Social and Emotional Support at School: A Qualitative Exploration of the Perspectives of Children Living with Asthma

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ABSTRACT
Stephanie R. McConville: Social and Emotional Support at School: A Qualitative Exploration of the Perspectives of Children Living with Asthma (Under the direction of Rune J. Simeonsson)

This study explored the perceptions of children living with asthma regarding their school experiences, focusing on the social and emotional impact, management of asthma at school, and sources of support at school. This qualitative exploration of children’s perceptions included a sample of 19 children (8-12 years old) with asthma and their mothers. Data were collected through semi-structured interviews with the children, child drawings based on the Child Drawing: Hospital task (Clatworthy, et al., 1999), and a parent questionnaire to obtain demographic, asthma, and school data. Transcribed interviews were analyzed using thematic analysis, and drawing and parent questionnaire data supplemented the interview findings. The themes from the interviews were presented across five categories: 1) Living with Asthma [There’s Nothing Good, It Could Be Worse, “When I have asthma...”] 2) Having Asthma at School [It Gets in the Way, “I Can’t...”] 3) Social Impact [Peer Support, “People treat me the same,” Negative Consequences] 4) Emotional Impact [Worries, Vigilance, Coping Strategies], and 5) Sources of Support [Gatekeepers, Helpful Adults, Comparing Child and Parent Sources of School-based Support, Shift Toward Self-Reliance]. Across the themes, child participants described unique experiences and conceptualizations of their asthma and its management. All children expressed some asthma-related limitations at school, mostly during physical activity, and all had engaged in asthma management at school, most with medication in addition to other strategies. Children
downplayed their asthma and expressed wanting to be seen as normal compared to their peers. Many children also endorsed feeling supported by their peers. Adult support in school was mostly surrounding access to medication, to which few children had immediate access. Children with asthma viewed teachers more favorably when the teacher was reliable, understanding, and knowledgeable of asthma. Parents and children differed in their communication with teachers, and parents seemed to be responsible for establishing a relationship with the school nurse. For future practice, schools should assess their asthma medication practices and promote teacher knowledge and understanding of asthma symptoms and management. Building parent-teacher communication and relationships can also improve teacher support of their students with asthma.
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CHAPTER 1: INTRODUCTION

Children with chronic illnesses represent a population with growing needs in communities across the United States. The World Health Organization describes chronic diseases, or noncommunicable diseases, as conditions that are not transmitted between people, are often slow to progress, and are long in duration (World Health Organization, 2014). A more descriptive definition by the Chronic Illness Alliance (2015) explains chronic illness as

"...an illness that is permanent or lasts a long time. It may get slowly worse over time. It may lead to death, or it may finally go away. It may cause permanent changes to the body. It will certainly affect the person's quality of life (retrieved December 29, 2015)."

Though chronic conditions such as asthma, diabetes, sickle cell disease, cancer, kidney disease, and chronic heart problems may vary in nature of impact, severity, and duration, they are similar in that they negatively affect quality of life. Improvements in modern medicine have led to an increase in survival rates among individuals diagnosed with chronic conditions, such that, in the US, nearly half of all adults are living with a chronic disease (Ward, Schiller, & Goodman, 2012). By 2006, it was suggested that over 25% of children in the US were affected by a chronic illness (Van Cleave, Gortmaker, & Perrin, 2010).

For children, the impact of a chronic illness could relate to pain, social interactions, limited involvement in typical activities like school and sports, and in some cases impairment in cognitive abilities and/or academics. Given these findings, it seems that at least a quarter of children in the US are living with a chronic illness and are likely experiencing the negative
impact of their illness and/or its treatments. Even with increasingly optimistic outcomes through modern medicine, many of these children are feeling the impact of their disease in their physical, psychological, and academic functioning, with the risk for potential decline.

Among significant chronic conditions, asthma is the most common childhood chronic illnesses worldwide, and one of the most common chronic conditions affecting children in the US, after tooth decay and obesity (WHO, 2014; Centers for Disease Control, 2013). A CDC survey in 2014 determined 8.6% of American children under 18 years of age were living with asthma (Bloom, Jones, & Freeman, 2015). According to the National Asthma Education and Prevention Program’s (NAEPP) *Guidelines for the Diagnosis and Management of Asthma* (2011),

“asthma is a chronic inflammatory disorder of the airways…this inflammation causes recurrent episodes of coughing (particularly at night or early in the morning), wheezing, breathlessness, and chest tightness.” (p 9).

Common symptoms of asthma include wheezing, coughing, labored breathing, and chest tightness, with symptoms often worsening at night, during exercise, and/or with the addition of environmental factors including stress. Although genetic and environmental factors have been identified as potential causes of asthma, the etiology of asthma is uncertain and appears to vary between individuals. There is no cure for asthma and treatments are individualized to reduce symptoms (NAEPP, 2011; Ratcliffe & Kieckhefer, 2011). Environmental risks, or “triggers” that can induce or exacerbate asthma symptoms include poor air quality, allergens, infections, weather changes, and even psychosocial triggers such as anxiety or family stress (Global Initiative for Asthma, 2015).

The direct impact of asthma ranges from intermittent to persistent and mild to intense depending on the child’s level of severity and control over symptom management. There are
a number of risks across the illness spectrum, regardless of severity. The sudden and severe onset of asthma-related breathing problems is demonstrated in that asthma is a leading cause of emergency room visits for children (Wier, Yu, Owens, & Washington, 2013). Further, asthma is the 6th most common cause of limited activity among children in the US, following more expected causes of limitation such as intellectual disability, ADHD, learning disability, and other psychological and behavioral problems (CDC, 2007). This is not surprising given that physical activity and indoor and outdoor allergens are common triggers of asthma that children might encounter often or attempt to avoid. There is also evidence to suggest that children with asthma are more likely to be absent from school than healthy peers, which has potential negative ramifications for a child’s schooling and general sense of wellbeing (Mizan, Shendell, & Rhoads, 2011; Pontes, Pontes, & Bonilla-Santiago, 2014).

Chronic illnesses can be associated with social stigma, cause stress and anxiety, and treatments can interfere with cognitive functioning and other aspects of development (Taylor, Gibson, & Franck, 2008; Venning, Eliott, Wilson, & Kettler, 2008; Lightfoot, Wright, & Sloper, 1998). There are a number of needs related specifically to children living with asthma. For example, evidence shows children with asthma are more likely to experience anxiety and feel socially isolated (Trollvik, Nordbach, Silen, & Ringsberg, 2011; Feldman, et al., 2013). Asthma may also have a negative impact on academic performance (Kohen, 2010).

A growing prevalence of children living with chronic illnesses, including asthma, means there are more children experiencing chronic illnesses in American schools. The needs of this population are rising, as are the challenges in serving them effectively within the schools, and it is unclear how prepared teachers and other school personnel are to meet the
needs of these students (Barraclough & Machek, 2010; Kaffenberger, 2006; Worchel-Prevatt et al., 1998). It is expected that understanding how children experience asthma and access management and support within their school setting can inform how teachers and school staff approach meeting the needs of their students with asthma, though few studies have explored child perspectives of having asthma at school.
CHAPTER 2: LITERATURE REVIEW

Asthma

The focus of the present study is on the experiences and needs of children with the respiratory condition, asthma. Asthma is a chronic respiratory illness caused by inflammation of the airways characterized by a number of symptoms that impact breathing. Asthma is typically diagnosed by a physician, who reviews patterns of symptoms including coughing, wheezing, shortness of breath, and chest tightness. The physician looks for variability in symptoms, worsening at night or in the morning, and clear triggers of symptoms. They usually confirm a patient’s diagnosis through airflow assessments using peak expiratory flow (PEF) or more accurately using spirometry, which measures the amount of air one can exhale in a forced breath over time (Global Initiative for Asthma, 2015; Wikipedia). Once diagnosed, asthma severity can be classified as intermittent or persistent with mild, moderate, or severe presentation, based on symptom frequency, spirometry results, impact on normal activities, and level of medical intervention required (National Heart, Lung, and Blood Institute, 2012; GINA, 2015). Follow-up care is designed to help assess level of symptom control characterized as well controlled, not well controlled, or poorly controlled, and to aid patients in improving their asthma control (NHLBI, 2012). Most cases of asthma are sporadic and manageable, but the NAEPP has made it clear that severe and life-threatening exacerbations of asthma can occur at any of these severity levels and should always be taken seriously (NAEPP, 2011).
The reasoning behind the choice to explore the impact of asthma for the present study was threefold. First, asthma is the most common chronic illness, affecting over 6 million children in the United States (Bloom, et al., 2015). Asthma is considered heterogeneous in that there are multiple causes and it can affect a wide range of individuals, yet the impact of environmental triggers of asthma has led to a disparity in certain groups of people who are at higher risk of developing the illness (Ratcliffe & Kieckhefer, 2011). In particular, asthma has been found to occur at higher rates among low-income, ethnic minority, and urban populations, with research citing both genetic and environmental factors as likely contributors (McQuaid & Abramson, 2009). More specifically, asthma is most commonly found among school-aged children, as it occurs in 10.3% of children ages 5 – 14. Overall, boys are more likely to have asthma at a rate of 10.1%, compared to girls at 7.0%, though this reverses in adulthood. There are also noticeable ethnic/cultural discrepancies in rates of asthma, such that 13.4 % of Black children and 23.5% of Puerto Rican children have asthma diagnoses, compared to 7.6% of White, Non-Hispanic children. Further, asthma is more likely to affect children living below the poverty line, with a rate of 10.5% (Bloom, et al., 2015). Poor air quality, over-crowded living situations, pests, and other allergens such as mold or dust often characterize urban environments, particularly in low-income areas. African American children in particular are at greatest risk for insufficient outpatient care and a disproportionate rate of asthma-related emergency department visits, hospitalizations, and mortality (NAEPP, 2011; Laster, Holsey, Shendell, McCarty, & Celano, 2009).

Second, asthma is known to have a significant impact on the daily activities (i.e. play, self-care, learning) of children, causing limitations for over 5% of children (CDC, 2007). Considering the relevant daily activities of children, attending school is universal. During a
typical school week, children spend up to a third of their day at school, making it a crucial context for development (Bruzzese, Unikel, Evans, Bornstein, Surrence, & Mellins, 2010; Miller & Wood, 1991). School is about more than academics; it is a prime setting for all types of learning, including social, emotional, and behavioral, in addition to acquisition of reading, writing, and mathematics skills. The school setting creates opportunities to form and navigate social relationships, navigate demands and possible stressors, and adapt to behavioral expectations from adults and peers. As asthma is most common in the school-age population, particularly elementary-aged children, with about 1 in 10 children having asthma (Bloom, et al., 2015), it is the most commonly found illness in schools. As such, management of asthma at school is substantial and it is therefore important to understand the needs and challenges faced by a large number of children at school as they navigate typical development with the added challenge of a health issue.

Third, though there is a growing literature base addressing the needs of children with asthma in school (Kohen, 2010; Mizan, et al., 2011; Pontes, et al., 2014), few studies have been found to focus on the perceptions of children regarding their illness experiences at school (Gabe, Bury, & Ramsay, 2002; Walker & Reznik, 2014). Children with asthma have been identified as a population with unique needs, but it appears they have not been given a voice to share their experiences regarding the important context of school. It is becoming clearer that asthma has an impact on children, but the mechanisms behind this impact are unclear. It is also imperative to examine the impact of asthma in a practical sense both within and across the contexts regularly encountered by children with asthma. To this end, a review is made of the existing literature on the theoretical models of child development and chronic illness, the development of children with asthma, specific areas of risk and need for children
with asthma in the schools, and the potential challenges and barriers to successful outcomes for children with asthma.

**Theoretical Framework**

The present literature review references a wide base of research, from psychological, sociological, and public health, to medical perspectives, in an attempt to fully define the range of approaches that have been employed to explore the experiences of children with asthma and other chronic illnesses. Children, at any given point, have a history of maturation and experiences that have impacted their development. As with any complex field, to understand outcomes it is essential to have an awareness of the process by which those outcomes come to be. In order to adjust outcomes, the process must be changed. In this instance, there are a number of outcomes to be examined, but the process of child development and the impact of asthma on that process must first be understood. The ultimate goal is to use research to strengthen interventions and sources of support throughout child development in an attempt to improve outcomes for children with asthma.

The primary theoretical focus of this study draws from theories of child development from a psychological perspective. This body of literature concentrates on social and emotional experiences of children and members of their families, often through questionnaires and parent or other adult reports, though with growing emphasis placed on child viewpoints. The present study adopted a qualitative approach to examine child perspectives, though there is a gap in the literature supporting the use of such an approach. Much of the relevant literature on children’s experiences of chronic illness is found in nursing and sociology research. In exploration of children’s lived experiences, a theoretical
framework from a sociological perspective was discovered as being highly relevant to the present study. This approach is based on the field of biographical research, which seeks to define all or part of a person’s life, examining the individual’s construction of their own life history, which includes experiences and social relationships (Miller, 2003).

The current review seeks to discuss both fields of research and their relevance to the topic of interest – children’s experiences with asthma. The following section is aimed first at discussing the history and establishing the rationale behind the author’s developmental ecological approach to children’s experiences with asthma in an educational context. Then, other relevant theories from a biographical sociological perspective will be introduced and compared with the primary psychological theories, to best understand how to answer the research questions.

Theories of Child Development

One goal of this literature review is to begin to identify the ways in which theories of child development can help inform the impact asthma may have on a child’s development and broader outcomes. As children grow, they move between environments and must learn to navigate their changing world while they themselves undergo maturational changes of a physical as well as a cognitive nature. A number of contextual factors have been identified as contributing to developmental outcomes, such as culture, family make-up and functioning, and socio-economic status (Miller & Wood, 1991). Each of these factors can exist as sources of risk and/or resilience for children as they grow, depending on a child’s intrinsic characteristics, like personality, and the physical and social environments in which they
develop. These elements reflect the complexities of child development as the basis for considering how a chronic illness may impact a child’s developmental trajectory.

A widely held view of child development is the constructivist perspective associated with Jean Piaget. Piaget viewed development as a maturational or stage process in which children learn about their environment through direct interaction. This theory suggests children develop physical cognitive structures that determine their development in each stage. These structures only take the child so far; the child must interact with their surroundings using trial and error to build upon previous skills and construct their understanding of the world. Development follows a chronological trajectory and children in one stage cannot be expected to gain skills at later stages without first mastering their present stage and undergoing further physical development. For example, infants form representations of their physical world that set the groundwork for later symbolic representations through language and other more sophisticated schema (Piaget & Inhelder, 1969).

This perspective has been supported by research on the development of children with disabilities, such that interruptions in the way a child interacts with their world disrupts their developmental trajectory often in predictable ways (Lewis, 2007). Piaget’s theories are still highly regarded as a framework for viewing the development of the child, though the rigidity of developmental stages has been questioned, with suggestions that development may be a more fluid process with greater emphasis on experience (Eiser, 1989). Eiser concluded that children of different ages were able to create understandings of their health that seemed to contradict the limitations of their proposed “stage” of development (Eiser, 1989). Further,
health issues are unlike from other forms of disability, in that they are less predictable and, particularly regarding asthma, more likely to be affected by the environment.

Though Piaget addressed the relevance of interactions between child and environment, his theory seems limited in terms of the complexities of context, particularly given the importance of environment when considering an illness such as asthma and the impact it can have on a child’s life. An important starting place for discussing contextual development lies within systems theory. General System Theory (GST), as introduced by Ludwig von Bertalanffy (1950), explains that all living systems share common rules. Such systems exist as open systems in constant interaction with their environments. The interactions are bidirectional, such that the organism acts on and reacts to its immediate settings. As the environment changes, the organism adapts in an attempt to maintain a state of homeostasis, which drives behavior (von Bertalanffy, 1950). This open system model challenged laboratory-based experimentation that attempted to isolate variables in a controlled manner through closed systems (stimulus-response), opting for a more naturalistic mode of study. The result was an increased recognition that living things are not isolated, but in constant adjustment and interaction with their surroundings (von Bertalanffy, 1969). General System Theory initiated a new realm of developmental research and set the stage for future researchers to expand on these ideas into current models of human development.

Urie Bronfenbrenner (1979) eloquently merged the tenets of Piaget’s theory of human development with those of GST through his Ecological Model of Human Development. He explained that children follow a biological trajectory, but it is sensitive to the influence of the outside world. Based on his theory, children not only interact with their immediate environments of home and school, but are influenced by greater, indirect contexts like policy
and culture as well. According to Bronfenbrenner, children exist within a series of nested, interconnected contexts that influence their development. This framework is commonly depicted graphically with concentric circles that represent the proximity of each setting to the child, with the individual and their personal characteristics such as age, ethnicity, and health situated at the center of this model (see Figure 1). Each of these environments is a system in itself, in constant motion and seeking balance. As children develop, they act upon, react to, and create concepts of their environments that change as they grow and mature, and further influence their interactions with the world (Bronfenbrenner, 1979). Bronfenbrenner described ecological transitions as important components of development characterized by changes in a child’s immediate environment like starting school or moving. Alterations in an environment change a child’s roles, requiring them to redefine their concepts of self within each context (Bronfenbrenner, 1979).

