Pilot Testing *Okay with Asthma*™: A Digital Story for Psychosocial Asthma Management

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ABSTRACT

Asthma, an obstructive airway disease characterized by recurrent episodes of breathlessness and wheezing, is the most prevalent chronic illness among children in the United States. An estimated 7.7 million American children have asthma. Health experts suggest that cognitive, emotional, and behavioral variables contribute to its severity. To date, asthma education programs have focused on asthma triggers, behaviors to manage asthma, and asthma medications; however, they have not addressed the emotional component of children's experience with asthma. This is important because the way children feel about their asthma, or their attitude, affects what they learn and how they apply it. The research reported here tested the effectiveness of an educational program for school-aged children with asthma that included not only traditional content to manage asthma but also psychosocial management strategies. *Okay with Asthma*™, a digital story and story writing program, was developed for children with asthma between the ages of 8-11 years, based on Gagne's conditions of learning theory and Egan's learning through story model.

The research tested the effects of *Okay with Asthma*™ on children's attitude toward having asthma and their knowledge of asthma. Using a one-group pretest-posttest non-experimental design, 35 children with moderate to severe asthma, who were enrolled in Albemarle county public schools completed a pretest to measure knowledge and attitude, then completed *Okay with Asthma*™. At 1-week and 2-week post intervention, participants completed the knowledge and attitude measures again.

Children had significant improvements in asthma knowledge scores at 1-week and 2-week evaluation and significant improvements in attitude scores 2 weeks after

completing the program. Children with severe asthma showed the greatest improvement in knowledge and attitude scores. The participant's learning style had no effect on the child's knowledge and attitude score indicating *Okay with Asthma*™ is well suited for children with varying learning styles. Since the goal of this project was to develop an educational program for children with asthma, it is recommended that school nurses incorporate Okay with Asthma™ in their current asthma education program and refer children and families to the program at http://okay-with-asthma.org.

TABLE OF CONTENTS

LIST OF FIGURES AND TABLES

CHAPTER ONE: INTRODUCTION

Nature of the Problem

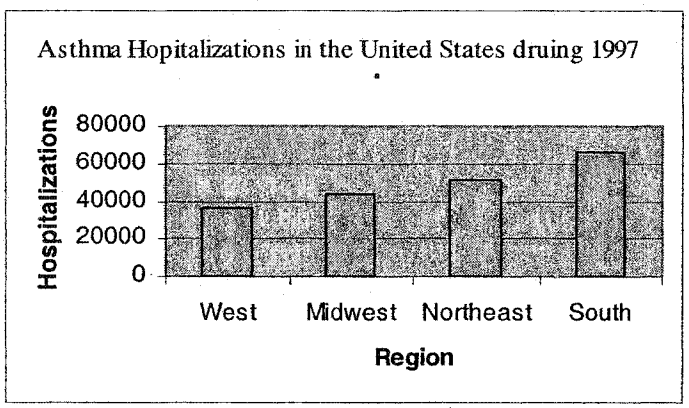
Asthma, an obstructive airway disease characterized by recurrent episodes of breathlessness and wheezing, is the most prevalent chronic illness among children aged 0-18 years in the United States. An estimated 7.7 million American children have asthma (American Lung Association, 2002). In the 1980s and 1990s, the prevalence of childhood asthma increased approximately 4.3% each year until 1995, when the increase reached 7.5% (AAAAI, 2002). Low income and African-American children are particularly hard hit with incidence rates that exceed those for children of other races and backgrounds. In 2000, the prevalence of asthma in African-American children was 76.8 per 1,000 compared to 53.4 per 1,000 in white children (Stapleton, 2002). Fortunately, the rate at which asthma increases has now slowed. While this slowing of the increase in prevalence is encouraging and in part attributable to improved asthma medications and intervention programs, a large number of children continue to be affected by this disorder.

Data from the National Center for Health Statistics (2000) National Health Interview Survey, a nationally representative sample of the United States population, revealed in 1998, a 5.3% prevalence of childhood asthma. According to the Health Care Costs and Utilization Project (HCUPNet), approximately 200,000 children were hospitalized in the U.S. with a primary diagnosis of asthma during 1997 with more hospitalizations reported in the South than any other region (see Figure 1).[1]

[1] Weighted national estimates from HCUP Kid's Inpatient Database, 1997, Agency for Healthcare Research and Quality (AHRQ), based on data collected by individual states and provided to AHRQ by the states.

Children with asthma experience school absences, and according to Bloomberg, (2002), approximately 71% are hospitalized at some point. In 2001, the estimated annual cost for treating asthma in children in the United States was 3.2 billion dollars (American Lung Association, 2002). During 1995 (the latest year for which data are available) in the state of Virginia alone, an estimated $17 million was spent in hospitalizations related to childhood asthma (Virginia Department of Health, 1997). Forty-eight percent of pediatric asthma hospitalizations are school-aged children and overall, an estimated 10 million school days are missed each year (National Institute of Allergy and Infectious Disease, 1997).

FIGURE 1 ASTHMA HOSPITALIZATIONS IN THE U.S.



School children are at high risk for asthma attacks. The exact cause of asthma is unknown, but numerous factors are known to trigger episodes including infections, allergic reactions, exercise, and stress. School buildings contain allergens such as cockroaches and other pests, mold resulting from excess moisture in the building, and dander from animals in the classroom (U.S. Environmental Protection Agency, 2002). Approximately 75 to 80% of children with asthma have allergies that trigger episodes (American Lung Association, 2002). Because children spend a significant amount of their

South region includes Alabama, Arkansas, Delaware, District of Columbia, Florida, Georgia, Kentucky, Louisiana, Maryland, Mississippi, North Carolina, Oklahoma, South Carolina, Tennessee, Texas, Virginia and West Virginia.

weekday in schools, they are highly susceptible to asthma attacks during school.

Children with asthma experience the stress of a chronic disease in addition to the everyday stressors of self-concept, school, family, and peer relationships (Walsh & Ryan-Wenger, 1992). The psychosocial stress of asthma can lead to negative feelings and attitudes about asthma and lower self-esteem, which in turn can produce asthma episodes (Miller & Wood, 1994; 1995; 1997). Children with severe asthma appear to be at greater risk for anxiety, depression, behavioral problems, and lower self-esteem than healthy children or children with other chronic diseases (Brook & Tepper, 1997; Gibson, Henry, Vimpani, & Halliday, 1995; Margalit, 1982; Padur et al., 1995; Panides & Ziller, 1980; Teiramma, 1979). The psychosocial disturbances associated with childhood asthma profoundly affect school performance, family and peer relationships, asthma management and overall quality of life (Austin, Huberty, Huster & Dunn, 1998; Brook & Tepper, 1997; Eiser, Havermans, Pancer & Richard, 1992; Gibson, Henry, Vimpani, & Halliday, 1995; Hamlett, Pellergrini & Katz, 1992; McLean, Perrin, Gortmaker & Pierre, 1992).

Children who are repeatedly hospitalized are likely to experience considerable psychological and social distress, and families of children with a history of hospitalizations due to asthma often doubt their ability to control asthma attacks (Bloomberg, 2002). For these reasons, psychosocial management strategies should be integrated into childhood asthma programs and focus on influences in a child's life such as family, peers and school.

