinical care as described by the children was episodic and illness-focused. When experiencing asthma exacerbations, children reported going to the doctor, rather than changing or increasing medications according to a pre-determined plan. Whereas, most of the children had been given inhaled corticosteroids by their doctors, only one child described regular use. Children's descriptions of the clinical care they received suggested that objective measures of lung function were not used by clinicians as recommended

(AAAAI, 1999). No child described procedures associated with objective measurement of lung function by their doctor, such as peak flow measurement or spirometry. These data are worrisome given evidence that asthma disability among children was more common when objective measures are not used by clinicians (Joseph-Bowen et al., 2004). Children described throat examination and auscultation of the chest as the primary ways their doctors found out how sick they were.

The children's descriptions did not suggest they received appropriate training for inhalation technique. Ineffective use of inhaled corticosteroids and quick relief medications likely contributed to disability among the children (O'Brien, 1997). Objective assessment and remedial instruction to improve inhalation technique for optimal inspiratory flow and time parameters favor deposition of medication deep into the airways (Amirav et al., 2005). Basic procedural steps required for effective use of inhaled medications were also missing in the 8 children's descriptions of their routines for taking medication. Descriptions such as "emptying my lungs before breathing in my medicine" and "holding my breath after inhaling my medicine" were missing in the children's responses. In such cases, if clinicians corrected these problems, the children would likely enjoy improved response to their medications and reduction in disease burden (Cunningham & Crain, 1994; Mazur, de Ybarrondo, & Miller, 1999).

The children's descriptions suggested that asthma education in the clinical setting was inadequate. Children's descriptions raised concerns about how they learned about new medications. Some children described learning about their medications at home from their parents, rather than from a health care worker. Other children reported not knowing the purpose and or correct use of medications. Children described worrying about aspects

of asthma that they did not understand, such as what could be done if their asthma was getting worse. No child described a written plan for responding to changes in their asthma. Only one child reported learning about asthma at the clinic from any form of educational media. Otherwise children described only verbal instructions about asthma. These findings suggest that clinicians caring for the children had not adapted multi-media approaches, despite strong evidence of effectiveness (Wolf et al., 2003). No child described understanding the value of or actually using a peak flow meter to assess their asthma status. These data raise questions about the likelihood care received by the children was consistent with expert asthma guidelines (AAAAI, 2004).

A final and critical implication of the findings relates to clinical definitions of asthma in childhood. Historically, wheezing was held to be pathognomic for asthma (Mak et al., 1982; Martin et al., 1982; Peckham & Butler, 1978). In recent years more clinicians have become aware that many children with asthma experience cough and other respiratory symptoms. These children who do not wheeze demonstrate similar lung function deficits and morbidity patterns as children with wheeze (Fuller, Picciotto, Davies, & McKenzie, 1998). The 8 children's descriptions of *knowing the trouble asthma causes me* expands and further validates the understanding that asthma-related breathing problems entail a much more varied array of symptoms than previously appreciated. Whereas, wheezing was one symptom described by the children, it was not as common as cough and hard breathing. Clinicians should expand inclusion criteria to improve detection of asthma-related symptom patterns and disability among school-age children.

### *The Significance for Rural Asthma Interventions and Research*

Findings support the need for further research and targeted interventions to address asthma among rural children. Data point to unique environment triggers, such as smoke exposure from the burning of fields prior to spring planting and agricultural chemicals that contributed to the children's illness experience. These findings are consistent with prior reports in the literature of particular environmental risk factors for asthma in rural communities, including chemicals and pesticides, agricultural dust, inhalant by-products of industries, high concentration of crop pollen, and mold (Wind et al., 2004). Additional research is needed to provide more specific knowledge about the occurrence and remediation of environmental triggers in rural communities.

The primary finding of significance from the 8 children's experience was the lack of essential care and support for asthma. It is known that rural families face particular barriers in efforts to care for their children, including inadequate access to specialists, lack of care at school, inadequate insurance or money for obtaining medications, and manual labor demands on family members (Barrett et al., 2001). Distance from specialty centers for children health services likely contributed to this problem. Only one child reported regular visits with a specialist. These data suggest the need for research and evaluation of innovative approaches that would sustain rural foci for asthma care in both clinical settings and in schools. A need for systematic training for rural primary care providers is apparent. Improved communication and affiliation with specialty centers for children's asthma would likely enhance quality of care.

Children's descriptions point to the need to examine ways of improving services and support from their rural school nurses. This finding is consistent with reports in the

literature that rural school nurses were less prepared than urban schools to manage the health needs of children with asthma. Rural nurses used peak flow meters less often, had limited access to educational materials, and reported fewer interactions with individuals who assisted them in meeting the health needs of students (Huss et al., 2001). The fact that asthma was identified as the first priority for school nurses in Missouri supports an aggressive research agenda (Bachman et al., 2000).

### *The Significance for Research*

The findings from this descriptive, phenomenological study employing Porter's (1994, 1998a) method demonstrate the value of qualitative research. It is significant that the method has been effective and productive with very young participants. Compared to other qualitative methods used in research with children, Porter's (1994, 1998a) method has yielded richer, more complete data sets. Use of qualitative software with modeling capability aided development of a detailed taxonomy of the experience, as well as figures that enhance communication of findings by use of graphic representations. These tools will allow other researchers to examine and discuss the findings in an efficient way. In addition these tools support translational efforts to apply findings to interventions likely to favorably impact the public health problem of disabling asthma. The research design has incorporated methods for including and comparing other populations of children.

Reintroduction of bracketed literature, constructs, and theories has demonstrated that the original objective was attainable and worthwhile, that is to seek empirical evidence that would strengthen scientific conceptualizations and lend support to the design of interventions. The description of the 8 children's experience of disabling asthma has both confirmed and challenged certain scientific conceptualizations. Self-

management as a construct has been critically reviewed and significantly questioned by analysis of the literature and new empiric data. Despite widespread popularity, self-management has fallen far short of providing an adequate understanding that can power new research and interventions. The children's experience has revealed much more. Many scientific concepts related to children's asthma have been confirmed. These results ring true with Husserl's (1929/1975) words, "The sciences and the world of experience are reaffirmed... as constitutive correlates" (p. 30).

Finally, this study both affirms and challenges the national asthma research agenda and stated strategy of the US Department of Health and Human Services.