This ecological model is clearly quite complex, and has been upheld and often cited as a useful model for understanding child development, including in the context of illness (Duis, Summers, & Summers, 1997; Christian & D’Auria, 1997; Rimm-Kauffman & Pianta, 2000). Later versions of Bronfenbrenner’s ecological model of development added the component of time to the already complex system of child development, which he called the ‘chronosystem.’ This context was established as the outermost ring of his model symbolizing how the many complex interactions within the system are affected by the passage of time (Bronfenbrenner, 1986).
Despite his emphasis on the nurture side of the age-old debate of nature versus nurture, Bronfenbrenner never fully lost sight of the importance of biology. He argued that biological characteristics were crucial to development, but would only take the individual so far, and were dependent upon the developmental context. Ultimately, Bronfenbrenner relabeled his theory a “Bioecological Model,” and he worked on demonstrating the effects of the complicated relationship between heredity and environment on a genetic level (Bronfenbrenner & Ceci, 1994). This theory argues that environment determines the potential to which heritable traits can be expressed and further developed, making an even stronger case for the interdependence between biology and context.
The theories reviewed above each contribute to the perspective of the present study on the role of both intrinsic and environmental factors on the development of the child with asthma. It is believed that children, with their set of unique inherent characteristics and common physical structures, grow and learn through interactions with their environment. While the environment shapes the child, the child acts upon the environment, as an open system. This relationship is more than bi-directional; it is multi-directional, as characteristics within the child interact (e.g. health, personality) and nested levels of developmental context also interact (e.g. school, home, government), all existing with the passing of time. This can best be imagined as Bronfenbrenner’s concentric circles with arrows connecting each and every level, from genetic to societal and global factors (Bronfenbrenner, 1979).

Chronic Illness Frameworks

In the context of the child with asthma, the child and their environments evolve as they interact with and change in response to one another throughout development. The child must adapt to new environmental demands, which often include making adjustments in social, emotional, and behavioral functioning. Assuming Bronfenbrenner’s model, asthma falls into the center of the design, as health is a quality of the child. The presence of a chronic illness such as asthma results in children having illness and treatment related interactions affecting the microsystem of family, school, and community contexts (such as relationships with doctors). Management of asthma across settings characterizes changes to the mesosystem, as families, school, and health care settings must interact to provide optimal care for the child. Children’s experiences within these interactions are likely to shape their conceptualizations of relationships and impact their social and emotional development over
time. A dynamic approach to development allows for the explanation of early risk and adjustment in both short and long term outcomes of student success, which may be applicable to the understanding of how asthma affects development.

In further exploration of literature that supports the focus of this study, it is worthwhile to consider an alternative, yet similar, approach from sociology of illness research. As mentioned previously, a biographical approach appears throughout the sociological literature on chronic illness experiences, with the seminal work of Michael Bury (1982) discussing the utility of such an approach to address the ways people reacted and adapted to an illness diagnosis. Bury introduced the idea of chronic illness as a ‘biographical disruption’ of the established life of an adult with an unexpected diagnosis of rheumatoid arthritis, which marked clear and individualized changes in one’s perception of their health and sense of identity (Bury, 1982). More specifically, individuals were faced with new problems they needed to define in relation to their own lives. Such problems impacted their interactions with peers, employers, medical professionals, and may have led to changes in their activities. It also seems Bury’s theory was designed to further explain the link between a diagnosis and observed outcomes, such as social withdrawal. His theory provided both an explanation for various outcomes, as well as a means to further explore the trajectory to additional outcomes.

Other researchers have explored the relevance of the biographical disruption model to understanding the impact of illness on children. Pitchforth and colleagues (2011) were interested in the effects of an allergic condition on children and families. They concluded that diagnosis of a nut allergy acted as a biographical disruption for families, with particular attention paid to parents and their new role as protector despite the risk of social stigma.
(Pitchforth, et al., 2011). In this instance, the greater burden was placed on the parents, as children were otherwise healthy when not exposed to their allergen, meaning the disruption existed more in the experiences of the parent than the child.

There has been some question as to the applicability of Bury’s perspective to children, particularly when an illness was diagnosed at birth or early in life, in which case, the individual’s biography does not experience disruption in the same sense as an adult with a new diagnosis, as the issue has always been part of the child’s life. By studying the experiences of children with cystic fibrosis, Williams and colleagues (2009) shed light on how feelings of normalcy can be affected by a congenital condition (Williams, Corlett, Dowell, Coyle, & Mukhopadhyay, 2009). They concluded that children based their understandings of self and normalcy on their personal experiences, which included living with an illness, and therefore many children did not see the illness as being out of the ordinary. Instead of chronic illness disrupting their sense of identity, it seemed the development of identity into adolescence initiated a disruption, as children’s definitions of self and normalcy began to shift toward more social contexts. Instead of biographical disruption, children experienced biographical continuity that was interrupted by a redefining of self, inclusive of their illness, during typical and expected development (Williams, et al., 2009). The relevance of these theories to children with asthma is unclear, though based on the models it is expected that experiences might differ depending on the timing of the child’s diagnosis in their development.

A number of other studies have emerged adapting Bury’s theory to better fit the experiences of children with chronic illnesses and their families, which may also be more applicable to the development of children with asthma. For example, Bray, Kirk, and Callery
(2014) examined how the biographical disruption and continuity models held up when applied to children with a long-standing condition. This study was different from others in that it was longitudinal in nature and followed children with continence problems, and questioned the children and their parents regarding experiences prior to and following a surgery designed to improve ongoing treatment. The authors’ findings suggested that while some families experienced disruption, through complications and expectations that exceeded outcomes, others demonstrated feelings of continuity, as they remained consistent in their routines. Additionally, there was another group of families that expressed something that did not fit either model. In some instances, children and parents expressed positive changes in their routines and activities following surgery that led to better opportunities and attitudes, suggesting what the authors coined ‘biographical enrichment.’ In all cases, the authors emphasized the importance of expectation. Children with unrealistic expectations were more likely to experience disappointment resulting in biographical disruptions whereas children with lower expectations ended up with more positive outlooks on the future course of their condition and overall lives, experiencing biographical enrichment. Other children and parents still felt that things remained roughly the same following surgery, suggesting a sense of biographical continuity. The role of parent-child relationships was also discussed, such that the biographies of parents could have a significant impact on those of their children.

Consider a parent who managed the child’s care, and felt it got easier following the procedure, leading to a sense of enrichment. Their child, who expected more independence following the procedure, might experience a sense of disruption if the parent continued to take on the majority of managing the child’s condition. A disconnect between parent and
child expectations has the potential to affect each party’s feelings of success, and could even lead the event to impact parent and child biographies in different ways (Bray, et al., 2014).

In a different approach, Monaghan and Gabe interviewed children with asthma, finding that many of the children minimized their symptoms and the impact asthma had on their lives, while also identifying times of stress or the direct or indirect impact of asthma on other aspects of their lives. Based on their findings, they concluded that asthma does not create a broad biographical disruption, but rather, its impact is dependent on contextual factors. In this sense, asthma does not affect every factor of a child’s life, and for many children, asthma symptoms occur sometimes or rarely. The authors argued children with asthma experience a ‘biographical contingency’ such that asthma leads them to change their thoughts and behaviors, but not all the time (Monaghan & Gabe, 2015).

The previous two studies, citing departures from the original biographical disruption model, namely biographical contingency and the expectation-driven understanding of the impact of illness on biography, are of particular relevance to the present study given their emphasis on context (Bray, et al., 2014; Monaghan & Gabe, 2015). Separately, each biographical model has support, but their lack of overlap suggests they each miss something important regarding the impact of a chronic illness. When considered together, they account for timing of diagnosis, expectations, impact of family relationships, and importance of context, which is reminiscent of core components of an ecological model of development. Within Bronfenbrenner’s framework, people experience their world and think about their experiences, constructing their views on the world from these thoughts. This construction of their life history and future projection is the focus of biographical research, which, when viewed alongside social relationships and other contextual factors, is again similar to the
ecological perspective assumed for the present study (Miller, 2003). Drawing on these different schools of thought to consider the effects of an illness on a child’s development, there is convergence of the literature on the sociology of illness in children and an ecological model of child development. The comprehensiveness of the developmental ecological perspective, as it accounts for the lack of agreement across the biographical models, provides further support for its application in addressing the research questions posed in the present study.

**Impact of Asthma on Development**

Considering the multitude of factors that contribute to a child’s maturation, how does asthma play into the developmental process? It is suspected that asthma, as well as other chronic illnesses, can create hurdles along the track of typical development as a child navigates and adapts to their world. There is evidence to support this idea in the literature exploring the impact of various chronic illnesses on child development and adjustment, with a growing body of research on asthma specifically.

Assuming the perspective of Bronfenbrenner’s graphical representation of development, asthma would fall in the innermost circle as a characteristic of the child. The presence of asthma in this ring could be expected to impact how the child interacts with and views the surrounding rings, for example gym class being a source of stress, and could possibly lead to the addition of new contexts such as medical specialists or emergency rooms. The goal of the child is to find balance within that inner circle with the added challenge of an illness, within the changing contexts that surround her. For many, this
balance would fall under the umbrella of “normalcy” or the desire to be seen as the same as peers (Lambert & Keogh, 2015).

All children are motivated to be accepted by peers and feel like they ‘fit in,’ but for children with a chronic illness, this can feel more challenging (Lambert & Keogh, 2105). A chronic condition such as asthma creates a disruption of normal life. Though not entirely unrelated, this idea should not be confused with biographical disruption, which suggests an illness changes a person’s entire sense of self and future trajectory. Normalcy is more an ongoing sense of general wellbeing and hope for many people, whereas an interruption in this delicate balance might be an indicator of something negative (Robinson, 1993). A recent review of the literature by Lambert and Keogh (2015) explored the reports of children and adolescents with chronic illnesses on feelings of being different throughout a number of qualitative studies. They found common themes across the different studies between children with asthma, diabetes, and epilepsy. When living with an illness like asthma, children might miss out on activities or have to stop to take medicine. For some, thoughts or worries about their illness might distract them from their usual activities. Asthma management and exacerbations interrupt daily activities, and have the potential to limit a child’s functioning and make them feel different from peers. Further, the fear of peers reacting negatively is a very real concern for many children with chronic health issues, and they might do whatever they can to avoid bullying or other forms of rejection from peers, even at the cost of non-adhering to their treatments (Lambert & Keogh, 2015). The desire to feel normal appears to be a wide-reaching issue for many children with chronic illnesses.

One way to measure an individual’s sense of coping and adjustment, or their homeostasis in an ecological sense, is through the construct of quality of life. Quality of life
(QOL) is defined as the degree of satisfaction an individual feels in areas of their life such as physical, emotional, and social functioning (Vila, et al., 2003; Sawyer, et al., 2000). Quality of life specific to health examines these domains in the context of living with an illness, including more objective measures of illness-specific symptom severity and functional impact (including limitations and social-emotional functioning), as well as the individual’s subjective perception of overall impact of the condition on their life (Wilson et al., 2011).

Given its complex nature, there is much debate over the construct of QOL and measurement of health-related QOL is generally inconsistent (Wilson, et al., 2011; Clarke & Calam, 2012). Several reviews of asthma-related QOL research have demonstrated some consistent findings in spite of these potential limitations. Asthma severity was linked to QOL inversely, such that increased symptoms correlated with poorer outcomes (Everhart & Fiese, 2009). Similarly, poor management of symptoms, which can be expected to contribute to worsening of symptoms, was found to be a barrier to positive QOL among children and their families (Li, et al., 2013; Clarke & Calam, 2012). Another study concluded that poor quality of life was not predicted by overall asthma severity, but rather recent symptoms (Goldbeck, Koffmane, Lechler, Thiessen, & Fegert, 2007). The idea that asthma management is closely tied with QOL, but is also reliant on factors such as socioeconomic status and family functioning, which suggests QOL is also dependent on these broader sociocultural elements, is not unexpected when assuming an ecological perspective.

As QOL is comprised of myriad other factors, it is likely affected when children experience problems of a social, emotional, and/or psychological nature, and children with asthma have been shown to be at increased risk for problems in these domains. Studies have found anxiety and other internalizing emotional concerns to be more common among
children with asthma than healthy peers (Wood, et al., 2007; Vila, Nollet-Clemenccon, de Blic, Mouren-Simeoni, & Scheinmann, 2000). The relationship between asthma and anxiety appears to be complex, with evidence suggesting the causality is bidirectional. Worries of asthma exacerbations can contribute to heightened anxiety, but acute severe stress and chronic stress have also been found to contribute to asthma exacerbations through physiological pathways (Chen & Miller, 2007). Feldman and colleagues (2013) concluded that both child depressive and anxiety symptoms are linked with asthma symptom severity and they found parent anxiety and depression to be risk factors related to disease severity as well (Feldman, et al., 2013). Family factors such as parental psychological function, as well as socioeconomic status and family functioning, have been found to predict poorer outcomes for children with asthma. Low maternal education and household income, when combined, were linked to poorer attention and social skills among a large sample of children with asthma (Chen, 2014). All of these findings are indicative of a host of potential concerns for children with asthma that tend to be context-dependent and contribute to decreased quality of life.

**Children with Asthma in School**

It is difficult to describe the experiences and needs of children with asthma without discussing school. According to DuPaul, Power, and Shapiro (2009), a child spends about 14,000 hours of their life in school, making it the site of a large portion of normal cognitive, social, emotional, and behavioral development. Much of the literature on children with chronic illnesses in the schools promotes the presence of the child in school as much as possible over alternative educational settings like homebound schooling (Katz et al, 1988;
Sexson & Madan-Swain, 1993; Shiu, 2001; Worchel-Prevatt et al., 1998). A primary role of children is that of student, and being in school reinforces a child’s value as a member of society (Prevatt, Heffer, & Lowe, 2000). Aside from academics, school represents normalcy and provides structure, which benefits the child emotionally and behaviorally. It provides a social forum for children to interact with peers and gain social support (Shiu, 2001). School also grants children the chance to experience a certain amount of control over their own lives, which can be reduced by an unexplainable, unpredictable illness such as asthma (Sexson & Madan-Swain, 1993). School is a quintessential component of life for a child and, as ecological development theories explain, disruptions in other areas of life are certain to affect the child within school.

One of the biggest concerns associated with a chronic illness in school is attendance. Children with asthma missed over 14 million days of school collectively in the United States in 2008 (American Lung Association, 2010). For children with asthma, these absences are more likely to occur as short, frequent absences as opposed to extended time away from school that are characteristic of other chronic illnesses (Mizan, et al., 2011). Frequent school absence has been linked to lower achievement outcomes, potentially placing children with asthma at risk for academic difficulties (Gottfried, 2011). One study found evidence that children with severe asthma are at increased risk of lowered academic performance and lower maternal reports of school performance, independent of days of school missed, though other elements like emotional functioning were not accounted for (Kohen, 2010).

Emotional and social functioning are important to consider as these factors interact with asthma and school absences. If a child misses school for health reasons, they run the risk of falling behind in their schoolwork, which has the potential to create anxiety for the child,
and school anxiety is likely to lead to more absences (Sexson & Madan-Swain, 1993). Social concerns have a similar pattern. Being away from school limits social interactions and opportunities to develop social support, while at the same time, lack of social supports and fear of social isolation due to illness can lead to school and social avoidance (Shiu, 2001). Absences from school can reinforce the presence of a problem, perpetuating feelings of helplessness and devaluation of self (Kaffenberger, 2006; Sexson & Madan-Swain, 1993; Shiu, 2001).

One way to reduce asthma-related absences is through regulation of symptoms. Poorly controlled symptoms have the potential to increase the chances of a child missing school, being sent home from school, or ending up in the hospital for more serious exacerbations (Lehrer, Feldman, Giardino, Song, & Schmaling, 2002). Asthma management encompasses medication adherence, knowing when to use preventive and reactive medicinal interventions, and avoiding specific activities or triggers that may exacerbate symptoms (Heyduck, Bengel, Farin-Glattacker, & Glattacker, 2015). Barriers to appropriate management have been linked to socioeconomic status and family functioning. Socioeconomic status often correlates with access to medical care and exposure to environmental triggers and stressors. Further, in low-income families, children are more likely to take on the burden of managing their illness, regardless of their ability to do so (Laster et al., 2009). Families that experience socioeconomic strain tend to live in conditions that are favorable for triggering asthma and have more difficulty adhering to medication regimens, a mixture that likely contributes to higher rates of asthma in poor, urban areas (Chen, et al., 2006).
Given the amount of time children spend in school and the presence of physical activity, a good deal of illness management also takes place at school. There are a number of suggestions, guidelines, and policies surrounding the rights of children with asthma at school designed to increase access to medication and improve asthma knowledge (ex: ‘How Asthma Friendly is Your School?’ – NAEPP, 2008; Asthma Action Plan – American Lung Association, 2008). A study surveyed schools across the US to determine how well they were adhering to the NAEPP’s recommendations for improving the quality of asthma-related accommodations (Jones, Wheeler, Smith, & McManus, 2009). Most schools allowed students to carry and self-administer medication, though it was unclear how many consistently established and followed individual student plans. Of greatest concern to the authors of the study was the limited access schools had to a school nurse, as less than a third of the schools surveyed had a full time registered nurse (Jones, et al., 2009). School nurses are valuable resources as they help facilitate asthma management and education in schools. Even when school nurses are present, they are not always conveniently accessible or available to students, and this can create problems when children need quick relief from their asthma symptoms. Teachers are often not well informed or prepared to help prevent, recognize, or treat the onset of symptoms, though teachers whose students show active symptoms are more likely to possess the information and skills needed (Bruzzese et al., 2010). The burden still seems to fall on the students to recognize and address their symptoms.