Current educational programs for children with asthma are based on the guidelines of the National Asthma Education and Prevention Program (NAEPP) developed by the National Heart, Lung and Blood Institute of the National Institutes of Health (1997). The

programs focus on asthma triggers, behaviors to manage asthma, and medications, and have been shown to increase asthma knowledge and improve asthma management behaviors. However, the programs do not address the emotional component of children's experience with asthma. This is important because the way children feel about their asthma affects what they learn and how they apply it. Further, asthma education programs for children traditionally have focused on the family's role in managing the child's asthma. While family involvement is crucial, it is also equally important to engage children themselves in the asthma management experience. A child involved in his or her own health and wellness will assume more responsibility and ultimately feel more in control of his or her health, which will promote a more positive attitude toward having asthma (Miller & Wood, 1991). Children in school or engaged in after-school activities must identify their own symptoms during an asthma attack and seek help outside the family relying on school, peer, and community interactions to assist with self-management. Miller and Wood (1995) suggested that school and peer group interactions are crucial in managing a chronic illness such as asthma. Such interactions not only support children with asthma but also may reduce their psychosocial stress. Clearly, asthma programs should promote a positive attitude toward having asthma so children are better able to manage their feelings and potentially improve health outcomes.

Some asthma programs for school age children are designed for classroom settings such as Open Airways for Schools® (American Lung Association, 2002) and Asthma Awareness: Curriculum for the Elementary Classroom™ (National Heart, Lung and Blood Institute, 1993). These programs integrate asthma education into the physical/health education curriculum. Because of increasing curriculum demands on

educators, such labor and time-intensive programs are difficult to implement, often are not integrated into the curriculum and are taught by persons who may not have sufficient experience with the management of chronically ill children.

The proposed research will address the gap in educational programming for school-aged children with asthma because the program developed for this research includes not only traditional content to manage asthma but it also includes psychosocial management strategies. It is believed that including psychosocial management strategies will promote positive attitudes toward having asthma, which may assist child adjustment to their asthma.

Some asthma education programs use multimedia to deliver content. Multimedia, which deliver information in several ways such as reading, viewing and listening, have been reported to be effective in increasing health promoting behavior (Lieberman, 1997). Children typically become more attentive to and involved in multimedia educational activities than traditional educational activities (Austin, 1995). Furthermore, this generation of children is accustomed to learning in audiovisual environments. Use of multimedia to deliver content to children about asthma and ways to adjust to asthma may be superior to using traditional methods.

Multimedia-based asthma programs use self-guided learning techniques. ClubHouse Asthma, by MindJourney©, for example, teaches children how to recognize signs and symptoms of an asthma episode and reviews common medications and treatments. Bronkie the Bronchiasaurus™, sponsored by the American Lung Association, challenges players to manage the main character's asthma by making decisions that will influence the character's health. Watch, Discover, Think and Act™, developed by Macro

International Inc. for the National Heart, Lung and Blood Institute, National Institutes of Health, focuses on the knowledge and skills needed for asthma control and knowing when to apply them. All existing asthma multimedia programs use game activities and fictitious characters to deliver information about asthma and have been reported superior to traditional educational programs because of the interactive nature of the programs (Lieberman, 1997). While these programs have been shown to be effective in changing behavior, they have focused primarily on imparting knowledge about asthma. This teaching approach is primarily useful for didactic but less useful for trying to change attitude. According to Gagne's conditions of learning theory (1985), a change in attitude requires role modeling or persuasive arguments. One useful role modeling strategy is story, especially for school-aged children.

Story is the communication of information through a storyline with characters, conflicts, and resolution to the conflict. There are two components of story, storytelling (receiving a story) and story writing (making a story). Storytelling and story writing have long been used as teaching tools in health education and as therapeutic interventions (Eder, 1994; Geanellos, 1996) especially when attitude and values are an important component of learning objectives. Storytelling and story writing have been used in alcohol prevention, behavior modification, food choices, first aid, healthy lifestyles promotion and special education programs for youth and children who are critically ill (Bauer & Balius, 1995; Cox, 1998; Daniels & Ubbes, 1996; David, 1994; Freeman, 1991; Marchand-Martella & Marchand, 1991 & Madlem, 1997).

Storytelling and Story Writing to Promote Asthma Management

The use of stories and story writing to engage a person in experiential learning is often referred to as *storyline* teaching. This form of teaching is particularly appropriate to promote active learning and enthusiasm among elementary and middle school children (Barr & McGuire, 1993). Story is also extremely useful for influencing attitude because characters in the story role model situations and resolve conflicts. The power of story is that it engages the reader and requires attention so that the reader learns the content of the story while also becoming emotionally engaged with the characters and events (Egan, 1992). Stories encourage learning because learning stems from imagination and stories exercise the imagination, which stimulates learning in multiple ways (Egan, 1986; Egan, 1997; McEwan & Egan, 1995).

When story is coupled with story writing the benefits are great. Bruner, a proponent of instructional uses of story, argues that telling one's own story is the primary tool for the creation of meaning. Bruner (1986) believes that story is context-rich and children quickly learn to create stories in order to succeed in school and at home. Story writing is a form of expressive writing for children. Children create stories that may be imagined, or may represent real experiences, perceptions and emotions. Storytelling and story writing help children gain insight into feelings and behavior and develop or change attitudes and values (Dicke, 1998). In a recent study of children with asthma who participated in an expressive writing program, Smyth, Stone, Hurewitx and Kaell (1999) reported asthma symptom reduction and improved health status in as little as two weeks. Gains in health status were still evident four months later. The recent resurgence of interest in storytelling may in part, be due to technology innovations that create interactive environments suitable for stories.

Digital storytelling is the creation, design, and engagement in interactive stories via technology and is rapidly evolving. Multimedia stories, often referred to as *living books*, can be found in many classrooms and are used to encourage reading, writing, character development and to teach content.

Okay with Asthma™

The interactive storytelling and story writing program *Okay with Asthma*™ was developed to provide resources to school nurses and to encourage children to become active participants in their own asthma management. *Okay with Asthma*™ is an Internet-based asthma management program designed to be used in school settings by children between the ages of 8 –11. The goal of the program is to influence children's knowledge and their attitude toward having asthma through an animated digital story and story writing program (Appendix A). *Okay with Asthma*™ is based on several theoretical perspectives. Austin (1990) and Miller and Wood's (1991) care models guided the incorporation of psychosocial strategies and school, peer, and friend involvement in the management of asthma. Egan's (1986) model of story guided the format of storytelling and story writing used in the program.

Okay with Asthma™ is an interactive story of Gina, a 13 year-old girl with asthma. She is slightly older than the intended audience since school-aged children tend to emulate teens. Gina has an asthma attack after petting a dog on the school grounds. She begins coughing and is unable to breathe because she is allergic to the dog. Her anger and embarrassment, because her friends see this, escalate the attack and coughing. Her friend Matthew accompanies her to the school clinic where Mr. White, the gym teacher, helps Gina with her asthma and teaches both Gina and Matthew about asthma through rap

songs. At the end of the story children are asked to write their own asthma story by adding text to a pre-written story. In this pre-written story, children are camping in the woods with two chaperones, Mr. White and Mrs. Koogler, when a child with asthma, Cole, begins coughing and is unable to breathe while sitting in front of a smoky campfire. Cole talks about having asthma, and children viewing the story are able to add their own words about feelings they associate with having asthma. The instructions encourage children to describe their own feelings and their support systems. At the end of the story, the children can print their story and a certificate of completion.