The mission of DHHS is to enhance the health and well-being of Americans by providing for effective health and human services and by fostering strong, sustained advances in the sciences underlying medicine, public health, and social services" (DHSS, 2000, p. not assigned).

The last of the DHHS six strategic goals - to "strengthen the nation's health sciences research enterprise and enhance its productivity" (DHSS, 2000, p. not assigned) can not be accomplished by investing only in traditional basic and clinical science research. A widening of the asthma lens (Sturdy et al., 2002), beyond the favored biomedical themes that have held the attention of researchers over the last decade, must include empiric research into the daily experience of living with asthma. The general perception that quantitative methods are inherently more precise and scientific than qualitative approaches (Ginzberg, 1995) has not been validated in the arena of human experience. Knowledge gained from Porter's (1994, 1998a) method, and from other approaches to qualitative research, provides data that has previously been missing. These

data are likely to benefit both professional and lay efforts to support children who have asthma (Abdulwadud et al., 2001; Zimbardo, 2000) and have specifically strengthened scientific constructs related to disabling asthma among children.

#### Limitations of the Study and Future Research

Limitations of the study relate primarily to sampling inclusion criteria. The participants were selected to obtain a homogeneous sample based on rural residence and age. Therefore, the results relate to specific aspects of the experience of disabling asthma that might be unique to young, rural, school-aged children. As a group, the 8 children recruited as participants were younger than anticipated, with a mean age of 7.5 years. Findings might relate more to the experience of younger children in the inclusion criterion for age, 7 to 12 years, compared to older children within this age range. Children were recruited from among a pool of children who had asthma based on specific factors related to asthma disability. Findings are expected to represent the experience of disabling asthma, rather than asthma in general. Therefore, findings would likely be different from data derived from a similar study of children who met inclusion criteria for well-controlled asthma.

The cross-sectional design with 8 participants and 24 interviews was appropriate for a descriptive, phenomenological study (Morse, 2000). However, the taxonomy and findings would likely be enhanced by further research involving additional participants. The understanding of the significance of findings would likely be improved by a contrasting study of rural school children who have well-controlled asthma. Use of alternative inclusion criteria would also likely yield unique and important data. Asthma disparity data (Akinbami et al., 2002) suggest that the experience of urban children and

minority children should also be studied. Unique aspects of the experience of asthma among differing populations of children would support targeted services and interventions that could more effectively aid children with asthma in their efforts to live normal lives.

### Conclusion

Findings from a descriptive phenomenological study involving young, school-age children demonstrate significance and implications for public health, school services, clinical practice, and research. The data include compelling explanations by children about what they experienced and what they were trying to do as they lived with asthma day-to-day. This study provides evidence that children should be considered important sources of information and knowledge about asthma. Their needs, rights, and potential should be advocated and protected. An understanding of and response to children's experience of asthma should guide efforts to improve their care at home, at school, in the community, and in the places where they seek health care services. Children's wisdom, initiative, and worth have been underestimated.

APPENDIX A  
IRB APPROVAL OF PROPOSAL



**Institutional Review Board  
Health Sciences Section**

University of Missouri-Columbia

125 Folk Hall  
One Hospital Drive  
Columbia, MO 65212  
PHONE (573) 882-3181  
FAX (573) 884-4401  
E-MAIL: [irb@missouri.edu](mailto:irb@missouri.edu)  
WEB: [www.research.missouri.edu/hsirb](http://www.research.missouri.edu/hsirb)

November 30, 2005

Benjamin Francisco, MD  
Child Health  
Dc120.00  
One Hospital Drive  
Columbia, MO 65212

Dear Dr. Francisco,

Regarding your application for approval of the research project, *The experience of rural children whose daily lives are limited by asthma*, the Health Sciences Institutional Review Board (HS IRB) took the following action:

- a. Approved your application through expedited review [as codified under 45 CFR 46.110 (f) (7)] on November 22, 2005.
- b. Found this protocol to impose minimal risk to the research participant.
- c. Requires approval from participating schools in the form of a permission letter before research can be conducted.
- d. Requires that the principal investigator obtain the informed written consent of each research participant.
- e. Reviewed and approved the final version of the consent form on November 23, 2005.
- f. Reviewed and approved any advertisements or other recruitment materials that were submitted with your application.
- g. Found that there is no HIPAA requirement for this project.
- h. The HS IRB has determined that the degree of risk is such that the approval for this protocol will expire on November 22, 2006. A Continuing Review Report must be submitted a minimum of one month prior to this date.

Please reference IRB Project # 1056517 in all future communications regarding this project.

**Before enrolling patients at the Truman V.A. Hospital, all research involving human participants must be approved by both the appropriate MU IRB and the V.A. Research and Development Committee. This requirement includes Principal Investigators who are V.A. employees conducting research outside of the V.A., and any non-V.A. employees who are either recruiting V.A. patients or using V.A. facilities for their research. If you meet any of the above criteria, please contact Karen Watson in the V.A. Research Office at 814-6550.**

Pursuant to the HS IRB conflict of interest policy, investigators who are HS IRB members do not vote on protocols in which they are involved.

Death occurring in a study at this site must be reported to the HS IRB office within 24 hours of occurrence, whether or not the death is related to the study. All on-site serious adverse events must be reported to the HS IRB office within five (5) days of occurrence.

No change may be made in an approved protocol or recruitment materials unless the change is submitted to and approved by the HS IRB.

Do not depend on the HS IRB for your record keeping. Pursuant to federal regulations, the IRB retains files of only three years after termination of a research project.

Sincerely,

Niels Beck, PhD  
Chair

Enclosure

APPENDIX B  
INFORMATION TO BE GIVEN TO POTENTIAL PARTICIPANTS

Dear Parent:

My name is Ben Francisco. I am a certified pediatric nurse practitioner and asthma educator. I have more than 10 years experience working as a specialist providing care to children who have asthma. I am also a doctoral student in nursing at the Sinclair School of Nursing at the University of Missouri-Columbia. I am doing my dissertation under the direction of Dr. Eileen Porter, who is a faculty member at the School of Nursing. I am interested in learning about the experience of asthma among rural school children ages 7 to 12 whose daily lives are limited by asthma. I would like to learn what it is like for your child to have asthma. The information children provide in this study will help health-care professionals understand how children view asthma and what children are trying to do in relation to having asthma. Little is known about these topics. I hope that information gained by interviewing children in this study will improve the care of other children who have asthma.