Though children may have access to their medications, there are still barriers to their effective use. Most states have legislation that allows children to keep their medications on them at all times to ensure quick access, but schools do not always interpret guidelines
similarly (Berg, 2005). Social factors are especially likely to limit adherence in school, in which children are more responsible for taking medications and where peers are more likely to influence behaviors. Some children have cited social reasons for not taking medications such as embarrassment or fear of being perceived as different (Penza-Clyve, Mansell, & McQuaid, 2004; Walker & Reznik, 2014; Lambert & Keogh, 2015). Walker and Reznik (2014) also found that children were not aware of or did not adhere to the use of their inhalers as preventative treatments. Instead the children missed activities to get their medicine or to rest as a means to relieve their symptoms (Walker & Reznik, 2014). Well-controlled asthma, with good management at home and at school, has the potential to contribute to greater time spent in school and engaged in both academic and physical activities.

School presence is an important factor of psychological well-being, particularly for a child with a chronic illness. School helps children feel more independent and ‘normal’, which reduces feelings of vulnerability (Robinson, 1993). Asthma includes a level of uncertainty as to when and where symptoms and exacerbations might occur, contributing to more internalizing problems in children (McQuaid & Abramson, 2009; Stewart, Masuda, Letourneau, Anderson, & McGhan, 2011). As mentioned previously, strong emotions, such as anxiety, have the potential to contribute to asthma exacerbations (Chen & Miller, 2007; McQuaid & Abramson, 2009; Lehrer et al. 2002). Additionally, symptoms of anxiety can mimic asthma symptoms, such as chest tightness and difficulty breathing. A child experiencing anxiety may believe they are having an exacerbation and seek medical attention to reduce their symptoms, further reinforcing their feelings of vulnerability over time (Marriage & Henderson, 2012). This sense of vulnerability and anxiety can be further
perpetuated by an anxious parent who is willing to let their child stay home from school more often for minor symptoms, validating the presence of a problem (Miller & Wood, 1991).

School can provide an environment of structure and normalcy that has the potential to help the child feel empowered by managing their illness at school (Sexson & Madan-Swain, 1993). It is important to note, though, that too much responsibility for illness management can contribute to additional stress and problems of adherence (Laster et al., 2009). Further, there is some evidence to suggest a higher risk of behavioral concerns, primarily attention, among children with asthma, but there is not enough research to understand this link as of yet (Chen, 2014; Hysing, Elgen, Gillberg, & Lundervold, 2009).

School is very important for social development as it provides a natural context for children to interact, practice social skills, and build relationships and support with peers. Asthma has the potential to negatively affect social development in several ways. First is the issue of participation, which includes school attendance and limitations in activities. One main component of asthma management is avoiding triggers, which for most children includes physical activity. Children with asthma are more likely than peers to stop in the middle of a physical activity to rest or seek medical intervention (Walker & Reznik, 2014). Such activity restrictions are potential missed opportunities for children to engage with their peers during the school day during gym, recess, or extracurricular activities like sports teams.

Second, missing these activities can lead children to feel different from their peers. As previously discussed, normalcy is an important component of development, and children generally use peers as their gauge for what is normal. How children view peers with an illness like asthma often brings up the topic of stigma. Recent research has suggested that perceived stigma is often greater than actual stigma, such that children with asthma worry
about peers rejecting them based on their asthma when peers are generally accepting (Hayes, Huang, Evans, & Bruzzese, 2013). Social acceptance by peers is more challenging for younger children, who may not understand the illness and be concerned about how it could affect them (Cole, Roberts, & McNeal, 1996; Hayes, et al., 2013). The need to be accepted by peers can have a negative influence on treatment adherence and fears of embarrassment or peer rejection can be strong enough to lead children to hide their illness and even risk their health by ignoring symptoms or avoiding taking medication in front of peers (Walker & Reznik, 2014; Lambert & Keogh, 2015). Interrupting activities is another common reason children do not take their medications, and children find the imposition of treatment schedules to be one of the biggest drawbacks of having asthma (Penza-Clyve et al., 2004).

School provides a crucial context for typical child development, but living with asthma may create barriers to accessing the full social, emotional, and academic learning opportunities. These issues have been linked to limitations in children being present and available in the learning environment, which relies heavily on successful management of asthma in school. Interventions aimed at improving management at school have shown a reduction in asthma-related absences, which is promising for utilizing the context of school to improve illness-based outcomes (Clark, et al., 2004).

**School Interventions for Children with Asthma**

Historically, much of the literature on school interventions for children with chronic illnesses has been based upon a transition back to school following an extended absence. These models focus on preparing the child, family, teachers, and peers for the ill child’s return to school providing support, communication between settings, and modifications as
needed (Sexson & Madan-Swain, 1993; Worchel-Prevatt et al., 1998). Such models are not relevant for the majority of children with asthma who do not typically spend long periods away from school, yet a more recent model of school reentry for children with chronic conditions provides a stronger basis for supporting children with asthma. Shaw and McCabe (2007) demonstrated that trends in health care lead children with chronic illnesses to spend less and less time in the hospital and rely more on outpatient care. This shift from inpatient to outpatient care means that children are spending less time in the hospitals and more time at home and in school, which is already true for children with asthma (Shaw & McCabe, 2007). The transition between healthcare and normal life is less defined than before and more responsibility is placed upon the child’s family and potentially their school to meet the child’s health, academic and social/emotional needs, as shown to be the case for children with asthma.

Shaw and McCabe (2007) have recognized that although children with chronic illnesses spend little time in the hospital, they are likely to have illness and treatment-related needs that create limitations and inconsistencies in their educational experiences. With this in mind, they developed a school-based program with four core components to support the health needs of children with chronic conditions at school. Consistent with attendance for children with asthma, it is expected that an increasing number of children with chronic illnesses experience shorter, more frequent absences or shortened days due to illness symptoms and doctor appointments. The authors discussed the importance of improving homebound instruction, preparing for a flexible school day and schedule, differentiated, individualized instruction, and the need for social and emotional supports in school. They also recommended strong relationships between the school and healthcare system, use of
technology to improve communication, working with the child in the context of their family, parent support, and ongoing evaluation (Shaw & McCabe, 2007). Shaw and McCabe’s revised school reentry plan recognized the need to develop a school-based program given the increased responsibility and lack of preparation of schools to provide for children with chronic illnesses. Though these recommendations may not all apply to children with asthma, specific components, such as good home-school communication and social-emotional supports, may be very useful in improving the overall functioning and adjustment of schoolchildren with asthma.

Shaw and McCabe’s (2007) plan for children with chronic illnesses provided an updated understanding of the unique challenges faced by students with health needs in school and the increased responsibility of schools to provide services and supports to these students. Along those lines, there is a growing literature base addressing interventions specifically for children with asthma to improve illness management, emotional health, and social interactions, with many emphasizing the utility of school-based programming. While most intervention programs are geared directly for the children with asthma to help them improve symptom management, coping, or academics, some are designed for teachers to aid in management at school or for improving peers’ understanding and social acceptance.

A majority of asthma interventions appear to focus on improving illness management and reducing symptoms through asthma education. For example, McGhan et al. (2010) examined the effectiveness of The Roaring Adventures of Puff - an interactive child-focused program designed to target asthma-based outcomes through improved asthma knowledge. The program took place in school, but was implemented by an outside healthcare provider. It included training for teachers and parents, and the program focused on psychological,
behavioral, and environmental components of asthma management with the goal of improving children’s self-regulation and self-efficacy, to further enhance asthma management. The authors found students missed fewer school days and gained skills to monitor their breathing and avoid triggers. Parents in the study reported reduced smoking in the home and a better understanding of asthma. Both parents and children endorsed improvements in quality of life (McGhan, et al., 2010).

Other school-based programs have employed various components of asthma interventions including asthma education, relaxation, coping skills, parent education and resources, school staff training, and peer education, to varying degrees of success. The most common effects of these school-based intervention programs appeared to be increase in knowledge of asthma and related management, reduction in missed school days, and higher reports of self-efficacy among children with asthma (Bowen, 2012; Clark, et al., 2004; Tinkleman & Schwartz, 2004). Computer-based programs are also seen as a potential modality for more seamlessly achieving stronger knowledge of asthma in school settings, though there is still uncertainty on the sustained effects of existing programs (Nabors, Kockritz, Ludke, & Bernstein, 2010). Though the link between asthma and academic problems is unclear, some evidence indicates that a program building literacy skills, in addition to asthma management, has potential to improve health, reading skills, and self-efficacy in a high-risk population of students with severe asthma, with stronger self-efficacy contributing to both improved management and literacy skills (Robinson, Calmes, & Bazargan, 2008).

As the primary caregivers of children in school settings, teachers wield the power to provide a great deal of asthma management and support to their students, though it seems
many teachers are unprepared to meet these students’ needs (Bruzzese, et al., 2010). One recent study found improvements in educator knowledge of asthma after a training program was implemented to inform teachers of asthma management and improve their efficacy in working with children with asthma, but no child-based factors were examined, so the impact on students is still unknown (Neuharth-Pritchett & Getch, 2015). Chronic illness literature endorses the need for improved teacher education and training in working with children with special health needs, but this continues to be an area apparently underrepresented in the literature (Bruzzese, et al., 2010; Shaw & McCabe, 2007). There is some potential for pairing teacher programs with student programs. For example, one comprehensive intervention integrated components of counseling and asthma education with academic curriculum and was led by teachers. Study findings suggested such a model promoted student openness to learning about their asthma and sharing with others, as well as stronger feelings of connectedness to teachers, creating prime opportunities for teachers to learn about asthma and be important sources of support for their students (Kintner, et al., 2014).

Emotional functioning is another area of growing interest related to interventions for improving asthma. One approach, using relaxation and guided imagery to build emotional regulation skills in children with asthma, found that relaxation strategies might be effective in reducing anxiety and improving lung functioning for children with asthma, though among a very small sample (Dobson, Bray, Kehle, Theodore, & Peck, 2005). Cognitive Behavioral Therapy (CBT) has also been explored as a possible means for reducing the suspected cycle between asthma and internalizing problems, particularly anxiety. A program coupling CBT and biofeedback techniques yielded improvements in both psychosocial and pulmonary functioning among elementary-aged children (Long, et al., 2011). Another CBT-based
intervention helped children to replace possible cognitive distortions about their illness with more adaptive thoughts. These participants demonstrated improved quality of life and a reduction in anxiety and symptoms of panic (Marriage & Henderson, 2012). Such studies support the literature linking emotional regulation with asthma symptoms and, when paired with appropriate medication management, demonstrate the usefulness of emotional interventions for improving asthma-related quality of life.

Few studies have been found to explore interventions to improve social functioning, despite the needs found among children with asthma (Miller & Wood, 1991). There is evidence to support the use of asthma education and management programs to also improve social functioning, with better knowledge of asthma contributing to effects such as reducing withdrawal and boosting independence (Yang, Mu, Huang, Lou, & Wu, 2012). Based on their findings, Petteway, Valerio, and Patel (2011) recommended interventions focused on strategies for communicating with peers, especially when deciding to disclose asthma information, to improve peer supportiveness. Children have also reported wanting more support from peers with asthma, suggesting potential benefits of a mentor-based intervention (Stewart et al., 2011). Additionally, there appears to be a dearth of research exploring various developmental strategies in improving the social functioning of children with asthma, providing a fertile area for future research.

Overall, interventions for improving the lives of children with asthma represent an exciting new field with a growing base of literature supporting the importance of school-based interventions. Development of such programs, geared toward students, educators, and peers, has the potential to improve not only asthma functioning, but also psychological factors such as self-efficacy, problem solving, and emotional competence, as well as social
skills and academic performance. Continuing to explore the needs of children with asthma will help inform the future of asthma intervention research to best meet the complex challenges of supporting students with asthma and other health conditions.

**Rationale for Study**

Asthma has been shown to affect the lives of children in complex ways. Based on the presented literature, the areas of illness management, emotional regulation, and peer support appear to be the most significant components of overall asthma-related quality of life and success. All three factors play into school success as well. The previous review has revealed both an area of need and a gap in the existing literature on children’s experiences with asthma at school. The present study attempts to address this gap by providing a voice to schoolchildren with asthma in order to better understand their experiences and needs surrounding having an illness in school.

Researchers have shown that children are excellent sources of information on their own experiences. It is important to recognize their unique perspectives, while also being aware of their special needs as participants in research (Ireland & Holloway, 1996; Sartain, Clarke, & Heyman, 2000; Greig, Taylor, & MacKay, 2007). Common expectations for limitations in child reporting have included issues with language development and concerns over how children respond to adults due to power differentials (Riley, 2004; Greig et al., 2007). Although these problems often exist when working with children, there are ways to reduce these effects by being aware of developmental abilities and building rapport with the interviewees (Ireland & Holloway, 1996). There is growing evidence that children as young as 6 years old are reliable reporters of their own subjective experiences (Riley, 2004), and
children as young as 7 can be reliable reporters of their own health (Olson, et al., 2007). Children are, after all, experts on their own thoughts, feelings, health, and beliefs. Comparisons of child and adult reports have demonstrated that parents and teachers as proxies for child experiences do not necessarily overlap with child reports of the same topic (Lara et al., 1998; Riley, 2004). Specifically, Lara and colleagues (1998) demonstrated that children were more reliable reporters of their asthma symptoms than their parents when compared to data on the child’s pulmonary functioning. Further, the concern that children may not be able to describe their experiences in the same way as an adult may not be a limitation at all. Children experience their world differently from adults and how they express their thoughts is an extension of who they are and provides useful information (Brady, Lowe, & Lauritzen, 2015).

As qualitative research with children has gained higher regard, the literature base for seeking the thoughts of children with asthma has grown. Even so, few studies have been found to explore the experiences of having asthma at school. Several studies have approached the broad topic of life with asthma, often encountering the social and emotional experiences of children. For example, some earlier studies used illness narratives to give children and adolescents a way to share their perceptions of living with asthma, with results shedding light on the emotional experiences of feeling restricted and wanting to be normal (McMullen & Yoos, 1996; Rydstrom, Dalheim Englund, & Sandman, 1999). These findings have remained consistent across later research, though investigators have used interviews with children to examine more specific aspects of asthma in addition to everyday experiences (Trollvik, et al., 2011), such as the physical and emotional experiences of breathing problems (Woodgate, 2009), and use of strategies to normalize asthma among children (Protudjer,
Kozyraskyi, Becker, & Machessault, 2009) and adolescents (Jonsson, Egmar, Hallner, & Kull, 2014). Each of these studies contributes a great deal to the literature on the experiences and perceptions of having asthma, but for the most part, they do not address the issue of context, or do so only briefly.

A handful of studies were found to touch upon the topic of living with asthma at school. For instance, Gabe, Bury, and Ramsay (2002), recognized the importance of the school context, though their approach seemed to lump school into the daily routines of children and adolescents, rather than focus more specifically on the details of the school day itself. Through the interviews, the authors concluded that management of asthma at school was a clear concern for children and adolescents, which included social issues and seeking support from teachers and peers (Gabe, et al., 2002). In their study on the suspected contingent impact of asthma, Monaghan and Gabe (2015), explored illness experiences with some discussion of contexts like school, particularly on the topic of social interactions. School was considered as one part of the focus on overall effects of living with asthma (Monaghan & Gabe, 2015).

Presently, only one study was found to directly relate to the current research topic, in that it had the primary goal of acquiring children’s perceptions specific to the school context. In their study, Walker and Reznik (2014) interviewed children ages 8 to 10 years to gain their perspectives on managing their asthma at school, particularly related to physical activity. The majority of children interviewed described limitations in their physical activity at school due to asthma symptoms, and though most had their own strategies to control their symptoms, few used medication as treatment, and even fewer used preventive measures to avoid exacerbations. It seemed access to medication and awareness of the uses were two of the
barriers that led children to seek other strategies such as sitting down or drinking water. Many of the respondents also admitted to feeling embarrassed or worried about using their medicine in front of peers, which further limited their effective symptom management. The authors concluded the barriers of access and stigma contributed to poorly controlled asthma among their urban sample of children and they advised improvements in teacher awareness and both child and teacher knowledge of asthma symptoms and treatment to help ratify the issues surrounding in-school illness management (Walker & Reznik, 2014). Though their study addressed crucial issues facing children and the management of their asthma at school, there were some limitations given the narrow focus on illness management. It is the goal of the present study to expand the existing literature base by shedding light on the emotional and social needs and perceived sources of support for children with asthma at school.

**Rationale for Qualitative Methods**

This study used qualitative methods to explore the experiences and perspectives of elementary school children with asthma. The goals of the study were best addressed by a pragmatic approach to qualitative research. This approach was used to allow the researcher to better examine a phenomenon through practical methods, allowing for a balance of description and interpretation of the data (Savin-Baden & Major, 2013). Based on a pragmatic approach, children were interviewed using a semi-structured interview encouraging them to share their school experiences relating to asthma. Specific topics included peer relationships, activities, emotional functioning, illness-specific stress, and asthma management. As demonstrated previously, children make good informants regarding their own subjective experiences, and previous studies have successfully generated
information using these methods with children (Ireland & Holloway, 1996; Woodgate, 2009; Walker & Reznik, 2014). There is presently a lack of research on the specific area of focus for this study, and therefore qualitative methods would provide a means to initiate theories about the population of schoolchildren with asthma without limiting the scope of what these children may share. Given the information presented, it was decided that interviews with child informants would be the most effective way to begin to establish relevant data on the experiences of children with asthma and what they identify as important regarding the school environment.