Okay with Asthma™ is delivered via the Internet for several reasons. In 1995, 95% of public schools in the United States had the capacity to access the Internet (Washington Associated Press, 1999) and today even young children have become proficient in the use of computers. Designing the program for the Internet ensures that school personnel, such as educators and school nurses, can access the program free of charge without the additional expense of purchasing CDs. The program is also ideal for schools because children can be relatively independent while using the program, freeing up already strained school nurses and other scarce resources in the school health setting and increasing the likelihood that the program will be adopted in schools. Further, in *Okay with Asthma*™ the story takes place in a school, where children are most likely to encounter the physical and social problems of having asthma. Finally, since the program promotes psychosocial management of asthma as well as successful self-management of asthma, it could be widely used in school systems to supplement comprehensive asthma programs and support school nurses in their care of these ill children.

The study reported here was a pilot-test of the effectiveness of *Okay with Asthma*™ in increasing asthma knowledge and improving children's attitudes toward their illness. The research was guided by Gange's conditions of learning theory and Egan's learning through story model. *Okay with Asthma*™ was tested with children enrolled in Albemarle County Public Schools using a one-group pretest-posttest non-experimental design. This proposed research project sought to answer the question;

> *Does promoting psychosocial management of asthma using an interactive digital storytelling and story writing teaching strategy (Okay with Asthma*™*) improve knowledge about asthma and attitudes toward asthma over baseline in latency-aged children with moderate to severe asthma?*

The hypotheses were as follows: In latency-aged children with moderate to severe asthma,

H 1 = one week after completing the *Okay with Asthma*™ program (T_2) participating children will have significantly higher scores on both the asthma knowledge and child attitude scales than at baseline (T_1).

H 2= two weeks after completing the *Okay with Asthma*™ program (T_3) participating children will have significantly higher scores on both the asthma knowledge and child attitude scales than at compared to baseline scores (T_1).

CHAPTER TWO: REVIEW OF LITERATURE

The major aim of many health educational programs is to increase knowledge about an illness, which presumably will lead to better management of that illness. This approach is similar in programs for adults and children. Many of the programs are ineffective, however, perhaps due to inadequacies in both the content and the delivery of the content. This chapter reviews literature on relationships between asthma knowledge, attitude, and asthma management, and the effects of educational programs in enhancing attitudes that lead to more effective asthma management. The discussion is embedded in Gange's conditions of learning theory and Egan's learning through story model, both of which propose to account for learning in children. These theories provide a framework for understanding the content and teaching strategies that effect change in children. The chapter begins with a discussion of knowledge and attitude as the building blocks for asthma management. This is followed by a description of the theoretical framework and its relationship to the proposed study. Then the chapter examines existing child asthma programs and their strengths and limitations, the *Okay with Asthma*™ program and how it represents an improvement over currently available programs.

Definitions

For the purposes of this proposed research, the following are operational definitions of the variables in this study.

Dependent Variables

Knowledge, is the capacity to acquire, retain and use information; a mixture of comprehension, experience, discernment and skill (Badran, 1995). Knowledge is

measured in this study to determine if *Okay with Asthma*™ facilitates development of basic knowledge of asthma.

Attitude, is a learned predisposition to respond in a consistently favorable or unfavorable manner with respect to oneself or characteristics of oneself (Rajecki, 1982). For this study, attitude is measured to determine if *Okay with Asthma*™ influences a child's attitude toward having asthma, which in turn may influence what they learn and how they manage their asthma.

Independent Variable

Okay with Asthma™, is an Internet based digital story and story writing program designed for children with asthma between 8-11 years of age. This program presents *asthma psychosocial content* through a *story* model. These two components have not been used in previous asthma interventions therefore each is defined below.

Story, is the communication of information through hearing, reading, watching, or telling of fictitious or true events in a storyline format, which includes characters, conflict, and resolution of the conflict. The story may be one's personal story or the sharing of another's story. For this study, story represents a method of role modeling and persuasive argument to effect attitude change.

Asthma psychosocial content, refers to strategies one exercises to adjust or manage feelings associated with having asthma. These strategies may include but are not limited to developing support systems, recruiting assistance from peers and friends and talking about feelings with trusted individuals. For the purposes of this study, asthma psychosocial content represents content that validates the relationship between emotions,

attitude, feelings and asthma and provides strategies to promote positive psychosocial adjustment.

Knowledge of and Attitudes Toward Asthma

Asthma knowledge cannot alone change health and psychosocial management behaviors, but asthma knowledge in combination with psychosocial asthma content may establish a foundation for managing asthma. If a child has misconceptions about asthma and its influence on health and well being, these misconceptions can be addressed to improve asthma outcomes (Grant et al, 1999). Attitude is thought to play a significant role in health intention, health behaviors, coping, and quality of life, thereby indirectly influencing physiological outcomes. In asthma, attitude is believed to affect the severity of disease and asthma management. There is anecdotal evidence that health care providers need to include interventions to promote positive attitude formation among children with asthma because attitude influences health.

Little is known, however, about children's belief and attitudes about illness. Bibace and Walsh (1980) and Natapolff (1978) have described a child's conception of illness as a negative event that interferes with normal life events. Studies of children's perceptions of illness have generally used the Piagetian construct on the assumption that a child's reasoning about illness parallels reasoning about the physical world. These studies confirm a shift in children's reasoning about illness from preoperational thinking in preschool children to concrete operational reasoning at later ages (Parmelee, 1992). Children with concrete reasoning view illnesses as external, requiring direct contact in order to contract them. With formal operational reasoning, the child begins to recognize both internal and external causes of illnesses (Bibace & Walsh, 1980). In this stage of

reasoning, children have a basic knowledge of the disease process. This knowledge influences their perception of the illness; however, a child's attitude and beliefs about illness are also influenced by his or her surroundings, social support system and ability to manage the disease (Kieckhefer, 1988). The following quote from Sammy, age 10, exemplifies the role of attitude in child adjustment to asthma:

> *Every spring my asthma gets real bad. I couldn't even finish the Presidential Physical Fitness Tests! But this year my teacher let me do the run inside before the air got so bad. I got the badge because I'm unstoppable if I take my medicine* (National Heart, Lung & Blood Institute, 1995).

Research on Asthma Knowledge and Attitude

A number of studies have examined knowledge, attitudes, and beliefs about asthma among persons with asthma. In the United States, asthma studies have typically examined the effects of intervention on knowledge and attitude toward asthma. Childhood asthma and attitude studies outside the United States conducted primarily in Israel, Australia and Portugal have typically evaluated the relationship of attitude to other concepts and its influence on health. These studies often compared psychological responses to different illnesses.