This study does not pose any serious risks to your child. No treatments for asthma are involved in this study. The study involves three interviews with your child that will take place in your home at a time of your choice at intervals of one week. Each interview will last about one hour. A small payment will be made for your child's participation after each interview.

To be sure your child is eligible to participate in the study you can read six short questions on the enclosed yellow contact form that were written to identify ways that asthma can interfere with a child's daily life. After answering these questions, if you believe that your child's life is limited by asthma, you can choose to mail the yellow contact form to me in the enclosed, postage-paid envelope. If you return the yellow contact form, I will call you within a few days. At that time I will review the six questions with you by phone. During that call I will also explain more about the study.

After we talk on the phone, if you and your child are interested in learning more about the study and I find that your child is probably eligible to be in the study, we will arrange a time when I can come to your home. We will review the six questions about ways asthma can limit a child's daily life. I will provide a detailed written explanation of the study. I will also explain the study in simple terms to your child. If you decide to give permission for your child to participate and your child wants to be in the study, I will ask you both to sign a form.

Then, on that same day, I will interview your child for the first time. I will interview your child in a common area of the house, such as the living room or kitchen. You must be in the house throughout the interview. However, it is important that your child and I talk privately, so your child can say anything about asthma that is important to her/him. It is important that we have the interview in a quiet place. Your child and I will wear headset microphones to improve the quality of the recording and to keep the conversation quiet.

If you and your child decide to be a part of the study, then you or your child can change your mind about taking part in the study with no penalty. Your child can choose

to stop being in the study at any time. If your child decides to stop being in the study information that you and your child have provided will not be included in the study.

During the second interview I will ask you to complete the Children's Health Survey for Asthma. This survey was developed by the American Academy of Pediatrics for parents of school-age children. Information you provide in the survey will help me understand how asthma affects your child and your family. This is important to know and it will help me to compare the experiences of different children.

Results from this study will not include any names or other identifying information that would allow others to know who participated in the study. Audio recordings will be edited to remove any identifying information after the study is completed.

If you have any questions or concerns about this study you can call Ben Francisco at 573-884-8629 or Dr. Eileen Porter at 573-884-7261. You can also return the yellow contact form in the self-addressed envelope included with this letter. I will call you a few days after I receive your contact form in the mail.

Sincerely,

Ben Francisco, RN, BC, PNP, AE-C

APPENDIX C  
TELEPHONE RESPONSE TO PARENTS WHO RETURN CONTACT FORMS

“Hello this is Ben Francisco. Thank you for returning a contact form requesting more information about the asthma study.”

“Is this a good time to talk about the study or would you like for me to call back later?”  
*If this is not a good time I will arrange for a time to call back. If this is a good time I will continue.*

“I would like to first ask if you have any questions about the study.”  
*I will address their questions first.*

“Next, I would like to ask you the six questions about ways asthma limits your child’s daily life. Is that Okay with you? Please, answer each of the following questions.

- 1) “Does your child sometimes stay indoors because of asthma?”
- 2) “Does asthma sometimes interfere with her/his playing with friends?”
- 3) “Has your child’s education suffered sometimes because of asthma?”
- 4) “Has asthma sometimes stopped your child from doing all the things that a boy or girl at this age should do?”
- 5) “Has your child’s asthma interfered with her/his life?”
- 6) “Has asthma sometimes limited your child’s activities?”

*If at least five of the six questions are answered affirmatively, then I will inform the parent that their child is likely to be eligible to participate in the study.*

*The next questions determine the likelihood that the child will have the ability and freedom to decide to participate or to decline to participate. An affirmative answer is required for all items.*

(a) “Is your child capable of making up his/her own mind about being in this study?”  
*A “yes” answer is required to ensure that the child has the developmental capacity to choose freely whether or not to participate in the study.*

(b) “Is there any reason why your child would not feel free to choose whether or not to be in the study?”  
*A “no” answer is required to ensure that the child has the freedom to choose whether or not to participate in the study.*

(c) “If your child decides not to be in the study, will you honor his/her decision?”

A “yes” answer is required to ensure that the parent will support the child’s decision whether or not to participate in the study.

*If the answer to any question (a) – (c) is in opposition to the desired response, I will inform the parent that the child is not eligible to participate in the study because the child has to be capable and free to decide whether or not to participate in the study.*

*If the answers to questions (a) – (c) are consistent with the desired responses I will continue with the recruitment procedure.*

“Your answers indicate that your child is eligible to be in the study and that your child’s rights can be protected. I would like to schedule a time to come to your home to provide you with a written explanation of the study. When I meet with you and your child we will first review the six questions about the ways asthma can limit a child’s life. Instead of asking for a yes or no answer, I will ask you to assign a number to each question to rate the amount of limitation your child experiences because of asthma for each item.”

*Then I will arrange a date and time to travel to the home to provide detailed information about the study. I will obtain the home address and travel directions. I will thank the parent for their time.*

APPENDIX D  
MESSAGE ON THE OUTER ENVELOPE AND THE CONTACT FORM

“Study Opportunity for Children 7 to 12 Who Have Asthma”

Your child might be eligible to participate in a study of asthma. The study is being conducted by a doctoral student from the Sinclair School of Nursing, University of Missouri. There is a small payment for your child’s time if you and your child decide that your child can be a part of this study. For details, please read the enclosed letter.”

APPENDIX E  
THE CONTACT FORM

Contact Form for the Asthma Study

“The Experience of Rural Children Whose Daily Lives Are Limited by Asthma”

**Please, check each item that applies to your child:**

- 1) My child has stayed indoors because of asthma \_\_\_\_\_
- 2) My child’s asthma has interfered with her/his playing with friends \_\_\_\_\_
- 3) My child’s education has suffered because of asthma \_\_\_\_\_
- 4) Asthma has stopped my child from doing all the things  
that a girl or boy at this age should do \_\_\_\_\_
- 5) My child’s asthma has interfered with her/his life \_\_\_\_\_
- 6) Asthma has limited my child’s activities \_\_\_\_\_

**For more information, please complete the contact information below.**

Dear Ben,

I am interested in learning more about the asthma study.  
My child has asthma and is between ages 7 to 12 years.

Please contact me at this phone number \_\_\_\_\_-\_\_\_\_\_-\_\_\_\_\_  
between the hours of \_\_\_\_\_(am or pm) and \_\_\_\_\_(am or pm).