The overarching goal of this study was to evaluate child perceptions of having asthma at school, with emphases on social experiences, emotional needs, medication management, and illness stress. The following research questions addressed this goal:

How do children living with asthma perceive their school experience?

• What do children living with asthma experience in the school environment?

• How does living with asthma affect children’s social experiences?

• How does living with asthma affect children’s emotional functioning in school?

• How do children living with asthma navigate illness management at school; where do they seek support?
CHAPTER 3: METHODS AND PROCEDURES

The present study utilized qualitative methods to explore research questions on the needs and experiences of children with asthma. A broad, exploratory qualitative approach was selected to best respond to the research questions, by systematically examining children’s social, emotional, and other needs regarding having asthma in an educational setting. Such an approach allows for examination of naturally occurring events through the lenses of children, allowing a glimpse at the meaning they make of their experiences (Miles, Huberman, & Saldana, 2013). Child perspectives were obtained through semi-structured interviews, based on the idea that children are reliable and important reporters of their health and schooling experiences (Riley, 2004; Olson, et al., 2007).

This chapter describes participant characteristics and recruitment for the present study, as well as the measures developed and selected to answer the research questions, the specific data collection methods, and data analysis procedures, as approved by the institution’s Internal Review Board. In addition, further information and rationale on the research design is provided to support the methods.

Participants

Characteristics and Criteria

The sample for this study was comprised of 19 children aged 8 – 12 years old (mean age was 10 years, 5 months) and their caregivers, which was the child’s mother in every instance. There were more boys (63.2%) than girls (36.8%) in the study. Age at diagnosis
ranged from 2 months to 8 years of age, with a mean age at diagnosis of 3.3 years, such that the average length of time since diagnosis was just over 7 years, ranging from less than one year to 10.5 years (see Table 2). Based on mother report, categorization of asthma severity found nine children had well-controlled asthma, nine children had partly-controlled asthma, and one child had poorly controlled asthma, due to the presence of frequent nighttime symptoms at the time of the interview (see Table 3). Parent report also indicated four children received educational services; three had a 504 plan (one specifically for a food allergy) and one had an Individualized Education Plan for a Learning Disability. Further, when asked to describe their child’s functioning at school, eleven mothers selected “excellent”, four endorsed “very good”, and four reported their child’s functioning to be “good”.

The children and their caregivers were recruited from several settings in a Midwestern metropolitan region: through local private and public elementary schools, a suburban allergy and asthma clinic, and a community mobile health center. Of the participants, thirteen attended public school and six attended private school (see Table 5). Also, six families were living in urban areas and thirteen were living in suburban areas at the time of the interview. Though urban versus suburban living tended to be indicative of family socio-economic status, this was not true in all cases. Criteria for participation included the child’s age and asthma status as reported by their caregiver.

Recruitment

Purposeful sampling was attempted through recruitment in multiple communities to allow for a broader, more representative sample (Miles, et al., 2013). Recruitment proved
challenging across the settings, which made purposeful sampling more difficult. The primary barriers to recruitment were gaining access to settings and participant interest and availability to participate, which may have inadvertently created a less representative sample of children with asthma. Of the families who provided consent to participate, seven ultimately did not participate due to family factors, scheduling conflicts, and for at least one, economic barriers (lack of transportation), though several of these non-participant families were suspected to be of middle or higher SES.

Children and their caregivers were recruited in several urban and suburban Midwestern communities through schools, an allergy and asthma clinic, and a community mobile health center that operates with local public schools. School nurses in one public school and two private schools, and a principal in another private school identified eligible students within their schools and sent study information home with the students or to the parents, allowing parents to contact the researcher if they were interested in participating. Information was presented directly to children and caregivers by the researcher through the community mobile care center, at which point consent was obtained if the families were interested in participating. Once consent was obtained, a time was scheduled with the families to conduct the interview. Child assent was obtained at the time of the interview by explaining the rights of the child as a voluntary research participant, answering any questions they had, and obtaining their signature if they agreed to participate. In the allergy and asthma clinic, eligible families were identified by the provider and given the study information. If they were interested, consent and assent were obtained, and the interviews were conducted in the office while the patients waited for their medical care.
Further, an informational incentive was offered to families. This incentive included information on obtaining support for asthma in public schools, specifically on Asthma Action Plans and 504 plans. This information was offered to families regardless of whether they participated in the study, such that the resources were not withheld if families declined to participate.

Measures

The study approach was to collect information from two primary sources, children and parents. One caregiver from each family completed a parent questionnaire comprised of demographic information, a survey on their child’s asthma symptoms and severity adapted from the Pediatric Asthma Control & Communication Instrument (Okelo et al., 2013), and questions on their child’s schooling. Children participated in a one-on-one interview asking about their experiences with asthma in the school setting. Children were also asked to complete drawings prior to the interviews that were used to help build rapport. The drawings also provided supplemental information on the child’s social and emotional functioning. Table 1 illustrates how the proposed measures were used to answer the research questions. The following sections provide detailed information on the individual measures used in the present study.

Parent questionnaire. The parent questionnaire was developed to collect demographic and other descriptive information about the child participants. Section I consisted of demographic information including ethnicity, parent age and relationship to the child. Socio-economic indicators of human and social capital, such as parent educational
attainment and household composition were also included as acceptable measures of family socio-economic status (Entwisle & Astone, 1994).

Section II of the parent questionnaire consisted of an asthma questionnaire adapted from the Pediatric Asthma Control & Communication Instrument (PACCI; Okelo, et al., 2013). The PACCI was designed to evaluate a child’s asthma risk, severity, and symptom control through parent report. It was adapted for the present study by means of omission, addition, and alteration of several questions, to meet the goals of this study, while maintaining a similar goal of obtaining illness severity and management information. Specifically, three questions were omitted from the original questionnaire: (1) the first asks about recent changes in the child’s asthma, which was seen as irrelevant for the purposes of the present study; (2) the second asked caregivers how “bothered” they were by their child’s asthma, which was viewed as unneeded and difficult to validate; (3) the third omitted item asked about specific medications that, while important, were not crucial to this study, and which the researcher lacked training to evaluate. Two added items included age of asthma diagnosis (Item A) and child’s independence in managing their asthma (Item D), as this may be related to socio-economic stressors (Laster et al., 2009). Questions about hospital visits (Items B1 and B2) were altered to establish a set time frame (i.e. ‘in the past year’ instead of ‘since last doctor visit’). Item C and Items E through I came directly from the PACCI and were designed for use by physicians to establish levels of asthma control and severity.

The final section (Section III) of the parent questionnaire asked parents to report on their child’s asthma management at school and general school performance. Questions included the parent’s opinion of child school functioning, the presence of an asthma plan at school, health and special educational needs and provisions, and communication with
teachers and other school staff about the child’s asthma (see Appendix 1 for the Parent Questionnaire).

**Child drawings.** Child drawings have long been used as measures of cognitive functioning and as projective measures aimed at evaluating psychological functioning, including variations of instruments based upon human figure drawings (Goodenough, 1926; Goodenough & Harris, 1950; Manchover, 1953; Koppitz, 1968). Child participants were asked to create two drawings of a person using a variation of the Child Drawing: Hospital (CD:H) task adapted for educational rather than medical settings, though serving a similar purpose (Clatworthy, Simon, & Tiedeman, 1999). The CD:H task was originally developed to measure emotional states of children in the hospital through the children’s drawings. The authors of the CD:H designed a detailed scoring manual with three parts: Part A consisted of 14 components of the drawing rated on a scale of 1 to 10 (low to high anxiety) based on given criteria; Part B was comprised of 8 items based on pathological indices; Part C was an overall judgment of the emotional state of the child’s drawing based on a provided rubric. These three scores were added to obtain a total score that could be interpreted by use of descriptive categories of the child’s anxiety level as provided by the authors in an article published in conjunction with the scoring manual (Clatworthy et al., 1999).

For the present study, children were instructed to create two drawings. First they were asked to draw a child in school, then to draw a child in school with asthma. The purpose of this drawing task was twofold. One, the drawings acted as an icebreaker to help the researcher build rapport with the child participants. Second, this task provided an interesting perspective on children’s perceptions of having asthma in school, with an emphasis on underlying social and emotional issues, used to supplement the information obtained from
the child interviews. Specific instructions used for the drawing task can be found in Appendix 2.

**Child interview.** Efforts were made to establish rapport with the child participants prior to and during the drawing task, which occurred before the interview. The child interview asked participants about their experiences of having asthma in school using a semi-structured interview format, which provided a set of questions with some freedom to follow-up in order to gain richer information from the participants (Savin-Baden & Major, 2013). The interview questions addressed the areas of general school functioning, social and emotional functioning, and asthma-related issues such as medication use and exacerbations (see Appendix 2). The interview concluded with a question that gave the child an opportunity to share advice they might provide to a peer with asthma, and the child was also given a chance to provide any information that may have been missed in the interview. The interview questions were designed to be clear, short, and easily understood by the participants. They were also written as open-ended questions to encourage children to elaborate on their experiences in an age-appropriate manner, allowing the researcher to provide prompts as needed.

**Procedures**

Families were provided recruitment information and, depending on the recruitment setting, were asked to contact the researcher or provide signed consent. The researcher worked with caregivers who expressed interest in participating in the study to set up a meeting time and place to complete the interview. At the meeting, consent was obtained if it had not yet been given. Children were provided information on their rights as voluntary
research participants, and they were given the opportunity to assent to their participation in an attempt to ensure the child’s comfort with the research study. Parents were given the parent questionnaire, which took only a few minutes to complete. At the same time, the researcher and child participant began the drawings and interview. In most instances, the parent was present, though not always in close proximity to the child and researcher (such as sitting at a nearby table or in the next room). Discretion regarding parent presence was granted to the family to ensure their comfort. In one case, two siblings were interviewed together at the younger child’s request. It is unclear how parent or sibling presence may have impacted the child’s interview responses, though the researcher has judged the impact to be minimal.

The interviewer spoke with the child initially to build rapport and to ensure the child understood their rights. Then the child was asked to draw the two pictures, as previously described, which further aided the researcher in building rapport with the child. No time limit was given, though the drawings took anywhere from two to ten minutes to complete. The child was then given the opportunity to describe their drawings.

The interview itself lasted between fifteen and thirty minutes, varying with the child’s verbosity. The child was asked nine questions regarding their opinions of school, their feelings about having asthma, their social and emotional experiences surrounding having asthma in school, advice they would give other children, and any additional information they wished to share. Child interviews were audio recorded and transcribed, and field notes were also taken to supplement the audio recordings.
Data Analysis

The analytical approach of the study was designed to address the primary research question, namely, ‘How do children living with asthma perceive their school experience?’ To that end, data from each of the measures administered to children and their caregiver were matched to four sub-questions as shown in Table 1.

**TABLE 1. Research questions and measures used to approach each question**

<table>
<thead>
<tr>
<th>Primary Research Questions: How do children living with asthma perceive their school experience?</th>
<th>Measures/Analyses Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do children living with asthma experience in the school environment?</td>
<td>Analysis of thematic responses from Child Interview (Q1 – Q4) Graphic support from Drawings</td>
</tr>
<tr>
<td>How does living with asthma affect children’s social experiences?</td>
<td>Analysis of thematic responses from Child Interview (Q5)</td>
</tr>
<tr>
<td>How does living with asthma affect children’s emotional functioning in school?</td>
<td>Analysis of thematic responses from Child Interview (Q6 – Q8),</td>
</tr>
<tr>
<td>How do children living with asthma navigate illness management at school; where do they seek support?</td>
<td>Analysis of thematic responses from Child Interview (Q7, Q9, Q10), Descriptive statistics from Parent Survey (Sections II &amp; III)</td>
</tr>
</tbody>
</table>

**Parent Questionnaires.** The parent interviews yielded demographic, asthma, and school-specific information. The PACCI portion of the questionnaire was scored to determine parent-reported asthma-related risk and level of symptom control. As directed by the PACCI, Item B was an indicator of risk, to be interpreted such that High Risk was determined as one or more ER visits or hospital admissions and Low Risk was determined as no ER visits or hospital admissions. Item C was an indicator of daily controller medication adherence that asked parents how often they forget to give the medication to their child. Items E through I contributed to the categorization of the child’s level of asthma symptom control. Each item was ranked on a Likert scale, with the options coordinating to different
colors. The colors, green, yellow, and red, were paired with the categories of Controlled, Partly Controlled, and Poorly Controlled, respectively. Severity was determined such that the highest level of concern on any one item was considered to be the child’s present level of control. For example, if a parent responded in the green range for 4 out of 5 items, but endorsed a response in the red range for one item, the child was considered to have Poorly Controlled asthma.

Descriptive statistics were derived from the parent questionnaire data as a way to describe the characteristics of the sample. A summary of the demographic data for the children is presented in Table 2 and for parents in Table 4. Based on the questionnaire, many of the participants appeared to fall in middle to high socioeconomic status, given educational attainment and household composition (Entwisle & Astone, 1994). The majority of mothers had at least a 2-year degree (89.4%), with over half holding a graduate or professional degree (57.9%). Most families had two adults living in the home (78.9%). Additionally, information on caregiver ethnicity was also collected, such that the majority of caregivers were White (73.7%), with a small representation of African American (5.3%), Asian-Pacific Islander (5.3%), and Hispanic (15.8%) caregivers.

**Child Interviews.** Thematic analysis was used to identify common themes among the interview responses. Thematic analysis is a widely used method of identifying rich, descriptive meaning from data by immersing oneself in the content to be analyzed and using expertise and intuition to derive meaningful themes (Braun & Clarke, 2006; Savin-Baden & Major, 2013). In following this procedure, the interviews were first transcribed. Then, the transcripts were examined in detail to explore patterns and relationships within and across interviews. Within each interview, meaningful units of information were identified, with each
interview being reviewed two or more times. Meaningful units were clustered into broader categories, or themes, which were then compared across interviews to examine similarities and differences in the children’s responses, to ultimately be held for comparison against existing literature (Miles, et al., 2013; Flick, 2009; Braun & Clarke, 2006).

**Child Drawings.** The child drawings were coded as indicated by the Child Drawing: Hospital scoring manual (Clatworthy, et al., 1999), with some minor modifications. The scoring manual outlined 3 parts (A, B, and C), which were broken down into more specific units. Part A was a general assessment of the drawing components, with 14 items rated on a scale of 1 to 10. Two of these items were omitted from the present study (both related to use of color, as color was not used), and one item was adapted for the present study (Hospital Equipment was used to indicate presence of asthma medications or treatments). Part B was comprised of 8 items that were more direct indicators of anxiety, such as distortions and shading. Items were given a score of 5 or 10 if they were present in the drawing. Part C was a single score indicating the gestalt or overall sense of the picture, from coping to disturbed, as described by the scoring guide. After scoring each section, the scores from each part were added to yield the total score, which was used in analyses. Further, the scoring manual contained a score sheet (which was adapted for the present study), a rubric to summarize the scoring criteria for Part A, and a guide with criteria to score parts B and C, all of which were used to aid in the scoring of the participants’ drawings, and can be found in the Appendix 3 (Clatworthy, et al. 1999).
# TABLE 2. Child Demographic Data

<table>
<thead>
<tr>
<th>Child Gender</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>12</td>
<td>(63.2%)</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>(36.8%)</td>
</tr>
<tr>
<td>Child’s Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>10.4 years</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>8.3 – 12.2 years</td>
<td></td>
</tr>
<tr>
<td>Age at Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>3.3 years</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>0.2 – 8 years</td>
<td></td>
</tr>
<tr>
<td>Time Since Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>7.1 years</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>&lt; 1 – 10.5 years</td>
<td></td>
</tr>
</tbody>
</table>

# TABLE 3: Child’s Asthma Risk and Level of Control Reported by Caregiver

<table>
<thead>
<tr>
<th>Child</th>
<th>Risk Indicators</th>
<th>Adherence</th>
<th>Level of Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Low</td>
<td>Some</td>
<td>Partly Controlled</td>
</tr>
<tr>
<td>2</td>
<td>Low</td>
<td>NA</td>
<td>Controlled</td>
</tr>
<tr>
<td>3</td>
<td>Low</td>
<td>Some</td>
<td>Partly Controlled</td>
</tr>
<tr>
<td>4</td>
<td>Low</td>
<td>None</td>
<td>Partly Controlled</td>
</tr>
<tr>
<td>5</td>
<td>Low</td>
<td>NA</td>
<td>Controlled</td>
</tr>
<tr>
<td>6</td>
<td>High</td>
<td>Most</td>
<td>Partly Controlled</td>
</tr>
<tr>
<td>7</td>
<td>Low</td>
<td>None</td>
<td>Poorly Controlled</td>
</tr>
<tr>
<td>8</td>
<td>Low</td>
<td>NA</td>
<td>Controlled</td>
</tr>
<tr>
<td>9</td>
<td>High</td>
<td>None</td>
<td>Partly Controlled</td>
</tr>
<tr>
<td>10</td>
<td>Low</td>
<td>NA</td>
<td>Controlled</td>
</tr>
<tr>
<td>11</td>
<td>Low</td>
<td>Some</td>
<td>Controlled</td>
</tr>
<tr>
<td>12</td>
<td>Low</td>
<td>None</td>
<td>Controlled</td>
</tr>
<tr>
<td>13</td>
<td>Low</td>
<td>NA</td>
<td>Controlled</td>
</tr>
<tr>
<td>14</td>
<td>High</td>
<td>None</td>
<td>Controlled</td>
</tr>
<tr>
<td>15</td>
<td>Low</td>
<td>NA</td>
<td>Partly Controlled</td>
</tr>
<tr>
<td>16</td>
<td>Low</td>
<td>All</td>
<td>Partly Controlled</td>
</tr>
<tr>
<td>17</td>
<td>Low</td>
<td>Some</td>
<td>Controlled</td>
</tr>
<tr>
<td>18</td>
<td>Low</td>
<td>Some</td>
<td>Partly Controlled</td>
</tr>
<tr>
<td>19</td>
<td>High</td>
<td>All</td>
<td>Partly Controlled</td>
</tr>
</tbody>
</table>