Self, Family, and Others Attitudes

Van Sciver and colleagues (1995) compared the influence of attitude in 75 males between the ages of 8 and 20 who were diagnosed with asthma, hemophilia, or sickle cell disease. Data were collected using the Medical Compliance Incomplete Stories Test,

which requires participants to complete a story based on five scenarios and assesses attitudes toward medical compliance situations. In this study, boys with hemophilia held a more positive attitude toward their condition and medical compliance than either sickle cell or asthma participants. Those diagnosed with asthma conveyed a neutral attitude but little confidence in their treatment actions. However, the study failed to measure participants' knowledge of their condition, which would influence confidence in treatment. Further, the study measured subjects between the ages of 8-20 without recognizing child development issues that may impact attitude and confidence in treatment regimens.

Brook and Kishon (1993) compared knowledge and attitudes of 151 students aged 14-18 with asthma to students without asthma. Students were asked to agree or disagree with statements indicating a favorable or unfavorable attitude toward asthma and agree or disagree with behaviors that expressed a favorable or unfavorable attitude toward peers with asthma. Moderate positive correlations were found between age and knowledge and age and attitude. Teens with asthma were found to have more tolerant attitudes than healthy teens. A low positive correlation existed between knowledge and attitude. These findings suggest that knowledge does not necessarily influence attitude toward having asthma.

Matus, Kinsman, and Jones (1978) focused on children with asthma between 7-15 years of age in the most complex investigation of attitude to date. A 78-item questionnaire developed for the study was administered to 80 children to collect information about attitude clusters or themes. The cluster analysis revealed seven attitude clusters: 1) minimization of severity, 2) passive observance of illness, 3) bravado, 4)

expectation of staff rejection, 5) moralistic authoritarianism, 6) stigma, and 7) external locus of control. Unlike other studies related to asthma and attitude, this study examined age as a factor and determined that age influenced the perceived severity of asthma, locus of control, and perceptions about staff rejection. As expected, the younger children aged 7-11, had less attitude formation. Unexpectedly, children aged 7-12 receiving asthma care through clinics with educational and follow-up components showed greater attitude change than children aged 12-17. The researchers concluded that older children who were considered "medical failures" and were not involved in a comprehensive asthma program reflected perpetual negative attitudes. This suggests that school-aged children show greater attitudes than older children if involved in an asthma program and able to successfully manage asthma.

Several studies compared the attitudes of children with asthma to family members or significant other members such as teachers. McNelis et al. (2000) compared self-concept in 134 children, aged 8-13 years, to their mother's attitude toward asthma. Several measures were used to identify attitude, stressors, and family adaptive resources. The Semantic Differential Attitude Scale was used to measure maternal attitudes and the Child Attitude Toward Illness Scale, to measure children's attitude. There were no significant differences in self-concept between males and females. Boys had similar self-concept scores regardless of asthma severity, but girls with severe asthma had lower self-concept scores than other girls. Age was weakly positively correlated with self-concept in both groups and there were moderate positive correlations among attitude, self-concept, and satisfaction with family relationships. These results suggest that a child's attitude toward asthma and self-concept, is influenced by family support.

Gibson et al. (1995) and Pinto et al. (1999) both investigated attitude, quality of life, symptoms, and knowledge of children with asthma, children without asthma, and teachers. The studies were large (n=5976 and n=1960, respectively) and the same questionnaire was used to collect data. Designed by Gibson, this questionnaire is a 64-item scale with sub-scales that measure symptoms, attitude, and knowledge. The instrument categorizes attitude into four components: tolerance, locus of control, powerful others (external locus of control) and chance. In both studies, children with asthma knew significantly more about asthma than non-asthmatic children. The knowledge level of teachers was the same as that of the children with asthma. Students without asthma viewed "chance" as playing a greater role in asthma than either teachers or children with asthma. The only differences in the findings of the two studies were in asthma tolerance. Pinto et al. (1999) reported no significant differences in tolerance between teachers and children with and without asthma. Gibson et al. (1995) found a moderately high degree of tolerance, with the greatest tolerance in children with asthma and the least tolerance in teachers.

One might conclude from these results that children with asthma accept the disease and adjust to having asthma without difficulty. But the attitude scores of children with asthma may have been higher because they were more knowledgeable about asthma. Without knowledge of asthma management strategies and ways to cope with asthma, their scores might have reflected less tolerance.

Often studies that investigate a child's attitude collect data from a family member. Donnelly, Donnelly, and Thong (1987) investigated family members' attitude, specifically parents' perception of children's attitude toward compliance. This

randomized controlled study with 238 parents of children with and without asthma of varying ages used a 77-item questionnaire specifically designed for the study. Parents of children with asthma reported that children used asthma to gain attention, their sporting activities suffered, school performance suffered, and relationships with peers and siblings suffered. Additionally, children with asthma were more dependent and slower to mature. Families without asthmatic children had more negative attitudes about asthma, viewing children with asthma as less mature, prone to self-pity, and having difficulty in school and relationships.

Effects of Programs on Attitudes

The most recent studies of childhood asthma and attitude conducted in the United States evaluated interventions such as summer camps and educational programs in schools. Brazil et al.(1997) compared the effectiveness of inpatient family treatment and a 3-week asthma summer camp in improving self-management outcomes and illness outcomes in 50 families. The inpatient intervention recruited families and children, ages 0-18, while the child was hospitalized and the intervention was done in the hospital. The 3-week summer camp was designed for children aged 6-12. When the two groups were compared before the intervention, the only difference between the groups was age: the summer camp children were younger. In the inpatient group, children's attitudes became more positive as self-management behavior improved; but as self-management behavior improved in the summer camp group, attitude became more negative. There were no differences between the two groups in knowledge and self-management behaviors.

Briery and Rabian (1999) evaluated the effects of another asthma summer camp program on attitude and anxiety in 90 children between the ages of 6 and 16. The 1-week

asthma summer camp was compared to a 1-week diabetes camp and a 1-week spina bifida camp, all occurring in the same location in three consecutive weeks. There were significantly more positive attitude scores on the Child Attitude Toward Illness Scale at posttest in all campers. This suggests that the benefits of summer camps are not specific to a condition or group; rather, the camps are beneficial for adaptation to chronic illness. Unfortunately, curriculum and learning strategies were not revealed in this study, so it is difficult to discern what mechanism in the summer camps contributed to the attitude change.

Hazzard and Angert (1986) also investigated the effectiveness of an asthma summer camp in 43 children, aged 7–15 years. The children were recruited from clinics and hospitals. Self-concept (attitude toward oneself), locus of control, knowledge, and behavior were measured using the 10-item knowledge scale developed for this study, the Children's Health Locus of Control Scale, and the Piers-Harris Self-Concept Scale. Gender, income of parents, and parents knowledge of asthma were not related to the child's asthma knowledge, self-concept, locus of control, or asthma behavior. Race was related to knowledge, with Caucasians having more knowledge. Age was related to knowledge and locus of control and knowledge and internal locus of control were positively correlated. Self-concept, attitude toward self, and adaptive asthma-related behaviors, such as coping or psychosocial adaptation, were positively correlated. These findings, however, may be flawed since there was no control for asthma severity. Nonetheless, these three studies showed that asthma camps were effective in influencing asthma outcomes such as knowledge, attitude, and behaviors.