You can also reach me at this phone number \_\_\_\_\_-\_\_\_\_\_-\_\_\_\_\_  
between the hours of \_\_\_\_\_(am or pm) and \_\_\_\_\_(am or pm).

My name is \_\_\_\_\_

My address is \_\_\_\_\_

\_\_\_\_\_

**Please return this form in the enclosed postage-paid envelope.**

Ben will contact you within a few days after he receives this information.

Thank you very much!

Ben Francisco, RN, BC, PNP, AE-C (pediatric nurse practitioner and asthma educator)  
Eileen Porter, PhD, RN (professor, researcher, and registered nurse)

APPENDIX F  
CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

INVESTIGATOR'S NAME: BENJAMIN D. FRANCISCO  
PROJECT # 1056517  
DATE OF PROJECT APPROVAL:

<b>FOR HS IRB USE ONLY</b>
<b>APPROVED</b>
  <hr/>
_____ HS IRB Authorized Representative Date
<b>EXPIRATION DATE:</b>  _____

**STUDY TITLE: THE EXPERIENCE OF ASTHMA AMONG RURAL CHILDREN WHOSE DAILY LIVES ARE LIMITED BY ASTHMA**

**INTRODUCTION**

**This consent may contain words that you or your child do not understand. Please ask Mr. Francisco to explain any words or information that you do not clearly understand.**

This is a research study about the experience of children with asthma that limits their normal life. You and your child have the right to know about procedures that will be used in this research study so that you and your child can make the decision whether or not to participate. The information presented here is simply an effort to make you and your child better informed so that you and your child may give or withhold your consent to participate in this research study.

Please take your time to make your decision and discuss it with your family and friends.

You are being asked to take part in this study based on two conditions. First, a doctor has told you that your child has asthma. Second, you have completed the Disabling Asthma Screening Form with a score of 12 or higher. This score indicates that asthma is interfering in your child's life.

This study is being sponsored by the 2005 Barbara J. & Kenneth W. Levy Nursing Fellowship, Sinclair School of Nursing, University of Missouri, Columbia.

In order for your child to participate in this study, it will be necessary for you to give permission in the form of a written consent. Your child's signature on that same form indicates that she/he has decided to take part in the study.

### **WHY IS THIS STUDY BEING DONE?**

The purpose of this study is to help health professionals better understand what it is like for children who experience limitations in life because of asthma. School-age children have an important role in their own asthma care. However, little is known about the point-of-view of children. It is important to know how children experience asthma so that health-care providers can be more effective in helping children.

### **HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?**

Eight children will take part in this study. Mr. Francisco will interview all the children.

### **WHAT IS INVOLVED IN THE STUDY?**

If you grant permission and your child decides to be in this study, she/he will take part in 3 interviews, each lasting about 60 minutes. One interview will be scheduled each week at your convenience within a one month period. The interviews will take place in a common area of your home such as the kitchen or living room. It is necessary for you to be in the house while your child and Mr. Francisco are talking. However, it is best that the conversation be private so that your child will feel free to talk about any aspect of her/his experience of asthma. Each interview will be recorded so that a written transcript of the conversation can be produced later. The actual recording will also be used to illustrate the research findings so that children's experiences will be better understood. Your child and Mr. Francisco will wear headsets with microphones to allow the interview to be quiet, for privacy, and to improve the quality of the recording. It will be important that distractions such as television, radio, or electronic games be turned off during the interviews.

During the first meeting Mr. Francisco will read the consent form and answer any questions you or your child might have about the study. If you give consent for your child to participate, Mr. Francisco will ask your child a series of questions about the study. This procedure is designed to be sure she/he understands her/his rights and that she/he wants to participate in the study. If you and your child decide that your child will participate in the study Mr. Francisco will ask you and your child to sign the consent form. Mr. Francisco will complete the first interview with your child during this first visit.

A second interview will be scheduled for the following week. At the second interview Mr. Francisco will ask you to complete a form to obtain background information about your child's asthma. This form was developed by the American Academy of Pediatrics so

parents could describe important aspects of a child's asthma. The Children's Health Survey for Asthma is a paper-and-pencil form that includes 48 questions with multiple choice or short answers. The form can be completed in less than 15 minutes. While you complete the form Mr. Francisco will interview your child to learn more about his/her experience of asthma.

A third interview will be scheduled. At the third interview Mr. Francisco will share with your child what he has learned. Mr. Francisco might also ask your child to comment on what other children have said about asthma or about what other researchers have reported. Your child will be able to clarify what they intended to say in the first two interviews and will be able to add other thoughts during the third interview.

If Mr. Francisco gains information during the interviews that he believes you should know about he will ask your child's permission to share this with you. Any information that is gained that might have a serious health consequence will be shared with you so that you can protect your child, whether or not your child agrees to this exchange of information.

If during the interviews you need to leave the house for any reason, the interview will stop and Mr. Francisco will also leave the house. The interview will be rescheduled at another time that is convenient for you and your child.

Interviews are designed to allow your child to talk about the experience of asthma in their own words. Mr. Francisco has prepared some questions to guide discussion of topics of interest over the course of the 3 interviews. However, there are no right or wrong answers to the questions. The study is designed to describe what it is like for your child to have asthma.

### **HOW LONG WILL I BE IN THE STUDY?**

Your child will be in the study for 3 weeks unless bad weather, sickness, or other problems require that an interview be rescheduled the following week. This would extend the time your child is involved in this study by a week or two.

**Your child can stop participating at any time. If you change your mind about wanting your child to be a part of the study or if your child decides she/he wants to withdraw from the study, your decision will be respected. A decision to withdraw from the study will not in any way affect your child's medical care, benefits, any other aspect of asthma care, or any involvement in school activities or services.**

### **WHAT ARE THE RISKS OF THE STUDY?**

This study does not pose any risk of serious medical harm or discomfort to your child. If any of the interview questions bring up unpleasant feelings, your child is free to say she/he does not want to talk about the topic. At the beginning of each interview Mr. Francisco will remind your child that he/she is free to choose not to talk about any subject. If your child has difficulty breathing or talking in complete sentences during an

interview, Mr. Francisco will let you know immediately so you can provide treatment or seek medical care for your child if indicated. In this event, the interview will be rescheduled at a time when your child can safely participate.