1 Risk Indicators: Low: No ER visits or hospitalizations, High: At least one ER visit or hospitalization (past year)

2 Adherence, based on question: How often do you forget to give your child’s daily asthma medicine when he/she feels fine?
### TABLE 4. Caregiver Demographic Data

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31 – 40</td>
<td>3</td>
<td>15.8%</td>
</tr>
<tr>
<td>41 – 50</td>
<td>16</td>
<td>84.2%</td>
</tr>
<tr>
<td><strong>Caregiver education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some high school or less</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>High school diploma/GED</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>2 year college degree (AA)</td>
<td>3</td>
<td>15.8%</td>
</tr>
<tr>
<td>4 year college degree (BA/BS)</td>
<td>3</td>
<td>15.8%</td>
</tr>
<tr>
<td>Graduate or Professional degree</td>
<td>11</td>
<td>57.9%</td>
</tr>
<tr>
<td><strong>Caregiver Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>Asian-Pacific Islander</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>3</td>
<td>15.8%</td>
</tr>
<tr>
<td>White</td>
<td>14</td>
<td>73.7%</td>
</tr>
<tr>
<td><strong>Caregiver Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single, never married</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>Married</td>
<td>13</td>
<td>68.4%</td>
</tr>
<tr>
<td>Separated</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>Divorced</td>
<td>4</td>
<td>21.1%</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>5.3%</td>
</tr>
<tr>
<td>** Household Composition**</td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Adults</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One adult</td>
<td>4</td>
<td>21.1%</td>
</tr>
<tr>
<td>Two adults</td>
<td>15</td>
<td>78.9%</td>
</tr>
<tr>
<td><em>Children</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One child</td>
<td>3</td>
<td>15.8%</td>
</tr>
<tr>
<td>Two children</td>
<td>5</td>
<td>26.3%</td>
</tr>
<tr>
<td>Three children</td>
<td>8</td>
<td>42.1%</td>
</tr>
<tr>
<td>Four or Five children</td>
<td>3</td>
<td>15.8%</td>
</tr>
</tbody>
</table>
TABLE 5: School Data Reported by Caregivers

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>School Type</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public</td>
<td>13</td>
<td>(68.4%)</td>
</tr>
<tr>
<td>Private</td>
<td>6</td>
<td>(31.6%)</td>
</tr>
<tr>
<td><strong>School Performance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>11</td>
<td>(57.9%)</td>
</tr>
<tr>
<td>Very Good</td>
<td>4</td>
<td>(21.1%)</td>
</tr>
<tr>
<td>Good</td>
<td>4</td>
<td>(21.1%)</td>
</tr>
<tr>
<td><strong>Asthma Action Plan</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
<td>(68.4%)</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
<td>(31.6%)</td>
</tr>
<tr>
<td><strong>Support Services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>504 Plan</td>
<td>3</td>
<td>(15.8%)</td>
</tr>
<tr>
<td>IEP</td>
<td>1</td>
<td>( 5.3%)</td>
</tr>
<tr>
<td><strong>Talked with Teacher</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11</td>
<td>(57.9%)</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>(42.1%)</td>
</tr>
<tr>
<td><strong>Contact Person</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teacher</td>
<td>2</td>
<td>(10.5%)</td>
</tr>
<tr>
<td>Nurse</td>
<td>12</td>
<td>(63.2%)</td>
</tr>
<tr>
<td>Both</td>
<td>2</td>
<td>(10.5%)</td>
</tr>
<tr>
<td>None</td>
<td>3</td>
<td>(15.8%)</td>
</tr>
</tbody>
</table>
CHAPTER 4: RESULTS

The purpose of the present study was to explore children’s perceptions of having asthma at school, with emphases on their social experiences, emotional needs, illness management, and sources of support. These life experiences are significant for schoolchildren living with asthma, yet little existing research is available from the child perspective. The current study addressed the following research questions and sub-questions:

How do children living with asthma perceive their school experience?

• What do children living with asthma experience in the school environment?
• How does living with asthma affect children’s social experiences?
• How does living with asthma affect children’s emotional functioning in school?
• How do children living with asthma navigate illness management at school; where do they seek support?

Data were collected through interviews with 19 children ages 8 to 12 years (mean of 10 years, 5 months) to gain insight into their experiences of living with asthma. One interview was terminated halfway through due to the child’s emotional distress discussing a traumatic event. The child was consoled and distracted from the topic and provided the option to continue, which he declined. The interview was still included in the analyses as the child provided rich information prior to becoming distressed. The child participants had been living with asthma for anywhere from a few months to over 10 years (mean of 7 years). The semi-structured interviews encouraged the children to share their general experiences of
living with asthma, and more specifically their thoughts on living with and managing their asthma at school, with attention paid to social and emotional factors.

The participants’ caregivers, in all cases their mothers, completed a questionnaire asking about demographics, the child’s asthma, and the child’s school. This information was used to obtain descriptive statistics to better identify characteristics of the sample. Socioeconomically, the majority of families were of middle to high status based on mother’s educational attainment and number of people living in the home. The majority of mothers obtained a 4-year college degree or higher (73.7%) and the majority of households had two adults living in the home (78.9%). Additional data from the parent interview can be found in the previous chapter.

A drawing task was also administered as an additional source of information on the children’s emotional functioning. The children were instructed to draw a picture of a child at school, then to draw a picture of a child with asthma at school. Analysis of the children’s drawings, based on the Child Drawing: Hospital protocol (Clatworthy, et al., 1999) unfortunately provided little information in the area of emotional functioning. In adapting the measure for use with children with asthma, it is suspected there was reduced variation in the scores compared to children in hospital settings. Further, the descriptive characteristics the original authors established did not apply to the present sample, despite adjustments, such that all drawing scores fell within normal limits. Overall, the intended use of the drawings was limited and, instead, review of the drawings in comparison with the interviews revealed they would be of better use in supporting the story that emerged from the child interviews. Drawing data can be found in conjunction with relevant themes, and all child drawings can be referenced in Appendix 4. The child interviews were transcribed and analyzed within and
across participants for themes that were relevant to the research question and sub-questions. Several themes were identified from child responses. These themes are organized under five topic categories: 1) Living with Asthma, 2) Having Asthma at School, 3) Social Impact, 4) Emotional Impact, and 5) Sources of Support.

**Living with Asthma**

When asked about their asthma, all children discussed symptoms and ways to alleviate their symptoms, and all but one child brought up triggers of their symptoms. Each child gave some description of the physical sensations of their asthma and/or the impact it has had. The most commonly reported symptom, mentioned by twelve children, was difficulty with breathing, described as being “out of breath” or “losing” their breath. Coughing was also a common symptom mentioned by ten of the respondents, and represented in eleven of the drawings of a child with asthma (Figure 2). Other symptoms the children shared were wheezing, loss of energy, tightness in chest or throat, pain or discomfort, and fast heartbeat. Two of the participants also used more unique descriptors like “bubbly” feeling in their throat or feeling like their mouth was “white” to describe a sensation of dryness. For many, these symptoms interfered with the ability to run, and some said it was hard for them to speak, either due to shortness of breath or persistent coughing.

Running or physical activity was a reported trigger for fifteen of the children, which was depicted in three of the drawings of a child with asthma (Figure 3). Illness and allergens like dust, pollution, pollen and animals were the next most frequently discussed causes of symptoms, with five children endorsing each of those triggers. All of the children reported medication as a source of relief from their symptoms, with the exception of one child who, it
was noted, had the most recent asthma diagnosis at less than one year. Seven children depicted medication in their drawings of children with asthma. Only two children reported using their inhalers almost daily at school. Four children said they used their inhalers at school once or twice a month, and the rest of the children used them a few times a year or less. About half of the children reported taking breaks or slowing down as a way to feel better. Other means of relief included drinking water, taking deep breaths, staying calm, and splashing water on their face. One child said he raises his arms sometimes to open his lungs. Further, nearly a third of the children mentioned using their inhalers as a preventive treatment before certain physical activities. Through the interviews, it was evident the children had formed their own understandings of their symptoms and ways to prevent or alleviate them. In addition to symptoms and management, other themes emerged regarding life with asthma including broader impact, minimization, and transience of asthma.

*There’s Nothing Good*

In general, children endorsed negative thoughts of asthma more than positive thoughts. Not surprisingly, when asked, few children (5/19) reported anything good about having asthma. Conversely, the majority of respondents (all but three) gave examples of what is bad about having asthma, mostly discussing symptoms and limitations. One 8-year-old boy reported a negative social impact through peer rejection and one 11-year-old girl said asthma could be “kinda scary.” Also, seven children expressed feeling that asthma has a negative impact on their lives, describing asthma as being “hard,” “not fun,” or even “it sucks.”

The negative impact of asthma was further supported by findings that all the interviewees could identify a time when asthma was a problem for them, and for half of the
children, these reported incidents seemed significant and distressing based on the level of intervention required (leaving school early, ambulance) or on the child’s descriptions (“terrible” or “scary”). The milder events tended to require the children to stop an activity and maybe take their medicine, whereas the major events involved feelings of worry or fear, feeling unable to breathe and, in a few instances, having to go to the hospital. Some of the events happened years earlier, though they were still clearly relevant to the children through their detailed descriptions. For one child, discussing the event of being taken from a basketball game in an ambulance in front of his peers was so difficult that the interviewer terminated the interview due to the child’s intense emotional state. In general, the participants endorsed negative feelings of asthma when they reported on the negative impact it has had on their lives.

It Could Be Worse

Children found few good things about having asthma, but some were able to see some positive aspects. For example, two children said asthma could be a means to avoid non-preferred physical activities, like running the mile. Two others pointed out the social benefits of having asthma such as friends being supportive, or the connection asthma creates with other children who have asthma. For example, one 10-year-old boy said, “…it’s kinda good because another kid has it so it’s like we’re like, got something in common, that’s a good part.” The other suggested benefits to having asthma included viewing the onset of symptoms as a warning system to slow down to avoid feeling worse and enjoying the smell of the medicine. One optimistic 8-year-old boy described a time when he stopped running due to
his symptoms and narrowly missed being hit by a falling branch, which might have hit him had he not stopped.

Further, many of the participants reported that having asthma was not so bad, comparatively speaking. For instance, five children expressed marked improvements in their own asthma severity, while two others mentioned peers who experienced worse symptoms. Additionally, two children said that asthma was not so bad when compared to other illnesses like diabetes or cancer. They explained their asthma could be controlled and managed, unlike other, more serious illnesses. As one 11-year-old boy explained,

“Well, I mean like it’s not like terrible, it feels terrible for me but it’s not like it could really hurt someone else like a terrible disease, but all I have to do is do my inhaler twice and I feel better...”

These kinds of examples were indicative of attempts to downplay the impact of asthma. In other instances, some children made contradictory statements describing negative aspects of their illness, but also talked about how it was not so bad. Some had difficulty listing examples of what was bad about having asthma, saying it was okay, but then using more negative language. One such example was provided through an 11-year-old girl who minimized her need for an inhaler during gym,

“…it doesn’t happen a lot to me during school because we usually are not doing, unless it’s summer and we, or fall or spring, and not winter, except winter we have to do something outside.”

After making it sound as though her asthma occurred only part of the year, she then went on to indicate it happened most of the time whenever the gym class did an activity outside. Five other participants made similar contradictory statements throughout their interviews in which they talked about the negative impact of their illness, but then suggested asthma was not a big deal in another part of the interview. An example of this was a 10-year-old boy who
referred to asthma as a “disability”, but throughout the rest of interview emphasized that asthma was not so bad and that he was an “ordinary person”. Such contradictions by the participants seemed to indicate attempts to assuage the impact asthma had on their lives.

“When I have asthma...”

There were two children who clearly referred to their asthma as temporary or intermittent by equating their illness with the presence of symptoms, for example, referring to when they “get” or “have” asthma. This theme occurred across other interviews, though more subtly, when children discussed worrying only when they actively have or anticipate symptoms (8/19 children). In contrast, other children expressed a more pervasive sense of asthma through statements like:

“…nothing because I had it ever since I was born” (10-year-old boy, regarding what is bad about having asthma)

“I don’t know how it is to not have asthma because I’ve had it for my whole life.” (11-year-old girl)

For five others, asthma was something that was often on their minds. They reported thinking about their asthma and its management even when not experiencing symptoms, discussed in more detail in a later section.
Having Asthma at School

The majority of the children had experienced some form of medication management at school, with fourteen participants endorsing having medication currently or previously at school. Six participants reported having to use medication only at home or none at all at the time of the interview. Asthma symptoms and medication use for prevention or relief of
symptoms proved to create potential hurdles for students in their school routines. For some, this caused minor distractions and inconveniences and for others, illness management led to bigger, more significant disruptions in the child’s school day.

_It Gets in the Way_

Throughout the interviews, children expressed a sense of inconvenience due to having asthma. This idea was typically related to managing asthma at school, having to remember to take or carry medicine, or needing to get medicine from the nurse, which could be disruptive or stressful. For instance, three children conveyed frustration when they realized a certain running activity was happening at PE, which meant they had to rush around to get their inhalers to be able to participate. One used the word “Ack!” to express her sense of being flustered by the unexpected inconvenience. In addition to being inconvenient, asthma symptoms were a source of disruption for some of the children, getting in the way of normal tasks like schoolwork or even talking. In his drawings, one boy depicted a child reading, followed by one still holding his book while coughing, suggesting an interruption in his reading (Figure 4). Three children reported times when they had difficulty speaking due to breathlessness or coughing. Four students also reported occasions when their asthma was a distraction to themselves or others in the classroom, including an 8-year-old girl who said,

“I think it can sometimes get in the way of your working, like say you are taking a test and then you suddenly have to have, you suddenly feel a little tightness in your chest um then that sorta disturbs you from doing your test.”

Children reported that coughing and wheezing could be sources of disruption for them as well as for their classmates. Given the fact that asthma impacts breathing and causes
symptoms like coughing and wheezing, it is not surprising to find the children were annoyed by these disturbances at school.

*I Can’t...

Interruptions during the school day caused by asthma were more than just a nuisance, as many of the children expressed feeling limited in their activities at school. Specifically, ten children reported having to miss activities at PE or recess, and all but four children had to reduce or stop their physical activity at some point. The onset of symptoms or the need to retrieve medicine led to time spent out of academic classes for two students, and three children reported having to leave school at some point due to their asthma. Of the students who said they did not miss out on activities, three described limitations in their activities, particularly when running, as they could not keep up with peers and had to slow down. Three children admitted they tried not to let their asthma get in the way of their activities. For example, an 11 year-old girl explained her dislike for the PACER, a running activity at PE, as it required her to rush to take her inhaler, but she did not want to avoid the task, explaining, “Yeah, I mean I don’t wanna not do it just because of my asthma.”
Social Impact

Peer relationships are an important component of child development, with a large amount of peer interaction occurring at school. With asthma management also happening at school, there is bound to be an overlap between asthma management and social interactions with peers. The participants shared their thoughts on peer support, being seen as normal by peers, and potential negative social consequences related to peers knowing about their asthma.

Peer Support

Only two participants reported their peers probably did not know about their asthma, one of who had not had symptoms in several years, and the other who was hesitant to share his asthma diagnosis. All other participants said at least some of their friends knew about their asthma – some through witnessing symptoms or management, others through
disclosure. For three children, the knowledge of their asthma status was expressed as privileged information that was to be shared with trusted peers, but not acquaintances. Further, on multiple occasions, peers with asthma came up when discussing friends. One child even reported only telling his friends with asthma about his asthma, stating, “I don’t really feel like sharing that I have asthma with my other friends that don’t have asthma.” When asked by the interviewer what advice they might give to a new classmate with asthma, two of the children were also enthusiastic about wanting to befriend the classmate and provide them with social support.

Reported benefits of telling friends about asthma included feeling understood by them and gaining comfort and support in potentially stressful situations. For example, one child (11 years old) said her best friend would stay with her during the mile run, explaining, “…it’s nice to have someone there for you when you can’t breathe and they will rest with you so you don’t have to run the rest of the way alone.” Other children reported friends would check in, asking if they were okay or in need of help. The majority of the respondents expressed positive, or at least neutral, thoughts about friends’ awareness of their asthma.