Other asthma intervention studies have investigated the effectiveness of traditional educational programs such as programs in asthma clinics and those integrated into a school curriculum. Colland (1993) for example, evaluated the effects of an education program on knowledge, coping and attitude, and anxiety. One hundred twelve children aged 8-13 with asthma whose asthma management was inadequate based on Asthma Coping Test scores, were recruited for the study and were randomly assigned to either a treatment group or one of two control groups. The ten 1-hour sessions combined self-management training, cognitive behavior therapy, gaming, and learning materials. The objectives included improving psychological adjustment and coping by improving attitude toward asthma. One of the two control groups received written materials at an informational session while the other control group received no information or training. As expected, the educational program influenced knowledge, coping, attitude, and anxiety.

Open Airways™ is a 6-week asthma program designed to improve self-care for children with asthma. The program is often integrated into public school health curricula. Honer (1998) tested its effects on 15 third grade children using the Parcel Asthma Knowledge Scale and the Asthma Inventory for Children, which measures management behavior. Both knowledge and management behavior posttest scores improved over pretest scores, but management behavior showed no significant improvement between pretest and posttest. Although the Open Airways™ curriculum has psychosocial content to assist children in managing asthma, the curriculum does not account for other variables that my influence behavior change.

Overall, the research on attitude and knowledge in children with asthma has given little attention to child development and asthma severity even though the research suggests that severity influences psychological adjustment. Further, though attitude plays a significant role in psychosocial adjustment and knowledge attainment about asthma, few intervention programs have addressed this issue or focused on the relationships between emotions, anger and asthma and the role of significant others outside the family structure, such as peers and school personnel. And many of the programs, such as summer camps or educational programs, are time and labor intensive.

Multimedia or interactive programs may overcome the limitations of programs that are time and labor intensive or do not appeal to children. Interactive technologies and various forms of computer-aided instruction have been used in health promotion since the 1980s and numerous studies have demonstrated their effectiveness. Computer-aided health promotion is most commonly used with children; this form of learning, known as 'edutainment' is often animated with games and songs. The programs that are most effective use storylines or story to present the content.

Some studies evaluated asthma intervention programs were delivered through multimedia. Although there are claims of effects on knowledge, attitude, and behavior, there is no data to support the claims in part due to the proprietary nature and commercialization of multimedia for children. Proprietary programs to date include ClubHouse Asthma, owned by MindJourney© (1999), a leader in health related multimedia; this program teaches children how to manage their asthma by recognizing signs and symptoms of an asthma episode and reviews common medications and

treatments. The program includes self-concept and self-esteem building through a male cartoon character who participates in normal activities.

A second multimedia program for children with asthma is Bronkie the Bronchiasaurus Asthma Game, owned by Prairie Public Broadcasting Inc© and sponsored by the American Lung Association. This program challenges players to make decisions to manage the main character's asthma. The program reportedly increased asthma knowledge, improved attitude, and increased the frequency of communication about asthma with friends and parents; however, no available data support this claim. Further, while the program focuses on asthma management and behaviors, it lacks content on psychosocial adjustment to asthma.

Asthma Busters, a CD-ROM asthma management program developed by American Research Corporation of Virginia (ARCV) ™, uses a storyline to deliver the curriculum through an animated comic book-style adventure. Asthma Busters was tested on 22 subjects and yielded improvements in knowledge, attitude and health locus of control, but the evaluative data to support this claim have not been published.

Several projects are currently underway to examine the effectiveness of interactive asthma programs. A comprehensive on-line program called Environmental Cyber Schoolhouse (ECS) is being tested at Wayne State University (NIH, CRISP, 2000). The lessons are for middle school children and focus on environmental factors and their role in asthma, as well as other topics like air pollution and lead toxicity. A similar CD-ROM is being developed to educate 7-12 year old children about asthma. The project is funded by the National Institutes of Health. Both of these projects are ongoing, so there is no available data.

Two multimedia programs designed for children with asthma have been tested and the findings published. Watch, Discover, Think and Act is a multimedia program designed to enhance self-management skills and improve asthma outcomes, including attitude (Bartholomew, 2000). This program incorporates strategies to improve quality of life, but content is presented in a gaming environment rather than through a digital story. The multimedia program was tested on 133 children between the ages of 7-17; with 64% were males and 95% were minority, the sample had moderate to severe asthma. The research used a prospective pre-test post-test design over a period of 4 to 15 months. The control group and intervention group were similar in gender, ethnicity, insurance, asthma severity, and marital status and education of parent(s). Self-efficacy, asthma knowledge, and child management including attitude, were measured using instruments created for the study. The multimedia program had no effect on self-efficacy but affected functional status, knowledge, and quality of life.

Homer and colleagues (2000) tested a multimedia game that requires decision-making, knowledge of allergens, medications, and symptom recognition. In this study, 137 participants between the ages of 3 and 12 were evaluated on satisfaction, attitude toward asthma, behaviors and knowledge. Participants were recruited from outpatient clinics, emergency rooms departments, and inpatient hospital rooms. When the treatment group and the control groups were compared, no differences were found in age, race, gender, insurance coverage, illness, and asthma severity. The multimedia had no effect on attitude.

The *Okay with Asthma*™ program developed for this research uses interactive technologies and stories to deliver information about asthma to children. The program

focuses on the psychosocial adjustment to asthma and the importance of the support of friends, peers and school personnel. The program is designed to be used in schools. Successful asthma management requires collaborative efforts by family, affected children, and clinicians (Kieckhefer, 1995). Therefore, professionals providing care in schools must become involved in the education and psychosocial development of children with asthma. A 1999 survey of 110 Virginia school nurses by Allman and Harris revealed that only 19.6% had an asthma education program in their schools and the school nurses were caring for 5,803 children with asthma indicating a need for asthma resources in Virginia schools.

Theoretical Framework

Gagne's conditions of learning theory and Egan's learning through story model guided the pilot testing of *Okay with Asthma*™. According to Gagne's conditions of learning theory, there are five levels of learning; verbal information, intellectual skills, cognitive strategies, motor skills and attitudes (Gagne, 1965). Each of these requires various learning tasks. For example, learning cognitive strategies requires that the learner practice developing new solutions to problems, while attitude changes are best accomplished through role modeling and persuasive argument. Gagne also described four phases in the learning process. The first is receiving the stimulus. The second phase, the stage of acquisition, requires the learner to acclimate to the stimulus or new knowledge received in Phase One. The third phase of learning is the process of storing the information and the fourth phase requires the learner to retrieve the information previously stored (Gagne, 1985). While a learner moves through these four phases of learning, two conditions, internal and external, influence the process. The internal

conditions are 'states' and include the learner's attention, motivation, and recall. The external conditions are factors surrounding the learner such as the arrangement and timing of the instruction. A child's state of attention, motivation, and recall to asthma content depends in part on the child's self-perception and attitude toward asthma. The program *Okay with Asthma*™ is designed to influence attitude through role modeling and persuasive argument through the story, enabling the child to progress through the four phases of learning. When the psychosocial needs of a child with asthma, are attended to, their internal factors or states can be altered and their attitude influenced so that they are better able to receive the knowledge that is being provided. Attitude change also is facilitated through role modeling with characters and the resolution of conflict in the story and story writing section of *Okay with Asthma*™. Gagne provides nine instructional events to guide the teaching/learning experience, regardless of the level of learning that is required. These events are listed in Table 1 beside the corresponding learning processes used in the *Okay with Asthma*™ program.