**ARE THERE BENEFITS TO TAKING PART IN THE STUDY?**

If you grant permission for your child to take part in this study and your child chooses to be in the study, there is no direct benefit to your child. You and your child may expect to benefit from taking part in this research to the extent that you are contributing to knowledge about children who have asthma. Mr. Francisco hopes that information learned from this study will benefit other children with asthma in the future.

If you or your child have questions or concerns while or after your child participates in this study, you can call Mr. Ben Francisco at 573-884-8629 or his advisor Dr. Eileen Porter at 573-884-7261.

**WHAT OTHER OPTIONS ARE THERE?**

Instead of being in this study, you have the option to not participate in this research study.

**WHAT ABOUT CONFIDENTIALITY?**

Each interview will be recorded so that a written transcript of the conversation can be produced later. The actual audio recording will be used to illustrate the research findings so that children's experiences will be better understood. Information produced by this study will be stored in Mr. Francisco's file and identified by a code number only. The code key connecting your child's name to specific information about your child will be kept in a separate, secure location.

The code key will be destroyed at the conclusion of the study to protect confidential material. At that time all unique identifiers such as names and places will be removed from transcriptions and audio recordings. Information contained in your child's records may not be given to anyone unaffiliated with the study in a form that could identify your child without your written consent, except as required by law.

It is possible that your child's research record, including sensitive information and/or identifying information, may be inspected and/or copied by the study sponsor (and/or its agent), the Food and Drug Administration (FDA), federal or state government agencies, or hospital accrediting agencies, in the course of carrying out their duties. If your child's record is inspected or copied by the study sponsor (and/or its agents), or by any of these agencies, the Sinclair School of Nursing will use reasonable efforts to protect your child's privacy and the confidentiality of your child's information.

The results of this study may be published in a book, journal, or other scholarly form, or used for teaching purposes. However, your child's name or other identifying information

will not be used in any publication or teaching materials without your specific permission.

Audio recordings obtained during the study that could identify you or your child, will not be used for purposes other than this study, unless you give special written permission for their use. In that case, you will be given the opportunity to listen to the audiotapes before you give your permission for their use if you so request.

### **WHAT ARE THE COSTS?**

There is no cost to you or your child for being part of the study.

### **WILL MY CHILD BE PAID FOR PARTICIPATING IN THE STUDY?**

Your child will be paid \$10 for each interview. (If a child takes part in 3 interviews, a total of \$30 will be paid.) This money is compensation for your and your child's time.

### **WHAT IF I AM INJURED?**

It is not the policy of the University of Missouri to compensate human subjects in the event the research results in injury. The University of Missouri, in fulfilling its public responsibility, has provided medical, professional and general liability insurance coverage for any injury in the event such injury is caused by the negligence of the University of Missouri, its faculty and staff. The University of Missouri also will provide, within the limitations of the laws of the State of Missouri, facilities and medical attention to subjects who suffer injuries while participating in the research projects of the University of Missouri. In the event you have suffered injury as the result of participation in this research program, you are to contact the Risk Management Officer, telephone number (573) 882-1181, at the Health Sciences Center, who can review the matter and provide further information. This statement is not to be construed as an admission of liability.

### **WHAT ARE MY RIGHTS AS A PARTICIPANT?**

**Participation in this study is voluntary. You do not have to give permission for your child to agree to participate in this study. Your child's present or future care will not be affected should you choose not to participate.** If you and your child decide that your child will participate, you or your child can change your mind and drop out of the study at any time without affecting your present or future care at school or at any health care facility. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. In addition, the Mr. Francisco may decide to end your participation in this study at any time after he has explained the reasons for doing so.

You will be informed of any significant new findings discovered during the course of this study that might influence your health, welfare, or willingness to continue participation in this study.

### **WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?**

If you have any questions regarding your rights as a participant in this research and/or concerns about the study, or if you feel under any pressure to enroll or to continue to participate in this study, you may contact the University of Missouri Health Sciences Institutional Review Board (which is a group of people who review the research studies to protect participants' rights) at (573) 882-3181.

You may ask more questions about the study at any time. Please feel free to ask Mr. Ben Francisco or Dr. Eileen Porter if you have additional questions about this study or your participation in the study. You may contact Mr. Francisco at (573) 884-8629 or Dr. Porter at (573) 884-7261.

A copy of this consent form will be given to you to keep.

**Signature**

I confirm that the purpose of the research, the study procedures, the possible risks and discomforts as well as potential benefits that I may experience have been explained to me. Alternatives to my participation in the study also have been discussed. I have read this consent form and my questions have been answered. My signature below indicates my willingness to participate in this study.

\_\_\_\_\_  
Subject/Patient\* \_\_\_\_\_ Date

\_\_\_\_\_  
Legal Guardian/Advocate/Witness (if required)\*\* \_\_\_\_\_ Date

\_\_\_\_\_  
Additional Signature (if required) (identify relationship to subject)\*\*\* \_\_\_\_\_ Date

\*A minor’s signature on this line indicates his/her assent to participate in this study. A minor’s signature is not required if he/she is under 7 years old. Use the “Legal Guardian/Advocate/Witness” line for the parent’s signature, and you may use the "Additional Signature" line for the second parent’s signature, if required.

\*\*The presence and signature of an impartial witness is required during the entire informed consent discussion if the patient or patient’s legally authorized representative is unable to read.

\*\*\*The "Additional Signature" line may be used for the second parent’s signature, if required. This line may also be used for any other signature which is required as per federal, state, local, sponsor and/or any other entity requirements.

“If required” means that the signature line is signed only if it is required as per federal, state, local, sponsor and/or any other entity requirements.

**SIGNATURE OF STUDY REPRESENTATIVE**

I have explained the purpose of the research, the study procedures, identifying those that are investigational, the possible risks and discomforts as well as potential benefits and have answered questions regarding the study to the best of my ability.

\_\_\_\_\_  
Study Representative\*\*\*\* \_\_\_\_\_ Date

\*\*\*\*Study Representative is a person authorized to obtain consent. Per the policies of the University of Missouri Health Care, for any 'significant risk/treatment' study, the Study Representative must be a physician who is either the Principal or Co-Investigator. If the study is deemed either 'significant risk/non-treatment' or 'minimal risk,' the Study Representative may be a non-physician study investigator.