“People treat me the same”

Across the interviews, there was a feeling among children that, in addition to feeling supported, positive peer responses included acting as if nothing was different. For example, four children reported that peers “don’t really care” about their asthma status, indicating it was not something that bothered their peers. Similarly, two children expressly appreciated that their asthma was not a topic of conversation for their friends. Four children stated specifically that they were not treated differently because of their asthma. For example, one
11-year-old girl said, “…they don’t treat me like any different kind of person. Just because I have bad lungs doesn’t mean I’m a bad person.” A 10-year-old boy also reflected this idea throughout his interview by making statements like, “they just treat me equal, just like them.” For many of the participants, it was important that their peers viewed them as just another normal kid.

Similarly, it seemed some children might have been trying to convince the interviewer, or even themselves, that having asthma was normal. As mentioned previously, several respondents made contradicting statements that seemed to be an attempt downplay the impact of their illness. Combined with the desire of children to be seen as normal, such downplaying could have been a way to deal with and normalize their experiences with symptoms and treatments. Also, the recurring mention by children with asthma of others with asthma further supports the idea of normalization, by pointing out that there are other kids like them.

**Negative Consequences**

Though many children expressed positive feelings about the social impact of their asthma, less desirable consequences were also discussed. Given that feeling normal was found to be important for many of the children with asthma, it is not surprising that being treated differently was perceived as a potentially negative consequence of asthma. Feeling different came across in multiple interviews, as four children shared they could not always keep up with peers at gym or recess. One 11-year-old girl said, “Well, yeah you have to stop, but if you don’t have asthma you can just keep on running, which is awesome.” Seven children expressed feeling left out of activities when symptom exacerbations caused them to
have to sit out of games, while other children continued to play and have fun. In their drawings, two girls switched genders between their pictures, such that the drawings of the children with asthma were boys. Though the reason for this was unclear, it is possible the girls drew boys with asthma as a way to separate themselves from the illness (Figure 5).

Although most respondents reported peers were supportive, understanding, and/or not overly concerned with their asthma, they expressed worries of peer rejection, and in some cases, experienced it. Several children were concerned with what others might think about their asthma. One 11-year-old boy did not want to “make a scene” by telling his teacher that he was starting to have trouble breathing. An 8-year-old boy reportedly risked losing friends because they did not believe he had asthma at first and just thought he was lazy. He also worried about being picked on because of his asthma. Similarly, one 11-year-old girl explained that kids can be competitive, and when engaging in a race or game, asthma could be seen as an excuse for slowing down or stopping. She felt advocating for herself prior to the competition was important, and other children were usually understanding.

**Figure 5:** Drawings of children without and with asthma at school by an 8-year-old girl
Emotional Impact

A number of different feeling words were verbalized by the participants across the interviews, such as sad, scared, worried, anxious, overwhelmed, and mad, reflecting the fact that asthma was associated with a range of emotions. Two children expressed feeling sad about sometimes missing activities and another felt mad when he coughed a lot. Other than this, the most consistent emotions children expressed were a sense of anxiety and fear surrounding life with asthma. As such, the themes extracted from the children’s reports of their emotional functioning related to worry, vigilance, and the types of coping strategies the children employed to reduce worry and stress.

Worries

One of the interview questions asked specifically how often the children felt worried about having problems with breathing, with follow-up questions probing their experiences of feeling worried and specific coping strategies the children used. Seven of the participants reported having no worries about their asthma, and two more said they used to worry in anticipation of symptoms, but did not worry anymore because their symptoms had improved. Girls were more likely than boys to report feelings of worry related to their asthma, as six out of the seven girls (85.7%) expressed at least some worry, whereas six of the twelve boys (50%) endorsed at least some feelings of worry. Reasons for not worrying included mild, improved, or resolved symptoms, a feeling of predictability, and a feeling of safety in the school, as exemplified by the following statements:

“Not really. Cuz I know it’s gonna happen only when I run really fast a long time.”
(9-year-old boy on whether he worries and the predictability of asthma symptoms.)
“I really don’t ever worry because I know that I’m in a safe place and we have the technology to the point that we can get an inhaler if we don’t have mine.” (11-year-old girl when asked if she worries about having problems with breathing.)

Ten children did reported feeling worried or anxious about their asthma at some point during the interview. The degree of worry varied from being situational and occasional to more general and frequent. Two students endorsed worried feelings for particular activities, specifically running the PACER and during basketball games. Six other children voiced feeling worried only when experiencing some symptoms. One child reported a recent increase in worrying due to worsening of her nighttime symptoms. Another source of anxiety was the fear of being without medication, which was a very “intense” worry for one 8-year-old boy who explained, “Like if it really happens then what will you do? Like if you’re somewhere else like not in school, and your inhaler’s nowhere to be found, what will you do?” A similar fear was more reality-based for an 8-year-old girl who had experienced breathing problems when she was without her medication. She explained, “I literally couldn’t breathe. That was actually really scary.” Both she and her sister described the nerve-wracking situation of the family trying to obtain medication while away from home. The child with the most severe asthma at the time of the interview mentioned death, and though she did so by saying “I’m not gonna like die or anything…” the mention of death at all is significant, because it indicates it is on the child’s mind. Lastly, one student expressed more pervasive feelings of anxiety throughout the interview, and expressed a potential cyclical relationship between his asthma and anxiety. When feeling stressed at school, he said, “…I start getting anxiety and my asthma starts working up…” and later in the interview regarding what was difficult about a significant asthma-related event he said, “The fact of not being
able to breathe and then it starts putting anxiety on you.” For him, asthma led to feelings of anxiety, but he also suggested that stressful situations contributed to his asthma symptoms.

Vigilance

Discussion of asthma experiences unearthed an impression of vigilance among several of the respondents. Vigilance is defined as, “the action or state of keeping careful watch for possible danger or difficulties” (Oxford Dictionary). It can be characterized by frequent feelings of worry, but is also related to awareness and watchfulness, and to being proactive as a result of the individual’s worry. This theme was found among the conversations with one 10-year-old girl and three 11-year-old girls, who explained they had to keep their asthma in mind throughout the day or when encountering certain activities. For example, the 10-year-old girl described thinking about her asthma more often saying, “…you have to really check in with yourself a lot and really make sure that you’re doing, that you’re getting the right medicine that you need…” The other three girls experienced being alert to potential problems more specifically before or during physical activity, reporting worries about triggering symptoms, having to be aware of their asthma, and possibly deciding whether or not to participate in an activity that might trigger symptoms. For example one said,

“…it’s hard because we do a lot of activities that have to do running or something that I have to run or jump and do things that will give me asthma which means I sometimes can’t participate, well usually I do participate, but it, that means I may get asthma after.”

Further, when providing advice to other children with asthma, two 8-year-old boys used phrases like “stay safe” and “watch out” to advise others to be alert to their bodies and
activities. Three other boys and one girl suggested their peers should be aware of their limitations with physical activity, knowing when to slow down or avoid certain activities. Though these pieces of advice by the children demonstrated less consuming thoughts on asthma, they still suggested a sense of needing to be vigilant about asthma symptoms and triggers to avoid bigger problems.

An interesting aspect about the findings on vigilance related to asthma management was that there seemed to be a fine line between feelings of worry and watchfulness and an expression of more internalized responsibility for one’s own asthma care. It is possible these feelings of vigilance expressed by children with asthma are indicators of children developing a greater sense of independence in their illness management.

*Coping Strategies*

Of the twelve participants who reported having worries about their asthma at some point in time, ten provided examples of what helped them feel better when they were worried about their asthma. Results related to this theme indicated a variety of sources of coping for the participants in this study. The most common way to reduce worry was through symptom relief, primarily through use of medication (four children), though one student used deep breaths and drinking water. Seeking reassurance from parents was a way to feel better for two respondents, and slowing down or taking a break reportedly provided stress relief to two others. The other strategies, each endorsed by one child, were telling a teacher, distraction, self-talk to stay calm, seeking help from friends, feeling confident in one’s own abilities, and one 11-year-old girl said that proving she could still do the running task made her feel better.
The variety of reported strategies suggests coping and seeking relief was highly individualized across the sample.

**Sources of Support**

Regarding support for asthma, one finding was evident from the interviews: children have a variety of thoughts and experiences on who is supportive in the school context and what that support means for them. Their responses were categorized into four themes, which describe how the children accessed their medications, viewed supportiveness from adults, how these views compared with their parents, and the beginnings of the transition toward independence.

**Gatekeepers**

The most basic form of support for asthma in school is through access to medication, primarily inhaled corticosteroids or ‘inhalers’. Two children depicted scenes of a child with asthma seeking help from an adult. One drawing was of a child in the nurse’s office with a thought bubble containing an inhaler (Figure 6). The other drawing was of a child telling the PE teacher he couldn’t breathe and needed his inhaler. Of the fourteen students who had medication at their school, ten reported having to go to the nurse’s office to get their inhalers, and two had to go to the front office, as they did not have a school nurse as a resource. Only three children reported keeping an inhaler in their backpacks, one of who no longer does so, and another of whom only does so because his teacher does not allow him to have his inhaler without a note from the nurse. For nine of the fourteen students, getting their inhalers was a multi-step process that involved first telling or seeking permission from a teacher, then going
to see the school nurse or other keeper of the medication. Four of these nine students reported that accessing their medication when needed was challenging due to the lack of proximity of the nurse’s office to their classrooms or gym, with two of these children expressing this as a source of stress.

**Helpful Adults**

Though adults in the schools acted as gatekeepers much of the time, for some children there were clear distinctions in the levels of additional support they provided. Teachers were the most commonly reported source of support at school. Children described the degrees to which teachers understood their needs, had knowledge of asthma, or provided a sense of safety. One 11-year-old girl said of her PE teacher, “She told me once that she had asthma as a kid, but she got over it, um so I think she just understands.” Though no other students reported connections with their teachers quite like this one, five children said their teachers knew how to help them or were reliable sources of support. Two girls described how when they were younger, teachers helped them remember to take their medicine, and they both expressed still feeling comforted by having teachers around. In general, girls were more likely than boys to seek the school nurse (6/7 versus 3/12) and endorse the importance of reporting symptoms to their teachers (5/7 versus 3/12). Children who attended private schools also reported seeking help from their teachers more often than those in public schools (6/7 private versus 2/12 public school students).

Across the interviews, there were a number of children who did not always seek help from adults or from specific adults. Reasons for this included increased independence, perceived lack of a supportive figure, and social stigma. Feelings of independence and self-
reliance emerged as a separate theme to be described in more detail later, but these feelings reflected several children’s choices to handle their symptoms without adult assistance. One boy was responsible for his own care because his teacher did not allow him to keep medicine in the classroom without a note from the nurse. Instead, he had his inhaler in his backpack, which he administered at his discretion. On several occasions, interviewees mentioned specific adults they tended to avoid due to lack of trust and/or dislike of the adult, for example, one 11-year-old girl said she did not seek help from an adult because,

“…it was my gym teacher and I knew she wouldn’t really do anything, cuz she didn’t have anything to you know any medicine to help asthma and she didn’t have my inhaler, so I didn’t turn to her to fix the problem.”

It should also be noted that earlier in the interview, this girl reported a general dislike for the gym teacher, a view reportedly shared by her peers. Two children described negative feelings regarding their school’s nurse. One said the new nurse is much more helpful and the other still went to the nurse for his medicine, so his negative feelings did not impact him seeking care. An 11-year-old girl implied different levels of trustworthiness among teachers when she said, “I’d probably go tell like a teacher I know that would actually, like, do something about it.”

One 10-year-old girl expressed a high level of adult support at her school, but also felt that there was some risk when asking to take a break that the PE teacher or coach would not allow her to go back to the activity. The girl admitted that this caused her to weigh the decision to seek help when experiencing milder symptoms. Further, one student avoided seeking help because he did not want to “make a scene” or be “over-dramatic” by telling his teacher he was having trouble breathing, suggesting possible avoidance due to fear of stigma. His feelings of being understood and unsupported were further demonstrated in his drawing
of a child with asthma at PE being pressured by a teacher and peers to continue running (Figure 7). Regardless of the reasons for not seeking help, it seemed to be important for many of the children to have an adult at school who was a reliable source of support.

Comparing Child and Parent Sources of School-based Support

The children’s reported sources of support were compared to two items on the parent questionnaire asking the mothers if they had spoken to their child’s teacher about their child’s asthma and with whom they spoke most regarding their child’s asthma (see Table 4 in previous chapter). In comparing the child and parent reports, there were two interesting findings. First, the majority of parents listed the nurse as a point of contact at the school (14/19), and many of their children also discussed seeking help from the school nurse (8/14). Interestingly, children did not mention the school nurse when their mothers did not also list the nurse as a contact person at the school. This was observed among five dyads, though in one instance the school had no nurse.

Second, the reports of parents having spoken with their child’s teacher were compared to the children’s accounts of seeking help from their teachers. Of the eleven mothers who endorsed speaking with their child’s teacher, only five of their children also reported seeking support from their teacher. Three children mentioned teacher support when their mothers said they had not spoken to the teacher and five child-mother dyads did not endorse any asthma-related support or communication with the child’s teacher.
Shift Toward Self-Reliance

As reflected in their responses, the child participants exhibited their own conceptualizations of their asthma and their own strategies for relieving or avoiding symptoms. Five of the children expressed confidence in identifying symptoms and finding relief on their own, and were more likely to seek adult help when symptoms were increasingly severe. For example, one 11-year-old boy with milder symptoms reported, “…well I kinda just hold it in a little unless it gets like really uncomfortable…” at which point he would seek assistance from the school nurse.

Several of the older children, in particular, were more explicit about their confidence in taking care of their own management, as demonstrated by two 11-year-old girls who said, “…I’m older now so I kinda know what I should be doing” and “…I knew I could handle it myself so I didn’t really want any help.” Notably, the oldest seven participants (11 and 12 years old) expressed having some responsibility for taking their medication at school and/or shared feelings of increased independence in their asthma management. Conversely, the four youngest participants (all 8 years old) discussed recognizing symptoms and using strategies such as slowing down or taking breaks, but none of them reported being responsible for their own medication at school. Younger participants also reported missing activities more often than the older participants, which could be due to improvements in symptoms or better understanding of how to handle symptoms and management to be able to participate. These findings could be an indicator of developmental changes that occur leading up to pre-adolescence, as children seek greater independence.
Figure 6: Drawing of a child with asthma in the school nurse’s office by a 10-year-old boy

Figure 7: Drawing of a child with asthma at PE by an 11-year-old boy
CHAPTER 5: DISCUSSION

The goal of the present study was to contribute to current knowledge about the school experiences of children with asthma. In particular, the research questions and methods focused on the areas of illness experience, illness management, social interactions, emotional functioning, and sources of support. Through semi-structured interviews with nineteen children with asthma, along with mother-reported demographic, asthma, and school-related data, a number of findings emerged from the present study in response to the initial research questions. The child interviews painted a rich picture of what it is like to be a student with asthma, showcasing the range of experiences, similarities and differences, and the variety of needs of the children in this study. These findings are summarized with regard to main topic areas of Living with Asthma, Emotional Impact, Having Asthma at School, Social Impact, and Sources of Support. Findings in each area are discussed in their relevance to the literature base and connected with the study’s theoretical framework. Limitations of the study are then discussed followed by further directions for research and practice.

Living with Asthma

Children appear to have a relatively good understanding of how asthma affects them physically, at least in terms of triggers and symptoms (Woodgate, 2009). Based on the responses of participants in this study, all children seemed to have formed their own conceptions of their specific asthma symptoms and means for symptom relief. The most
common symptoms reported by the children were breathing difficulty, coughing, and wheezing, which are typical of asthma presentation (NAEPP, 2011). Though many children reported some common symptoms or triggers, each child had their own unique descriptors of how asthma made them feel, physically and emotionally. In accordance with existing findings, the majority of the participants (79%) reported physical activity as a trigger of symptoms, which led to missed activities for a subset of these children (Walker & Reznik, 2014; Woodgate, 2009; Gabe, et al., 2002). Relief of symptoms was most agreed-upon, as all but one participant reportedly sought their inhalers for symptom relief. Other children also reported one or two other strategies they felt helped alleviate their symptoms, which differed across participants, such as slowing down, resting, or drinking water.

Based on their descriptions, the children’s conceptions of their asthma indicated a negative impact on their lives, as they characterized asthma as being uncomfortable, difficult, and not fun. More specifically, most of the children could find something bad about having asthma, which included symptoms, limitations in activities, inconvenience, and emotional impact (“scary”). All participants were able to remember a time when their asthma was a problem, a finding similar to children’s descriptions of dyspnea in a study by Woodgate (2009), who associated this result with feelings of asthma being overwhelming.

Despite the general feelings of asthma being unpleasant, some children expressed a potential positive impact. A few children viewed asthma as a means to avoid non-preferred physical activities and a few others saw asthma as a social opportunity to connect with other children who had asthma. Children also appeared to diminish the impact of their asthma. This phenomenon was found among adolescents with asthma who, like the children in the present
study, made positive or neutral statements about their asthma in addition to statements indicative of problems (Woodgate, 1998).

In keeping with the literature on normalcy (Lambert & Keogh, 2015; Robinson 1993), children want to be seen as normal and will take measures to ensure their sameness. This concept was observed among the participants of the present study, as many children appeared to underscore the severity of their asthma through minimizing statements that often contradicted previous reports they made about the impact of their illness, a finding common among the literature (Protudjer, et al., 2009; Monaghan & Gabe, 2015). In addition to minimizing the impact of asthma, other attempts to normalize asthma were made. These attempts included children describing improvements in their asthma symptoms or explaining that it could be worse by discussing other children with more severe asthma or more serious chronic illnesses, a finding also observed among children with asthma in Ireland (Monaghan & Gabe, 2015).