Kieran Egan (1986; 1992; 1997), a leader in the use of story in learning and education, proposes that learning stems from imagination. Learning also "entails the ability to transcend the obstacles to thinking with which easy acceptance of conventional beliefs, ideas, interpretations, and so on, confront us" (Egan, p, 47, 1992). Story and story writing inherently exercise the imagination, which stimulates learning in multiple ways, as advocated by Gardner (McEwan & Egan, 1995). Individuals remember events in a story much better than lists or sets of explicit instructions. Story engages readers so that they learn the content of the story while becoming emotionally engaged by characters and events (Egan, 1992).

TABLE 1 GAGNE'S INSTRUCTIONAL EVENTS REFLECTED IN OKAY WITH ASTHMA™

Gagne's Nine Instructional Events	*Okay with Asthma*™ Instructional Events
Gain attention	• Multimedia design with upbeat music, fast paced scenes and a character, Gina, experiencing an asthma attack • Gina's emotional response in first scene triggers asthma.
Inform learners of the objectives	• Characters in the story ask questions about asthma and how to help Gina during her attack. • Matthew, Gina's friend, asks about emotions associated with asthma and ways to handle emotions and feelings.
Stimulate recall of prior learning	• Gina's coach asks her how she usually deals with her attacks. In the story writing section of the program, learners are asked to identify their triggers and action plans. • Story writing section encourages users to add feelings and emotional responses in the story.
Present the stimulus	• Misconceptions about asthma are identified and asthma information is reviewed in the story. • Gina's coach presents emotional content and give examples of how to handle feelings.
Provide learning guidance	• Asthma fun facts are provided throughout the story, and learners can print asthma tips and the story that they wrote in the story writing section.
Elicit performance	• Learners complete the pre-written story in the story writing section by adding content related to asthma triggers, action plans and specific strategies to deal with the emotions associated with asthma.
Providing feedback	• The program is a self-guided learning experience and does not provide feedback or assess performance.
Assessing Performance	
Enhancing retention and transfer	• Learners are provided with printed asthma tips, a certificate of completion, and the story that they wrote for future reference. The program is also available on the Internet so learners can refer to it often and frequently.

Egan's writings on story are strongly influenced by Jerome Bruner's constructivist position that learning is a process in which learners construct new ideas, possibly in the form of narrative or story, based upon their current and past knowledge. Egan makes three points about story and learning. First, while it is thought that young children's thinking is concrete, fairy tales challenge this idea because the youngest of children are able to relate to abstract concepts such as courage, conflict and love through fairy tale stories. Not only are children able to understand, but also they often favor fairy tale stories over stories that use relevant lessons, events or ideas in today's society. In fairy tales, abstractions are organized with concrete content. Therefore, to make abstract content understandable by children, it should be organized and combined with concrete content (Egan, 1992). The second point is that stories are based on binary concepts, making them appealing and aiding in the child's ability to mediate between the opposites imposed in the story such as 'well' and 'sick' or 'happy' and 'sad'.

This discrimination between two opposites, or binary mediation model, establishes binary logic in the story by implying that any given concept is defined by what it is not (i.e., sick is not being well). Egan's third point about stories and their influence on learning is that children gravitate toward and show interest in exotic or fantasy stories. In fact, overwhelmingly children write fantasy narratives. This phenomenon challenges the ideas that a child's understanding progresses from familiar content and experience to unfamiliar content in a linear fashion; and the binary mediation model present in stories accounts for a child's engagement with both fantasy and exotic real-life content (Egan, 1997). This discrimination between two opposites, or binary mediation model, establishes binary logic in the story by implying that any given concept

is defined by what it is not (i.e., sick is not being well, healthy, happy). Egan's third point about stories and their influence on learning is that children gravitate toward and show interest in exotic or fantasy stories. In fact, overwhelmingly children write fantasy narratives. This phenomenon challenges the ideas that a child's understanding progresses from familiar content and experience to unfamiliar content in a linear fashion; and the binary mediation model present in stories accounts for a child's engagement with both fantasy and exotic real-life content (Egan, 1997).

It is through story that a child is able to relate to and make meaning of his or her world. It is also through story that a child is able to use the imagination, which is a tool for learning (Egan, 1986). Egan (1997) offers a model for story construction. The first task in story development is to identify the importance of the topic and why it should matter to children. To engage children in the content, Egan suggests using binary opposites or conflicts. Conflict between opposite characteristics or traits such as healthy eating habits versus poor eating habits is embedded in an effective child's story. The characters in the story portray and resolve these conflicts, which guide the organization of the story. Through a story, a learner may use imagination to engage in fantasy, experience feelings, and manipulate events to control outcomes that ultimately shape both cognitive and psychosocial learning.

Story also influences memory and attitude. Memory, or the manner in which information is stored and retrieved, is fundamental to thinking. Three strategies used to store information in the brain are rehearsal, organization and elaboration (Berk, 2000). Rehearsal of information is necessary to store content for future retrieval; however, preschoolers and early school aged children lack the cognitive ability to effectively

rehearse unless the rehearsing is meaningful. It is not until approximately 11 years of age that children are able to rehearse in schemes. Therefore, content that is constructed in meaningful schemes with persuasive arguments, as in stories, is more likely to resonate with school-aged children. If content is presented in a meaningful story, organization of the content requires less cognitive manipulation by the child. Elaboration involves creating relationships between facts that are not necessarily related (Berk, 2000). If a story has delivered information that is meaningful, the child is able to retain, elaborate and recall the information and make connections or transfer the knowledge more readily. For this reason, story is an effective approach to changing attitude, as described by Gagne's theory.

Using Story with Interactive Technology

There is increasing interest in examining the ways in which learning is constructed through storytelling and computer interface design (Berg, 2000). The Meno research group at British Open University has evaluated the use of storytelling and narrative in the construction of computer-based educational programs. Computer-based learning or interactive technology is defined as multimedia that allow the user control of responses or selections through icons or buttons, with the multimedia responding to the selections. The advantage of interactive technology for health promotion is its ability to promote active learning and information seeking (Street & Rimal, 1997). Interactive technology has the ability to deliver content using multiple modalities such as text, narration, motion picture, graphics and sound. A user of an interactive program that involves multiple methods of delivery is more engaged in the content because of sensory stimulation. This form of

learning, known as "edu-tainment" often features animation, songs and games appealing to the multi-senses of children.

But interactive educational technology is not widely accepted. Some critics argue that the technology in no way influences learning and that any change in learning is a result of a change in curriculum that occurred while using the technology (Clark, 1983). Clark suggests that technology is merely a vehicle to deliver instruction and says that the lack of evidence to support the effectiveness of technology in influencing learning has been documented since 1912.Yet the Center for Applied Research in Education Technology[2], a project of the International Society for Technology in Education reports countless studies demonstrating the effectiveness of instructional technology as a mechanism to deliver content (Cradler, McNabb, Freeman & Burchett, 2002). The debate continues between those who believe that interactive or educational technology is merely a medium to deliver instruction and those proponents of technology who suggest the use of technology influences learning that occurs with its use.