## APPENDIX G

### INTERVIEW GUIDE

#### The Experience of Rural Children Whose Daily Lives are Limited by Asthma

- 1) Tell me what it is like for you having asthma.
  - a. Has asthma made your life different? Tell me about this.
  - b. Do you know when your asthma is getting worse? Tell me more about this?
    - i. What makes asthma worse for you?
    - ii. Are there places where you have more asthma trouble? Tell me more about these places?
    - iii. Are there places where you have less asthma trouble? Tell me more about these places?
    - iv. Has your asthma ever been real bad? Tell me how you felt when this happened?
  - c. What helps you have less trouble with asthma?
  - d. Who helps you with asthma? What do they do?
  - e. Who else helps you with asthma? What do they do?
  - f. Has anyone else helped you with asthma? What did they do?
    - i. Who do you talk to when your asthma is getting worse?
    - ii. Whose job is it to make sure you take asthma medicines?
    - iii. Who makes sure you have the medicines and things you need because of asthma?
  - g. How do you learn about asthma? Tell me more about this.

- h. Are there bad things about having asthma? What is that like for you?
  - i. Are there good things about having asthma? What is that like for you?
  - j. Does having asthma change the way other people treat you? What is that like for you?
  - k. What things do you need because of asthma?
    - i. What medicines do you have for asthma?
    - ii. Tell me what these medicines do.
    - iii. How do you feel about your medicines?
    - iv. What would you change about your medicines?
    - v. How well do your medicines work?
    - vi. Which medicines are most important to you? Tell me more about this? (for each medicine named by the child)
    - vii. Have you ever you run out of medicines? Tell me what happened.
    - viii. How often do you take your medicines? Why do you take this medicine? (for each medicine named by the child)
    - ix. What are reasons why you sometimes don't take your medicines?
    - x. What things help you with asthma? Please, explain how this helps you? (for each item named by the child)
- 2) What do you think causes asthma?
- a. Why do you think you have asthma?
  - b. When did you first know you had asthma? How did asthma begin for you?
  - c. Has asthma changed for you? Tell me more about this.
- 3) What do you do for yourself because you have asthma? What is it like for you?

- 4) What do other people do to help you with asthma? What is it like to have them help you?
- 5) Is anything different at home because you have asthma? Tell me more about this.
  - a. Are there things at home that make your asthma better? Tell me about this.
  - b. Are there things at home that make your asthma worse? Tell me about this.
  - c. What do you differently at home because of asthma?
  - d. Who helps you with asthma at home?
  - e. What would you change at home so your asthma would be better?
- 6) Is anything different at school because you have asthma? Tell me about this.
  - a. Are there things at school that make your asthma better? Tell me about this.
  - b. Are there things at school that make your asthma worse? Tell me about this.
  - c. What do you differently at school because of asthma?
  - d. Who helps you with asthma at school?
  - e. What would you change at school so your asthma would be better?
  - f. What problems does asthma cause at school?
  - g. Do your friends treat you differently at school because of asthma? Tell me about this.
- 7) Where do you and your family go to get help with your asthma?
  - a. Tell me about the people there.
  - b. What do they do?

- c. What do you wish they would do?
  - d. What are the best things about going there?
  - e. What are the worse things about going there?
  - f. Tell me about the main reasons you go there?
  - g. How do you know when they are doing a good job?
- 8) Are there other places where your life has been different because of asthma?
- What was that like for you?
- a. Have there been times when you felt good about asthma? Tell me more about this?
  - b. Have there been times when you felt bad about asthma? What was that like for you?
  - c. Have other people helped you with asthma?
  - d. Has asthma changed what you do in your free time?
  - e. Are there other places that change your asthma? Tell me about this.
- 9) How do you think asthma will be different for you in the future?
- a. When you are older how do you think asthma will make your life different? Tell me about this.
  - b. What would it be like if you did not have asthma?
  - c. If you had 3 wishes about your asthma what would these be?
- 10) What do you want to change about having asthma?
- 11) Tell me what it would be like if asthma did not bother you.
- 12) What are you thinking about doing to change the way asthma affects you?

## APPENDIX H

### TAXONOMY OF FINDINGS

#### The Experience of Disabling Asthma Among Rural Children 7-12

1. Discovering that asthma changes what I can do
  - 1.1. Being unable to run and play like other kids
    - 1.1.1. Having trouble keeping up in physical education
    - 1.1.2. Giving up on active sports
    - 1.1.3. Having breathing trouble riding my bike
    - 1.1.4. Having breathing trouble in the pool
  - 1.2. Being unable to go outdoors at certain times
  - 1.3. Being unable to enjoy pets and animals
  - 1.4. Missing school
    - 1.4.1. Missing out on fun things
    - 1.4.2. When I can't sleep I don't go to school
    - 1.4.3. What I do when I stay home from school
    - 1.4.4. Making up the work
  - 1.5. Getting sicker and staying ill longer than others
  - 1.6. Finding it hard to sleep
    - 1.6.1. I wake up my mom or dad
    - 1.6.2. I try to fall asleep again
      - 1.6.2.1. Being unable to breathe well after a treatment
      - 1.6.2.2. Being unable to fall asleep when my breathing is OK
      - 1.6.2.3. Moving from place to place trying to fall asleep
  - 1.7. Missing out on playtime with friends
  - 1.8. Spending time taking all my medications
  - 1.9. **making the best of things**
    - 1.9.1. **accepting my limitations**
    - 1.9.2. **hoping things can be normal for me**
2. Becoming the one who knows my asthma
  - 2.1. Knowing the trouble asthma causes me
    - 2.1.1. Coughing more
    - 2.1.2. Breathing hard
    - 2.1.3. Wheezing
    - 2.1.4. Having trouble talking
    - 2.1.5. Having a sore throat
    - 2.1.6. Waking up because it's hard to breathe
    - 2.1.7. Being unable to walk
    - 2.1.8. Having trouble eating
    - 2.1.9. Feeling my chest hurting
    - 2.1.10. Feeling tired
    - 2.1.11. Feeling stuff going down there
    - 2.1.12. Having good days when asthma is not so active
    - 2.1.13. **Noticing when my asthma is getting worse**