Further, several children explicitly reinforced the belief that peers treated them equally and their asthma did not make them different in the eyes of others, which emphasized the importance of being seen as normal. Feeling left out and wanting to keep up with peers was noticed throughout the interviews as well. In other studies, children reported testing the limits of their asthma and risking their health in order to participate with other children and not feel singled out or embarrassed (Lambert & Keogh, 2015; Walker & Reznik, 2014). Unlike these studies, only one or two children even alluded to a willingness to risk exacerbating their asthma symptoms in order to participate in an activity. Further, children in the present study endorsed greater social support than in the aforementioned studies. These findings support those of Woodgate (2009) by demonstrating that social support might be a
protective factor for reducing children’s feelings of isolation and improving treatment adherence. Lastly, another way in which the children expressed normalcy was through making asthma seem normal, specifically through mentioning other children they knew who had asthma. In other studies, children expressed feelings of being different and isolated (Lambert & Keogh, 2015), and perhaps talking about other children with asthma serves to demonstrate the child is not alone in their illness experience.

**Emotional Impact**

Studies have found a variety of emotional concerns for children with asthma, supported by the range of feeling words used by participants (Feldman et al, 2013; Wood et al, 2007). The present study found anxiety to be the greatest concern among many of the children, particularly among the girls, which is consistent with statistics that indicate anxiety disorders are more common in female children and adults (Merikangas, et al., in press). Worries were present for children in anticipation of symptoms and during asthma exacerbations. The bi-directional link between asthma and anxiety, though not directly examined, was observed in interviews with three participants; one child reported anxiety as a precedent for asthma symptoms at times, while also expressing worry when having breathing difficulties, and two girls used calming strategies to help relieve their symptoms (Chen & Miller, 2007, Marriage & Henderson, 2012). There was a link between asthma severity and worry, such that children with less-controlled asthma, as reported by their mothers, were more likely to endorse feelings of worry. Other studies have found mixed results on the connection between asthma severity and anxiety (Everhart & Fiese, 2009; Goldbeck, 2007; Sawyer, et al., 2001).
All students had strategies for coping with their symptoms and any asthma-related worries they experienced. Medication was the number one source for alleviating asthma symptoms, which also served as a means to reduce worry in several children who experienced anxiety during exacerbations. Other coping strategies for relieving anxiety included seeking help or reassurance from others such as parents, teachers, or peers, or self-help through distraction, self-talk, or feelings of self-confidence.

**Having Asthma at School**

Given the added anxiety facing children with asthma, there is expected to be some outward effect on children’s daily functioning, particularly at school. Several interviewees expressed having thoughts related to alertness and anticipation, which has been denoted as a sense of vigilance. Vigilance, for these children, led them to check in with themselves, be aware of their surroundings, think about upcoming activities, and make decisions about participation and seeking medical prevention or intervention. To some researchers, vigilance is viewed as an important part of asthma acceptance (Kintner, 1997) and could even be a step toward the development of independence, judging by the present observation that more vigilant participants also demonstrated greater confidence in handling their own care. Others have related vigilance more to worry. For example, Rhee and colleagues found that adolescents with asthma experienced a sense of “guardedness” related to fears of asthma exacerbations (Rhee, Wenzel, & Steeves, 2007). Based on this understanding, it is expected that additional thoughts of vigilance of an illness could consume a child’s mind, making it more difficult to focus on schoolwork. It is known that high levels of anxiety impact attention, concentration, memory, and other executive functions, so it is possible that even
lower levels of frequent worry can have a negative effect in the classroom (Huberty, 2008). In fact, three participants endorsed experiencing such an impact by reporting times when worries about asthma made it hard for them to focus in the classroom.

Vigilant thoughts regarding asthma at school were not unfounded, as all participants had experienced symptoms at school that led to some form of interruption during the school day. These interruptions were categorized as minor disruptions and inconveniences, such as coughing, having to slow down, or having to go across the school to get medicine, and more impactful limitations on activities involving missed time doing what peers were doing. This was an expected finding, given statistics from the CDC (2007) that describe asthma as a leading reason for limitations in daily activities among school-aged children. Most participants reported restrictions in their physical activities that involved slowing down, stopping, or avoiding certain physical activities. A smaller number of participants reported missing academic activities while seeking relief for their symptoms. Although missing academic time presents clear concerns, it may seem less obvious that missing physical activity can have detrimental effects on children with asthma. Despite being a common trigger of asthma symptoms, physical activity can help improve children’s aerobic functioning over time and contribute to a reduction in asthma symptoms, such that missed physical activity can actually lead to more asthma-related problems (Butterfield, Mason, Tu, Lehnhard, & Schaper, 2015).

**Social Impact**

Missed activities also had a negative social impact on the children. Several children mentioned having to watch their friends play without them or feeling left out when friends
later discussed a fun activity the child had missed. Two children specifically reported feeling sad about being unable to participate. This missed time watching from the sidelines was not only a disappointment for the students, but also lead to missed opportunities to engage in typical social interactions with peers. Though it was a less common concern expressed by the participants, another possible social risk was that of rejection. Surprisingly, given results from other studies, only one child reportedly experienced social rejection through his descriptions of being teased and temporarily losing friends (Woodgate, 2009; Walker & Reznik, 2014). There were more subtle expressions of the fear of negative peer reactions, though these children seemed to either not experience rejection, or had established ways to help peers better understand them and their health issues.

On a positive note, the majority of children reported feeling supported by their peers, although some had more neutral impressions, suggesting their asthma had little impact on their relationships with peers. All but two participants had told at least some of their friends about their asthma. Some children were more selective about who among their friends should know, similar to other findings (Lambert & Keogh, 2015), as they disclosed knowledge of their asthma only to close friends or, in one instance, trusting only other children with asthma. Other children were more relaxed and open with peers about their asthma. One student endorsed sharing the information with peers, particularly before competitive physical activities, to reduce the chance that peers would see asthma as an excuse to quit. Another student was even more likely to seek help from her friends than her teachers when experiencing asthma symptoms.
Sources of Support

For a number of children, teachers and school nurses were the most common sources of asthma-related support at school, though this was mostly for access to prescribed asthma medication. Despite recommendations by the National Institutes of Health, few children in the present study carried their inhalers with them or even kept them in their desks or backpacks, which is a common finding (Berg, 2005; NIH, 2007; Walker & Reznik, 2014). Berg (2005) explained this finding is linked to “zero tolerance” drug policies found in many schools, and not on recommendations for asthma management in school. In the present study, most students were required to see the school nurse to use their medication. While this has obvious benefits, as the nurse is the medical professional in the school who can help monitor asthma medication administration and adherence, there are also downsides, as children are typically not in or near the nurse’s office when they experience asthma symptoms. More immediate access to inhalers allows children to gain faster relief from their symptoms and return to their activities sooner (Walker & Reznik). Such access could also improve prophylactic use of inhalers before physical activity, which reduces the chances of experiencing symptoms during the activity (NIH, 2007). Nearly a third of participants in this study utilized their inhalers to prevent symptoms prior to physical activity, a rate higher than that found by others (Walker & Reznik, 2014). All of these students went to the nurse for their inhalers, and several expressed a sense of inconvenience in getting their inhalers when needed before certain activities, sometimes even missing part of the activity.

Since students rarely had immediate access to their inhalers, adults typically acted as gatekeepers. Many of the students had to first go through their teachers and then the school nurse in order to use their inhalers. The majority of adults granted access to students, but it
was clear that when medication or aid was delayed or lacking, children developed negative impressions of those adults and tended to avoid their help. Conversely, children expressed positive feelings when they felt confident that adults were able and willing to provide help. The children seemed to appreciate adults who were understanding of their needs, had knowledge of asthma, and provided feelings of safety to their students. This sentiment was more commonly noted among female participants, who were more likely to remark on feeling supported by a teacher. Further, it was noted that private school students mentioned seeking teacher help more than those attending public schools, which could be due to smaller class sizes and stronger student-teacher relationships in private school settings. As this study was child-focused, information on teacher preparedness was not obtained, though evidence in the literature suggests teachers, particularly in urban areas, lack the knowledge to support children’s asthma needs, and communication between school nurses and teachers has been found to be inadequate (Bruzzese, et al., 2010). The present results provide evidence of the importance of positive student-teacher relationships, and the negative implications for children whose teachers do not play a supporting role in asthma management.

Also unclear was the role parents played in their children’s school support networks. Findings indicated children only mentioned the school nurse if their parents listed the nurse as a person of contact in the school. Several possible reasons were identified for this pattern. First, children with well-controlled asthma had little to no need for medical care at school, second, there was no nurse at the school, which was the case for one participant, and third, parents had not established the nurse as a resource for their child. Further, parent contact with the child’s teacher did not appear to be related to their child’s endorsement of their classroom teacher as a source of support. When parents said they spoke with the classroom teacher,
fewer than half of their children reported their teacher as someone they went to for help. Other children discussed gaining support from their teacher even when their parents had not spoken with their child’s teacher about the child’s asthma. Communication between parents and teachers is often viewed as protective for child success and wellbeing at school (Christenson & Carlson, 2005) and parent confidence and involvement in school has been shown to reduce the anxiety of children with asthma (Murdock, Robinson, Adams, Berz, & Rollock, 2009). There is more to be learned as to the ways in which parent-teacher relationships influence student-teacher relationships surrounding asthma management in the classroom.

Several older children expressed confidence in their abilities to handle their own asthma care. These students were less likely to rely on adults, opting to help themselves, though they typically sought aid with more severe symptoms. Evidence suggests adults have the potential to help or hinder the development of autonomy in these types of situations based on their responses to the children’s needs (Horner, 1999). For example, one girl relied more heavily on her friends than on teachers, reporting greater feelings of trust and reliability among her peers than adults at her school. Other children had similar feelings of peers being understanding, caring, and helpful, but it did not replace the need for help from adults. These results highlight the differing paths children take toward the development of autonomy in health management and the important role adults can play in helping children transition to greater self-reliance. It is likely that planning and communication between home, school, and child can enhance the ease of this transition.
Connections to the Theoretical Framework

Within a developmental ecological framework, it is expected that having asthma affect the individual child and their interactions with different people and contexts in complex ways. This perspective, based on Bronfenbrenner’s nested model of development, defines children as active participants who shape their world as much as it shapes them (Bronfenbrenner, 1986). Given the range of findings of the present study, an ecological model of development accounts for the unique characteristics and experiences of each participant. This study also explored the utility of sociological frameworks of living with a chronic illness and examined their goodness-of-fit in supporting the present findings. Of consideration was the recent debate on conceptualizing the impact of childhood chronic illness on the child’s biography as disruption, contingency, or continuity (Bury, 1982; Monaghan & Gabe, 2015; Williams, et al., 2009; Bray, et al., 2014). After examination of the interviews and themes, the current study found that when determining the level of disruption asthma creates, there were occasions where each of the models could apply. For example, a small number of children in the present study, when considering the overall sense or “gestalt” of their interviews, indicated a general sense of negativity, anxiety, and apparent difficulty to reconcile asthma with other aspects of life. This overall sense is in keeping with the concept of biographical disruption created by the illness (Bury, 1982).

Further, two participants used language that strongly indicated feelings of transience in their asthma experience, for example, “when I have asthma…” and other similar statements. Other children more subtly described worrying about their asthma only when they experienced or anticipated symptoms. Asthma as a temporary experience fits the findings of a biographical contingency model, such that the illness experience was contingent
upon the active impact on the child’s life, for example during a particular outdoor activity or when the child had a cold (Monaghan & Gabe, 2015).

Other children’s perceptions of their illness appeared to be more consistent with the idea of biographical continuity, through statements made about not knowing what it is like to live without asthma because they were diagnosed at a very young age (Williams et al., 2009). Yet, when taking a broader look at those interviews with children endorsing continuity, they also expressed improvements and positive outlooks on their asthma, as did other children, which is indicative of biographical enrichment (Bray, et al., 2014).

Bray and colleagues (2014) found similar differences among their sample of children undergoing a procedure to improve their illness management. They understood the divided experiences as being based on the children’s expectations for the future and sources of support. Presently, children with reported improvements in asthma symptoms also reported fewer problems at school. Conversely, one child had been experiencing a recent worsening of her nighttime symptoms and endorsed feeling more worried than usual, demonstrating a recent, asthma-related disruption in her daily life.

Though sociology of illness models such as biographical disruption, contingency, and continuity were helpful in explaining and categorizing the children’s views on the impact asthma had on their lives, these models did not seem to account for variations in the impact across participants (Bury, 1982; Monaghan & Gabe, 2015; Williams, et al., 2009). The model presented by Bray and colleagues (2014) explained variations in impact outcomes as being based on children’s expectations for the future, but this model did not consider the unpredictable nature that often characterizes an illness such as asthma, as explained by biographical contingency. Considered individually, the models create an incomplete picture
of the impact of asthma, but when examined in conjunction with one another, they provide a clearer explanation of the differences in children’s experiences with asthma based on their expectations, situations, and age at diagnosis.

The beauty of a developmental ecological perspective was that it could account for these variations in children’s experiences and perceptions, as well as age of onset and fluctuations in asthma presentation. The ability of this framework to explain the differences between the biographical models further demonstrates its applicability to understanding the myriad of ways a chronic illness can impact human development. The developmental ecological model explained the individual differences of living with asthma, as the development of no two children occurs under exactly the same conditions, though they may overlap (such as siblings or classmates). Specifically, the children described illness-related similarities in their experiences of symptoms and treatment, but their emotional experiences, social interactions, and engagement with school personnel all varied greatly, with only some variability explained by age, gender, or asthma severity. There are unlimited factors that could have contributed to these differing outcomes that were not studied, such as the influence of siblings, parent functioning, social dynamics of the classroom, teaching styles, and many others. With such a wide range of potential contributing factors, there is a greater chance that similarities between participants are related to their commonalities, further supporting the findings as being connected to the children’s asthma.

Conclusion

The goal of this study was to gain children’s perspectives on life with asthma specific to the school setting. First, this study provided a voice for children with asthma to share their
stories. The findings from these stories indicated a wide range of experiences and needs, which further denotes the importance of hearing children’s voices and learning their individual needs (Ireland & Holloway, 1996; Woodgate, 2009; Walker & Reznik, 2014). The children provided rich, detailed information that granted access into their thoughts and worlds, demonstrating the importance of securing information directly from the children themselves.

Though there were many similarities across the interviews that indicated areas of need across participants, it was also found that much of the information gleaned from the narratives demonstrated differences and individuality among the children in the sample. The participants expressed a range of thoughts, feelings, experiences, and needs relating to their personal experiences of living with asthma. This finding is not unexpected given the theoretical framework advanced in this study based on Bronfenbrenner’s contextual model of human development (Bronfenbrenner, 1979; 1986; Bronfenbrenner & Ceci, 1994).

Specific findings from the interviews demonstrated the ongoing impact of asthma on the development of children, with potential social, emotional, and academic implications. Pulling these results together, there were some key findings among this group of children regarding their experiences with asthma and its management at school. First, asthma was generally seen as having a negative impact, and positive statements were viewed as attempts to downplay or normalize the experience. Anxiety and worry seemed to be common experiences for children with asthma, and they varied in frequency and intensity between children.

Further, feelings of support in school seemed to matter for the children. Social support was more common than expected across the participants, and it is possible such
support acted as a protective factor that contributed to the children expressing greater awareness and appropriate reactions to their symptoms, such as taking breaks or getting their medicine. Teacher support was viewed positively, but was more often sought by girls and by those attending private schools. For the others, teachers and nurses were the keepers of medication as few children had easy access to their inhalers at school, which is concerning for several reasons. For one, children demonstrated knowledge of their asthma symptoms and triggers, and can be expected to know when they need their medication. Second, lack of medication access could be a barrier to the children’s development of autonomy, as it requires them to rely on adults to manage their care.

Additionally, some children experienced a heightened awareness, or vigilance surrounding their illness. While this vigilance could be attributed to emerging independence, it seemed to be linked with an increased sense of anxiety for some children. Perhaps the outcome of positive versus detrimental experiences of vigilance could be facilitated by better adult support and easier access to medication, which might ease anxiety and promote greater independence. Lastly, it was found that child and parent perceptions of support in school differed. Tying this back to the theoretical framework, management and relationships across systems fall within the mesosystem and have the potential to strongly impact the ways in which a child interacts with their different contexts. Perhaps improved parent-teacher communication, and involving the students in much of the communication, could strengthen children’s feelings of support with having asthma at school.
Limitations

Given the nature and size of the study, several limitations are recognized. First, when conducting a small, qualitative study, there are inherent limitations in generalizing results to a population of children with asthma. Despite concerted efforts, the present sample of participants was the result of convenience sampling and as such, certain characteristics were common across the sample including ethnicity, socio-economic status, access to quality medical care, and interest in participating in research, each of which could have impacted the present findings. It should be noted that a sample of families from generally white and middle to high SES is not representative of children with asthma, particularly given the existing statistics on the disproportionate impact asthma has on certain ethnic minority groups and children from lower income households (Bloom, et al., 2015). Even so, a substantial number of children characteristically similar to the present sample live with and experience the negative effects of asthma, and the present results are believed to be useful in informing the literature on similar children with asthma.