Various computer applications are used in health promotion. The advantage of interactive technology as a medium to deliver information about health promotion is its ability to promote active learning, information seeking, and problem-solving and the user's ability to select features, objects, or icons (Street & Rimal, 1997). The value of interactive environments in promoting health is their potential to promote self-efficacy through simulations of events that resemble direct experiences. Potentially, simulated environments can personalize experience, emphasize individual responsibility, and promote knowledge and skill acquisition (Street & Rimal, 1997). Users of an interactive

[2] Web site accessible at http://caret.iste.org

program with multiple methods of delivery are more engaged in the content because of the sensory stimulation.

Many of the interactive technology programs available for children use video games to deliver health promotion content (Lieberman, 1997). Often these games incorporate stories into the interactive program, but few if any programs use story and narrative to deliver information for the purpose of influencing health-promoting behaviors. Yet substantial literature exists to support the use of story for effective learning and to change behaviors, which are crucial elements in health promotion. Mayer's generative theory of multimedia learning posits that learning is enhanced when a learner constructs and coordinates visual and verbal representations of the same material (Mayer, 1997). Users of digital stories may choose to read the text, view an image of the character, or watch a movie of a character while acting out the scene. In some cases, readers may interact with the scene and determine the storyline by selecting icons or buttons. When both visual and verbal modes of information are present, more effective learning can be expected (Plass, Chun, Mayer & Leutner, 1998).

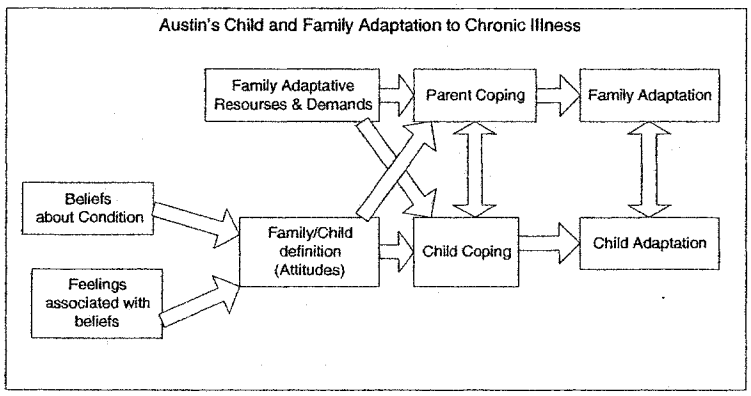
Digital story has great potential because it gets children's attention, organizes the content in a format that children are accustomed to, and develops a context in which ideas can be developed. *Okay with Asthma*™ uses the technique of digital story to deliver content to children with asthma, because story is effective in influencing a child's knowledge and attitude toward the content being presented.

Models used to develop *Okay with Asthma*™

The development of the *Okay with Asthma*™ program was guided by Austin's (1990) child and family adaptation model, Miller and Wood's (1995) model of

interaction with family, school and peer systems, and Kieran Egan's (1986) model of learning through story. Austin (1990) suggests that a child's adaptation to chronic illness is influenced by family and attitude, and notes that poorly adapted children with asthma as have negative attitudes (see Figure 2). Austin's model focuses on the children's attitude, with children acting in accordance with their beliefs. Austin's model provided a framework for the development of *Okay with Asthma*™ and guided the emphasis on attitude in influencing psychosocial adjustment. For example, in *Okay with Asthma*™, Gina, the main character in the story, discusses her feelings and attitude about having asthma. Her coach, Mr. White, offers strategies to help her cope with asthma that influence the way she feels, her attitude, and the way she ultimately manages her asthma. Austin's model explains the manner in which attitude is formed and influenced by family values, resources and the relationship between the child and the family. The strength of Austin's model is the awareness of psychosocial factors that influence a child's adaptation to asthma; however, the model fails to acknowledge other influences on child attitude formation outside the family structure. Peers, friends, schools, and the community may be more influential than the family, especially as children develop a sense of independence and engage in more activities outside the family. For this reason, Miller and Wood's developmental model of

FIGURE 2 AUSTIN'S MODEL



interaction with family, school and peer systems was also used to guide the development of the program.

According to Miller and Wood (1991), the psychosocial development of the child with asthma occurs in four crucial contexts: the family, the school, the peer group and the health care system (see Figure 3). The asthma diagnosis influences the interaction of the four systems with the child and the interactions between the systems as they relate to the child. This suggests that the interactions between the systems and the child either enhance the child's psychosocial functioning or prevents healthy functioning. This model acknowledges that the family is the single most important source of support for the child and influence on the child's development and within the family system there are complex factors such as sibling relationships, parental roles, economic and social considerations and family interaction patterns. For this reason, the family system is central to the interrelations of the other systems that influence the child. The role of the social environment is crucial for asthma adjustment, childhood development and cognitive development in children.

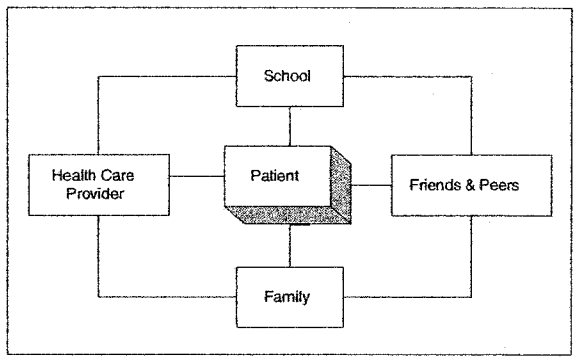


FIGURE 3 MILLER & WOOD'S INTERACTION MODEL

Egan's learning through story model also influenced the development of *Okay with Asthma*™. Austin's model emphasizes psychosocial factors such as attitude, beliefs, feelings, and coping, and these factors served as the foundation for the asthma curriculum in *Okay with Asthma*™. Miller and Wood's model acknowledges the importance of

influences outside the family, specifically peers, friends, school and the community. *Okay with Asthma*™ emphasizes friend, peer, and school support as well as family support in an interactive story interface design. The design was selected because according to Egan's story model, persuasive argument and role modeling influence attitude, especially with emotional content (i.e., psychosocial factors in asthma).

CHAPTER THREE: METHODS

This study used a one-group pretest-posttest non-experimental design to pilot-test the effectiveness of *Okay with Asthma*™ in increasing asthma knowledge and improving children's attitudes toward their illness. Using outcome measures of knowledge and attitude, participants were evaluated at baseline (T_1) and twice after completing *Okay with Asthma*™ at 1-week (T_2) and 2-week (T_3) post intervention.

Setting and Sample

Thirty-five children between the ages of 8 and 11 with moderate to severe asthma were recruited for the study. All subjects were enrolled in a public elementary school in Ablemarle County, Virginia. All but one school in Albemarle County participated in the study. One principal declined participation in the study due to scheduling problems and heavy demands on teachers to meet state requirements. School nurses assisted in the recruitment of participants, to maintain the anonymity of those children who did not wish to participate and those who were ineligible for the study. School nurses were able to identify children for this study because children with more severe asthma need access to medication while attending school. Since the goal of the study was to recruit the same number of males and females, over-sample minority populations, and target children with moderate to severe asthma, the investigator met with each school nurse to review the desired sample representation. School nurses discussed individual cases without revealing the child's identity. Collectively, the school nurse and investigator selected individuals to participate in the study based on the inclusion criteria and the desired sample.