- 2.1.13.1. **Seeing what makes my asthma worse**
- 2.1.13.2. Not knowing it's going to happen
- 2.1.13.3. Not remembering what happened last time
- 2.2. Knowing what makes my asthma worse
  - 2.2.1. Running, working, or playing hard
  - 2.2.2. Breathing certain kinds of air can make asthma worse
    - 2.2.2.1. Knowing weather or temperature change causes trouble
    - 2.2.2.2. Learning that strong odors can make my asthma worse
    - 2.2.2.3. Finding that chemicals and other things make my asthma worse
    - 2.2.2.4. Knowing that being in smoke makes my asthma worse
  - 2.2.3. Seeing that my allergies and my breathing are connected
  - 2.2.4. Catching a cold or getting sick
  - 2.2.5. Having problems with my stomach
  - 2.2.6. Having problems with my nose
  - 2.2.7. Having croup with my asthma
  - 2.2.8. Coughing and vomiting
  - 2.2.9. Lying on the carpet
  - 2.2.10. Talking too much
  - 2.2.11. Having a fever or flu
  - 2.2.12. My asthma is worse at night
  - 2.2.13. Not knowing what started the trouble
- 2.3. Watching for what makes my asthma worse
- 2.4. Wanting asthma to go away
  - 2.4.1. Forgetting about it
  - 2.4.2. Hoping I will outgrow it
  - 2.4.3. Believing it will get better
  - 2.4.4. Fearing my asthma might get worse
- 2.5. Knowing some things make my asthma better
  - 2.5.1. Finding what helps me breathe better
  - 2.5.2. **Making my breathing better**
    - 2.5.2.1. **Helping my breathing**
      - 2.5.2.2. Knowing some kinds of air make breathing easier
        - 2.5.2.2.1. **Getting fresh air**
          - 2.5.2.2.1.1. **Opening the bathroom door**
          - 2.5.2.2.1.2. **Holding my breath when a steamy bathroom**
        - 2.5.2.2.2. **Protecting myself from breathing cold air**
          - 2.5.2.2.2.1. **Breathing through a scarf**
          - 2.5.2.2.2.2. **Trading chores so I won't have to go outdoors**
        - 2.5.2.2.3. **Finding a place to play out of the wind**
        - 2.5.2.2.4. Wanting to be in air conditioned places
        - 2.5.2.2.5. **Spending time in air-conditioned places**
        - 2.5.2.2.6. Wishing for good weather
          - 2.5.2.2.6.1. **Staying indoors when its too hot or too cold**
      - 2.5.2.3. Staying well helps my asthma
        - 2.5.2.3.1. **Washing my hands**
        - 2.5.2.3.2. **Getting shots for the cat**

- 2.5.2.4. Believing certain foods are good for asthma
  - 2.5.2.4.1. Eating fruits and vegetables helps asthma
  - 2.5.2.4.2. **Eating soup** helps asthma
  - 2.5.2.4.3. Not eating junk food helps asthma
  - 2.5.2.4.4. Eating and drinking anything helps asthma
- 2.5.2.5. Finding breathing is easier with quite activities
  - 2.5.2.5.1. **Choosing physical activities that allow time to rest**
    - 2.5.2.5.1.1. **Choosing activities with less running**
    - 2.5.2.5.1.2. **Sitting down for a minute to catch my breath**
- 2.5.3. Finding ways to stop my breathing trouble
- 2.5.4. Stopping my breathing trouble**
  - 2.5.4.1. Waiting for asthma to go away**
  - 2.5.4.2. Knowing that medicines can help
  - 2.5.4.3. Using my medications**
    - 2.5.4.3.1. Knowing my routine
      - 2.5.4.3.1.1. Knowing how you are supposed to take it
        - 2.5.4.3.1.1.1. **Breathing my medicine in a special way**
        - 2.5.4.3.1.1.2. **Taking a regular breath**
        - 2.5.4.3.1.1.3. **Choosing to take it in the wrong way**
        - 2.5.4.3.1.1.4. Taking this medicine every day
          - 2.5.4.3.1.1.4.1. Forgetting to take my medicine
          - 2.5.4.3.1.1.4.2. Choosing to take it only at certain times
          - 2.5.4.3.1.1.4.3. Running out of medicine
          - 2.5.4.3.1.1.4.4. Knowing when you really have to take it
        - 2.5.4.3.1.1.5. **Brushing my teeth after my medicine**
      - 2.5.4.3.1.2. **Getting the nebulizer ready**
      - 2.5.4.3.1.3. Knowing when and why I take it
      - 2.5.4.3.1.4. Not knowing what I took
      - 2.5.4.3.1.5. Remembering to take them
        - 2.5.4.3.1.5.1. Being reminded by others
          - 2.5.4.3.1.5.1.1. My friend reminds me
          - 2.5.4.3.1.5.1.2. My mom (or dad) reminds me
        - 2.5.4.3.1.5.2. Forgetting for a week and still feeling good
    - 2.5.4.3.2. **Deciding to take a treatment**
      - 2.5.4.3.2.1. **Getting to my medicines**
        - 2.5.4.3.2.1.1. **Depending on someone else to get my medicine**
        - 2.5.4.3.2.1.2. Knowing where my medicine is supposed to be
        - 2.5.4.3.2.1.3. **Finding my medicine**
          - 2.5.4.3.2.1.3.1. **Carrying my medicines with me**
          - 2.5.4.3.2.1.3.2. Not being able to find my medicine
      - 2.5.4.3.2.2. **Choosing how to take my quick reliever**
        - 2.5.4.3.2.2.1. **Taking my quick reliever by puffer**
        - 2.5.4.3.2.2.2. **Taking my quick reliever by nebulizer**
      - 2.5.4.3.2.3. **Judging if the treatment is helping**
        - 2.5.4.3.2.3.1. **Waiting to see if the medicine will help**
        - 2.5.4.3.2.3.2. Feeling that the medicine is helping