A second limitation pertains to how asthma severity was defined for the sample. In general, there is a lack of consistency in the literature on how to measure asthma severity (Everhart & Fiese, 2009). The present study chose a measure designed for use by medical providers with demonstrated validity (Okelo, et al., 2009). Even so, the measure of asthma severity was based on caregiver report of symptoms and treatment use over a small window of time, which can be impacted by external factors, such as weather and illness. Despite these limitations, the measure was useful for the purposes of this study, as results were viewed as a snapshot of the child’s asthma symptoms and management at the time of the interview.
In an attempt to ensure the children’s and parents’ comfort in their participation, a parent, and in some cases a sibling, were present for some of the child interviews, which may have limited the child’s candor with the investigator. Although this was not suspected to be the case for many of these participants, there is some possibility that more intense topics, such as worries of hospitalization or death, could have been more commonly expressed if children had been interviewed individually. There was also some chance of the mothers influencing the interviews by interjecting information that the children built upon, making it difficult to know if the child would have otherwise discussed the matter. The downside to this uncertainty was that the interviews were designed to be child-focused and the results based on the children’s perspectives. On the other hand, the investigator was sensitive as to the source of information, and even when the parent contributed information, it may have led to additional interesting information from the child that enhanced the author’s understanding of the child’s world. Given the goal of ensuring comfort, it seemed difficult to avoid parent or sibling presence; however in future research, greater efforts should be made to establish rapport earlier on, to increase confidence in securing the child’s individual perspective.

**Future Directions**

An implication of most interest for future research is the family-school connection, as there seems to be a clear area of need in how this connection influences the child’s school-based asthma experiences and a dearth of research on this topic. The present findings seemed to indicate that parents were responsible for establishing a connection with the school nurse, but child and parent opinions of communication with the teacher varied. It would be
important to examine these between-context relationships and their outcomes on child perceptions of asthma-related support in school.

The influence of adult support within the school on the emotional functioning of students with asthma also constitutes a topic of interest, with little existing literature. Though there was some indication that children with more negative perceptions of their asthma sought help less often, these results were inconclusive and may warrant further investigation.

**Practical Applications**

The author recognizes the daily challenges faced by teachers and the amount of hard work they do for their students. There are clear challenges in recommending that teachers learn about different medical conditions of the children they teach. In this case, there is a very good chance that most teachers will encounter a student with asthma given the prevalence among school-aged children. It would be worthwhile to help teachers learn more about the needs of students with asthma. In particular, it would be helpful for teachers to learn to recognize the onset of symptoms and how to properly support students in using their medication, to ensure optimal asthma management. It is also important to keep in mind that asthma can create a great deal of added stress for children, but this might not affect a child every day. Having teachers who recognize symptoms is important not only in management of the child’s asthma, but also to be aware of the possible emotional complications paired with the physical experience of an asthma exacerbation, including the fear of worsening symptoms. Intervention programs aimed at improving teacher preparedness and supportiveness in school-based asthma management have demonstrated improvements in
teacher knowledge of asthma and in the establishment of stronger student-teacher relationships (Kintner, et al., 2014; Neuharth-Pritchett & Getch, 2015).

School psychologists also have the potential to be involved in enhancing support for children with asthma. Their existing role in identifying children with social and emotional needs could be expanded to focus more closely on children with asthma, given the increased risk for such needs among this population of students. School psychologists could conduct screenings or provide teacher education on indicators of risk. Further, it is recommended that schools, parents, and students all work together to create feasible plans for optimal asthma management at school, particularly given the differences found between child and parent reports of teacher involvement. This is another area in which school psychologists, with their expertise in team planning and problem solving, could provide leadership or support. The school psychologist could facilitate communication for teams comprised of the child’s primary teacher, physical education teacher, and the school nurse, along with the child and their caregivers, and guide the team process toward establishing comprehensive plans. Any other adults who might be involved in the child’s care, particularly during gym or recess, should also be informed of the child’s asthma plan. Lastly, school administrators, school psychologists, and/or school nurses should review existing policies on student access to asthma medications and work closely with one another as well as teachers and families to ensure the best plan for medication access is in place for each student.
APPENDIX 1: PARENT QUESTIONNAIRE

Child’s Date of Birth:_____/_____/________

The information you will be asked to provide is important and useful information that will help us better understand the experiences of children with asthma. All information you provide will be kept private and confidential. Your name and your child’s name will not be publicly linked to any of this information.

Please answer the questions as honestly as possible.

I. Demographic Information

Please answer some questions about you and your family.

A. What is your relationship to child?
Mother       Father       Grandmother      Grandfather       Other:___________

B. What is your age?
1. 20 or younger
2. 21-30
3. 31-40
4. 41-50
5. 51-60
6. 61 or older

C. What is your highest completed educational level?
1. Some high school or less
2. High school diploma/GED
3. Some college
4. 2 year college degree (AA)
5. 4 year college degree (BA/BS)
6. Graduate or Professional degree

D. What is your race/ethnicity?
1. African American
2. Asian-Pacific Islander
3. Hispanic
4. Native American
5. White
6. Other: ______________

E. What is your current marital status?
1. Single, never married
2. Married
3. Separated
4. Divorced
5. Widowed
F. How many people live in your home? _______
   How many adults? _____   How many children? _____

G. Does anyone in your home smoke?    Yes      No

II. Your Child’s Asthma

Please answer the following questions about your child and their asthma.

A. At what age was your child diagnosed with asthma? ______

B. How many times in the past year has your child:
   a. Been to the emergency room for asthma? ______
   b. Been hospitalized for asthma? ______

C. How often do you forget to give your child’s daily asthma medicine when he or she feels fine? (Daily asthma medicines include: Advair, Asmanex, Budesonide, Dulera, Flovent, QVAR, Pulmicort, Singular, Symbicort)
   ☐ My child is not supposed to take a daily asthma medicine
   ☐ None of the time
   ☐ Some of the time, 1-2 days/week
   ☐ Most of the time 3-4 days/week
   ☐ All of the time 5-7 days/week

D. How much responsibility would you say your child has over managing his/her own asthma (i.e. taking medications)
   ☐ All      ☐ Most      ☐ Half      ☐ Some      ☐ None

E. Over the past week, how many days has your child has asthma symptoms? [Symptoms include cough, chest tightness, shortness of breath, sputum (spit, mucous, phlegm when coughing), difficulty taking a deep breath, wheezing]
   ☐ None      ☐ 1-2 days      ☐ 3-6 days      ☐ Every day

F. Over the past week, how many days have you had to give your child medicine to quickly relieve asthma symptoms? (For example: Albuterol, Proventil, Proair, Ventolin, or Xopenex by Inhaler, Spray, Pump or Machine, Nebulizer)
   ☐ None      ☐ 1-2 days      ☐ 3-6 days      ☐ Every day

G. Over the past week, how many days did your child have an asthma attack? (For example: when it is harder to breathe for your child, when you give your child more quick-relief asthma medicine, when the asthma medicine does not work)
   ☐ None      ☐ 1 day      ☐ 2-3 days      ☐ 4-7 days
H. Over the past week, how much did asthma limit your child’s activities?

☐ Not at all   ☐ Slightly   ☐ Moderately   ☐ Very Much   ☐ Completely

I. Over the past TWO weeks, how many nights did your child’s asthma keep him or her from sleeping or wake him or her up?

☐ None   ☐ 1 day   ☐ 2 days   ☐ 3-7 days   ☐ 8-14 days

III. Your Child’s School

A. Where does your child attend school? _____________________________

B. How is your child doing in school?

Excellent   Very Good   Good   Okay   Poorly

C. Does your child have an Asthma Action Plan at school?  _____ Yes  _____ No

D. Does your child have any special educational needs?  _____ Yes  _____ No

If Yes, please specify those needs:

504 Plan ________  IEP ________  Other: ________

E. Have you spoken with your child’s teacher about your child’s asthma?  Yes  No

F. Who do you speak with most at your child’s school about your child’s asthma?

______________________________
APPENDIX 2: CHILD MEASURES

Child Drawing Task

I would like you to draw some pictures for me. First, please draw a picture of a child at school. [Allow the child to draw the picture] Excellent job! Now, on this new piece of paper, please draw a picture of a child with asthma at school. [Allow the child to draw the second picture and give appropriate praise] Would you like to tell me about your pictures?

Child Interview

Now, I would like to ask you some questions about what it’s like for you to have asthma at school. I don’t know very much about this, and I’m hoping you can help me better understand what having asthma is like for you. There is no right or wrong answer; these questions are about you.

Remember, if you do not feel comfortable answering a question, you can tell me at any time. You are volunteering to do this and can stop at any time. You can also tell me if you need or want to take a break at any time during our conversation. I have a tape recorder to record our conversation to help me remember what we talked about. These tapes will be kept private and will be erased when I am done using them. Are you okay with having the tape recorder on? I will also be taking notes to help me remember. Is this okay?

Are you ready to get started?

First, I’m going to ask you some general questions about school.

1. Tell me about your school:
   • What do you like about school?
   • What do you not like about school?

2. What do you think is hard about school?

3. What is it like to have asthma?

4. What is it like to have asthma at school?
   • What is good about it?
   • What is bad about it?
   • [If not already mentioned] Do you ever miss activities because of your asthma?
   • What is it like to miss out on those activities?

5. Do your friends know you have asthma?
   • [If no] What has kept you from telling them?
   • [If yes] What is that like?
6. How do you feel about having asthma when you are in school?
   • Tell me about a time you had an problem/hard time with asthma at school
   • Who did you go to talk about it?

7. Have you ever had trouble breathing at school? What was that like?
   • What did you do? Who helped you? What would you do if it happened again?

8. Some kids with asthma worry about having problems with breathing:
   • How often do you feel worried about this?
   • What does that feel like?
   • What do you do to feel better/what makes you feel better when you worry?

9. Do you take medicine for asthma at school?
   • Tell me about that: Who has the medicine? How often do you take it? Who makes sure you take your medicine?

10. Pretend there is a new student in your class. You just found out they have asthma. What advice would you give the new student?

11. We’ve talked a lot about having asthma at school and you have given me a lot of good information about what it’s like for you to have asthma. What else is important to you that I did not ask?
APPENDIX 3: CHILD DRAWING TASK SCORING RESOURCES

Drawing Task Scoring Sheet\(^1\)

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
</tr>
</thead>
</table>

**Drawing 1:**

**Part A**  
1. Person: Position  
2. Action  
3. Length of Person  
4. Width of Person  
5. Facial Expression  
6. Eyes  
7. Size of Person to Environment  
8. Use of Paper  
9. Placement  
10. Strokes: Quality  
11. Health Equipment  
12. Developmental Level  

**Part B**  
13. Omission: 1 Part  
14. Exaggeration of a Part  
15. Deemphasis of a part  
16. Absence of a part  
17. Total Part B  

**Part C**  
18. Distortion  
19. Transparency  
20. Mixed Profile  
21. Total Part C  

**Total Score:**  
A + B + C =

Child Descriptions of Drawing 1:

**Part C Rubric.\(^2\)**

<table>
<thead>
<tr>
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<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping</td>
<td>Light stress</td>
<td>Stressed</td>
<td>Disturbed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Realistic, pleasant, bright, well-proportioned, confident, happy</td>
<td>Less pleasant, some distortion of size, less bright and cheerful</td>
<td>Constricted, inhibited, drab, sad, scared</td>
<td>Overwhelmed, disorganized with sad, defeated feelings, bizarre</td>
<td></td>
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</tbody>
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\(^1\) The score sheet was adapted from the CD:H manual (Clatworthy, et al., 1999)

\(^2\) The scoring aids labeled Parts A, B, and C were obtained directly from the CD:H manual (Clatworthy, et al., 1999)
Part A Rubric.

<table>
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<tr>
<th>SECTION</th>
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<th>10</th>
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</thead>
<tbody>
<tr>
<td>1. Position of person</td>
<td>Standing - grounded</td>
<td>Standing - not grounded</td>
<td>Standing with crutches</td>
<td>Standing on bed</td>
<td>Sitting in chair</td>
<td>Sitting in bed</td>
<td>Sitting in bed, covered</td>
<td>Lying in bed</td>
<td>Lying in bed, covered</td>
<td>Floating or no person</td>
</tr>
<tr>
<td>2. Action / Life</td>
<td>Visibly moving</td>
<td>Person or picture lively</td>
<td>Shows some life</td>
<td>Potential for movement</td>
<td>No movement, no life</td>
<td>Rigid, no life</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Length of person</td>
<td>Body tall, occupies whole paper</td>
<td>Tall body appropriate to picture</td>
<td>Short body appropriate to picture</td>
<td>Short people, bodies exposed</td>
<td>Very small, constipated people</td>
<td>Upper torso only</td>
<td>Head only, body covered</td>
<td>Floating head, no body</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Width of person related to length</td>
<td>Width appropriate to length</td>
<td>Width slightly reduced compared to length</td>
<td>Width thin compared to length, clothed</td>
<td>Body thin, not clothed, or appropriate, but not clothed</td>
<td>Appropriate body size, covered</td>
<td>Stick figures, with clothing</td>
<td>Stick figures, no clothing</td>
<td>Very thin body or stick figure, covered</td>
<td>Ambiguous body shapes</td>
<td>No body, floating head, no evidence of body under covers</td>
</tr>
<tr>
<td>5. Facial expression</td>
<td>Smile</td>
<td>1/2 smile</td>
<td>Neutral</td>
<td>1/2 Frown</td>
<td>Frown</td>
<td>No face, no expression</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Eyes/pupils</td>
<td>Appropriate size</td>
<td>Medium to small</td>
<td>Small</td>
<td>Very small</td>
<td>Tiny eyes, no expression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Size of person in comparison to environment</td>
<td>Appropriate size</td>
<td>Medium to small</td>
<td>Small</td>
<td>Very small</td>
<td>Tiny eyes, no expression</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Color performance</td>
<td>Yellow</td>
<td>Green</td>
<td>Blue</td>
<td>Orange</td>
<td>Purple</td>
<td>Brown</td>
<td>Red</td>
<td>Black</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Number colors used</td>
<td>6</td>
<td>7</td>
<td>6</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Use of paper</td>
<td>All</td>
<td>3/4</td>
<td>1/2</td>
<td>1/4</td>
<td>Restricted use</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>11. Placement on paper</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Quality of strokes</td>
<td>Firm, dark</td>
<td>Dark, some light</td>
<td>Medium, equal light and dark</td>
<td>Light</td>
<td>Very light</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Hospital equipment</td>
<td>None included</td>
<td>Proportional in size</td>
<td>Slight increase in size</td>
<td>Larger equipment</td>
<td>Large and threatening</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Developmental level</td>
<td>Above normal</td>
<td>Normal</td>
<td>Slightly below normal</td>
<td>Below normal</td>
<td>Markedly below normal</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Glatt summ. 1985

Part B Guide.

**PART B**

Add 5 points for each of the following:

15. Omission of one body part
   - Hand on one side, but not the other. All persons should have body, head with a face with eyes and mouth, arms with hands and legs with feet. After age 7, should also have nose, hair, and ears. If the body part is under covers, do not count as missing part. Do not count ears as missing if covered by hair. Do not score omission of one part if you score omission of two or more parts.

16. Exaggeration of a body part
   - One leg is much larger than the other. Also, score if head or body is exaggerated.

17. Deemphasis of a body part
   - One arm is much smaller than the other. Also score if head or body is smaller.

Add 10 points for each of the following:

18. Distortion
   - A body part is distorted or disconnected. Whole body is misshapen.

19. Omission of two or more body parts
   - Two hands, two eyes, or one hand and one foot are missing.

20. Transparency
   - Organ showing through the skin (bones, heart, etc.) at any age. Body part showing through clothing or blanket or any other transparency after the child is 9 years of age.

21. Mixed profile
   - In a profile two eyes, two ears are seen after the child is 10 years of age.

22. Shading
   - Coloring over a body part which does not indicate clothing or skin color. Also may be seen as a different color extremity. Coloring in all or part of background (i.e., sky, ground, etc.) is scored as shading.
APPENDIX 4: CHILD DRAWINGS

Drawings of children without and with asthma at school by an 11-year-old boy

Drawings of children without and with asthma at school by a 9-year-old boy
Drawings of children without and with asthma at school by a 9-year-old boy

Drawings of children without and with asthma at school by a 10-year-old boy
Drawings of children without and with asthma at school by an 11-year-old girl

Drawings of children without and with asthma at school by a 10-year-old boy
Drawings of a child without and with asthma by a 10-year-old girl

Drawings of a child without and with asthma at school by an 8-year-old boy
Drawings of a child without and with asthma at school by a 10-year-old boy

Drawings of children without and with asthma at school by a 10-year-old girl
Drawings of children without and with asthma at school by an 8-year-old girl

Drawings of a child without and with asthma at school by an 11-year-old boy
Drawings of children without and with asthma at school by an 11-year-old boy

Drawings of a child without and with asthma at school by a 12-year-old boy
Drawing of a child at school who also has asthma by an 11-year-old girl

Drawings of a child without and with asthma at school by an 8-year-old boy
Drawings of children without and with asthma at school by an 11-year-old girl

Drawings of children without and with asthma at school by a 10-year-old girl
Drawings of a child without and with asthma at school by a 10-year-old boy
REFERENCES