- 2.5.4.3.2.3.3. Finding the medicine did not help
    - 2.5.4.3.2.3.3.1. Calling mom and going home**
    - 2.5.4.3.2.3.3.2. Going to the doctor
    - 2.5.4.3.2.3.4. Being a little better but not normal
    - 2.5.4.3.2.3.5. Going back for another treatment**
  - 2.5.4.3.2.4. Having problems after taking my albuterol
    - 2.5.4.3.2.4.1. Being unable to stand still
    - 2.5.4.3.2.4.2. Shaking uncontrollably
      - 2.5.4.3.2.4.2.1. Having trouble writing
      - 2.5.4.3.2.4.2.2. Having trouble drinking at the fountain
  - 2.5.4.3.3. Knowing about my medicines
    - 2.5.4.3.3.1. Knowing the cost is high
    - 2.5.4.3.3.2. Knowing what the medicine does
  - 2.5.4.4. Choosing quieter activities**
    - 2.5.4.4.1. Slowing down the pace**
      - 2.5.4.4.1.1. Cooling down**
      - 2.5.4.4.1.2. Going at a nice steady pace**
      - 2.5.4.4.1.3. Taking a break from the activity**
      - 2.5.4.4.1.4. Lining up early so I can running**
    - 2.5.4.4.2. Taking a nap**
    - 2.5.4.4.3. Lying down**
    - 2.5.4.4.4. Avoiding noise and people who bother me**
  - 2.5.4.5. Drinking or eating**
    - 2.5.4.5.1. Drinking water**
    - 2.5.4.5.2. Eating chicken soup**
  - 2.5.4.6. Getting fresh air**
  - 2.5.4.7. Forgetting about my asthma**
  - 2.5.4.8. Seeking comfort**
- 2.5.5. Wondering why I am having trouble**
- 2.6. Remembering things about my asthma
    - 2.6.1. Remembering when it first began
    - 2.6.2. Being unable to remember how asthma began
    - 2.6.3. Being unable to remember the last trouble I had
  - 2.7. Wanting my asthma to go away
    - 2.7.1. Fearing my asthma might get worse
    - 2.7.2. Hoping my asthma will get better
    - 2.7.3. Believing I will outgrow my asthma
    - 2.7.4. Wanting to forget about my asthma
3. Knowing how other people respond to my asthma
- 3.1. My asthma causes worry and concern
    - 3.1.1. Knowing people worry about you
    - 3.1.2. Knowing they are afraid of catching my asthma
  - 3.2. Knowing I sometimes get special treatment
    - 3.2.1. Knowing other kids are sometimes jealous
    - 3.2.2. Knowing they look up to me because I know about asthma
  - 3.3. Knowing some people don't treat me like a normal person

- 3.3.1. Asking to be treated like a normal person**
- 3.4. Knowing others help me with asthma
  - 3.4.1. Realizing some people know more about asthma
  - 3.4.2. Getting someone to help me**
    - 3.4.2.1. Deciding to go to the school nurse**
      - 3.4.2.1.1. Waiting to see what happens**
      - 3.4.2.1.2. Getting the coach to let me go to the nurse**
      - 3.4.2.1.3. Walking to the nurse
      - 3.4.2.1.4. Finding my class after my treatment
      - 3.4.2.1.5. Getting help when the nurse is not there**
      - 3.4.2.1.6. Deciding not to go to the nurse**
    - 3.4.2.2. Telling my teacher or coach**
  - 3.4.3. Going to see the doctor
    - 3.4.3.1. Getting a check up
    - 3.4.3.2. Seeking help when I'm sick
  - 3.4.4. Showing others my asthma**
    - 3.4.4.1. Not being asked
    - 3.4.4.2. Knowing they don't believe me
      - 3.4.4.2.1. Telling my parent when they won't listen**
      - 3.4.4.2.2. Telling them I am mad when they won't believe me**
    - 3.4.4.3. Answering their questions**
      - 3.4.4.3.1. Finding it hard to answer some questions
      - 3.4.4.3.2. Being unable to remember how it was
    - 3.4.4.4. Bringing a note from home**
    - 3.4.4.5. Knowing doctors and nurses could help them know
    - 3.4.4.6. Waking up my mom or dad**
    - 3.4.4.7. Moving to the couch closer to my parent's bedroom**
    - 3.4.4.8. Telling my parents**
    - 3.4.4.9. Deciding not to tell them**
      - 3.4.4.9.1. Not wanting to miss recess
      - 3.4.4.9.2. Hiding my asthma**
      - 3.4.4.9.3. Deciding not to tell them I have asthma**
    - 3.4.4.10. Sometimes they see my trouble first
      - 3.4.4.10.1. Having my mom as my asthma sidekick
      - 3.4.4.10.2. Knowing my grandmother sees my breathing trouble
      - 3.4.4.10.3. Having my friends tell me I'm not breathing well
    - 3.4.4.11. Using a smiley face scale to tell them about my trouble breathing**
  - 3.4.5. Knowing my family helps me
    - 3.4.5.1. Knowing they help me with my asthma medicine
      - 3.4.5.1.1. Asking family members to bring me my medicine**
      - 3.4.5.1.2. Expecting my family to remind me to take my medicine**
      - 3.4.5.1.3. Depending on my family to give me medicine**
    - 3.4.5.2. Knowing mom or dad will get me to the doctor
    - 3.4.5.3. Counting on them to remember things about my asthma**
- 3.4.6. Knowing some people stick up for me

- 4. Coming to know more about my asthma
  - 4.1. Not knowing about asthma
    - 4.1.1. Not knowing how I'll learn about asthma when I'm older
    - 4.1.2. Wondering what causes asthma
      - 4.1.2.1. Believing you are just born with asthma
      - 4.1.2.2. Believing some medicines cause asthma
      - 4.1.2.3. Believing that running and playing cause asthma
      - 4.1.2.4. Believing problems with my throat cause asthma
      - 4.1.2.5. Believing dogs, and cats, and fur cause asthma
  - 4.2. Learning about asthma**
    - 4.2.1. Finding out more about asthma**
      - 4.2.1.1. Discovering what I need to know**
      - 4.2.1.2. Thinking about how I want to learn**
    - 4.2.2. Knowing how I want to learn about asthma
    - 4.2.3. Knowing why I want to learn about asthma
    - 4.2.4. Knowing what I want to learn about asthma
    - 4.2.5. Knowing where I want to learn about asthma
  - 4.3. Seeing that others have asthma**
    - 4.3.1. Seeing others having breathing trouble**
    - 4.3.2. Grading their asthma**
    - 4.3.3. Watching them use asthma medications**
    - 4.3.4. Knowing some kids hide their use of asthma medicines
    - 4.3.5. Having asthma together**
  - 4.4. Thinking about having asthma the rest of my life**
    - 4.4.1. Worrying that asthma might get worse**
    - 4.4.2. Thinking it will go away**

## APPENDIX I

### Reference List

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## VITA

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