To be included children, needed to be able to complete assent forms that were approved by the University of Virginia's Institutional Review Board for the Social and Behavioral Sciences. Children with cognitive, psychiatric, or behavioral disturbances that might interfere with the interpretation of the results were excluded from the research. The table shown in Appendix B was used to guide the selection process and to ensure minority and gender representation as required of all research funded by the National Institutes of Health.

Once potential participants were identified, the school nurse sent a letter prepared by the investigator to the parents of the children identified. The letter described the study, explained why the child had been selected, and contained a request to contact the family (see Appendix C). Parents were asked to return a postcard addressed to the investigator indicating their willingness to be contacted. The school nurse sent a follow-up postcard to parents via their child 1-week after the letter.

Human Subjects Protections

The protocol for the research was approved by the Behavioral and Social Sciences Internal Review Board (IRB) of the University of Virginia. Since human subjects were used in both intervention development and implementation, approval was obtained for both aspects of the research. A parental consent and a child's assent form, based on the models used by the IRB, were developed for use in the study and approved by the committee (see Appendix D & E). All data collected were secured; the online database was password protected and the interview data were stored in a locked file cabinet accessible only by the investigator. Social security numbers and addresses were not recorded and protected health information (PHI) was not stored in the online database.

Procedures

Upon receipt of the postcard granting permission, the investigator contacted the family and set up an interview at a time and location convenient for the family. Meeting each child's family helped the investigator determine the child's eligibility, develop an alliance, obtain parental consent and child assent, and collect descriptive data (see Appendix F). During the interview, the investigator explained the study, the benefits and risks of participation, and the way the information collected from the family and the child would be used; answered all questions that arose; and obtained consent from the parent or guardian and assent from the child. All communication with the family and participants had the underlying goal of building trust and meeting the individual needs of the participant as a way to recruit and retain participation (Miranda, Organista, Azocar, Munoz & Lieberman, 1996).

Eligibility based on the severity of the child's asthma was evaluated using a severity rating scale (Appendix G) developed by the National Asthma Education and Prevention Program (1999). Descriptive data were obtained to identify potential confounding variables that might influence the results. These included the child's learning preferences and access to a computer, family structure, and current asthma care. Descriptive information was stored in a locked file cabinet in McLeod Hall, School of Nursing, to ensure that PHI remained secure based on policies established by Human Investigations Committee relating to the Health Information Portability and Accountability Act.

This study took place in computer labs of public elementary schools in Albemarle County, Virginia. At the participating schools, children completed the measures and *Okay with Asthma*™ using a computer. Participants' confidentiality was maintained by either

conducting the study when only the participant was in the lab or by selecting a section of the lab that was isolated from other children. Placing children at isolated computer workstations to promote privacy is practiced by all teachers when it is necessary to work with individual children. For this reason, participants were familiar with this arrangement and children were not alarmed. Computers were accessible in all schools because technology is a part of the statewide Standards of Learning curriculum (Virginia Department of Education, 2003). This curriculum requirement also ensured that children participating in this study had the basic computer skills necessary for the *Okay with Asthma*™ program.

The program was administered while the child was attending school. The intervention schedule depended on the child's school schedule, time of arrival, and time of departure. Subjects completed the story and story writing program in 30-40 minutes and the measurement scales in 10-15 minutes. The first evaluation (T_1) took approximately 45 minutes to an hour. Since participants did not complete the intervention at the second evaluation (T_2) and the third evaluation (T_3), participants completed the measures in 10-15 minutes. Prior to every evaluation, individuals responsible for releasing the child from activities to participate in the study (e.g. teacher, school nurse, or counselor) were sent a reminder. A modification in the protocol was made while the data collection was in progress, following a parental complaint. The investigator included a debriefing session with each child after viewing the multimedia program asking questions such as; Is there anything that you saw in the story that upsets you or makes you feel bad?

On the third evaluation (T_3), participants received a $10.00 certificate after completing the questionnaires on the web site. Participants who did not complete all three

evaluations and withdrew from the study were noted as well as their reason for withdrawal from the study, which in both cases was related to schedule conflicts. Those participants who withdrew from the study received their $10.00 gift certificate in the mail. Data collection took approximately 2 months. Once the study was completed, the security feature was removed from *Okay with Asthma*™ so that any school personnel, children, or parent could access the program.

Intervention

The intervention was the *Okay with Asthma*™, a 23-minute Internet-based multimedia program using animated digital story and story writing. The program allows children with asthma to personalize a pre-written story by adding their own text. Users are able to print the resulting story and a certificate of completion.

Program Development

Okay with Asthma™ was developed over an 11-month period. (The timeline is in Appendix H.) The program was developed using a rapid prototyping method. Rapid prototyping is the process of evaluating the utility of the project at various stages during the development (Kinzie, Cohn, Julian & Knaus, 2002). Table 2 outlines the rapid prototyping steps used to develop this program. The steps are briefly described in the narrative that follows.

TABLE 2 RAPID PROTOTYPING STEPS

Rapid Prototyping Step	Specific to *Okay with Asthma*™	Evaluation
Needs Analysis	Review of research related to asthma intervention programs for children and research related to effects of asthma on psychosocial functioning.	Asthma literature reviewed by investigator; gaps in interventions identified, along with effective delivery methods
Develop Goals and Timeline	Timeline developed based on needs assessment, required tasks, and availability of team.	Team selected based on skills, talent and availability; timeline developed.
Develop content and materials	Curriculum for program developed, including medical and psychosocial strategies for managing asthma.	Content experts evaluated material for accuracy & relevance.
Develop draft materials	Story developed with characters incorporating curriculum.	Storyboard (created paper versions) the material for evaluation by focus group & instructional designer.
Develop "mockups"	Mockup pages created for the different activities and instruction pages.	Mockup animated pages evaluated by focus group & instructional designer.
Develop entire instructional project	Developed remaining materials incorporating revisions and suggestions from previous evaluations.	Entire *Okay with Asthma*™ site tested by focus group from target audience and instructional designer.

To complete the needs assessment and analysis, literature was reviewed on childhood asthma, intervention programs, effective teaching learning methods, and psychosocial effects associated with asthma. The findings from the needs analysis and literature review were developed into a National Research Service Award proposal and submitted to the National Institute of Nursing Research. The service award funded the development of the project.

The goals of the project were developed based on the needs analysis. An international team from Canada, United States, and Czech Republic was recruited to develop this program. The curriculum for the *Okay with Asthma*™ program, which includes both medical and psychosocial strategies requisite for successful asthma self-

management by children, was developed first. Once the team was assembled, a timeline was developed based on the goals, tasks, and availability of the team. The team of developers was Joan Hinz, a storywriter identified by Dr. Flora Joy, Director of the Storytelling Center at the University of East Tennessee, who developed the story and the pre-written story for the story writing section based on the prototype. Programmers, illustrators and animators from Web-Space-Station® developed *Okay with Asthma*™ using Macromedia Flash© software. Dr. Gail Kieckhefer, asthma expert at the University of Washington, served as consultant for the medical management content and Dr. Emily Hauenstein served as consultant for the psychosocial management content. Both consultants reviewed and edited the curriculum, and the curriculum was modified based on their recommendations.

The initial prototype version of Okay with Asthma™ was developed with Hyperstudio©, which was used as a map by the storywriter, illustrators and programmers. They used the prototype to refine the story and examine various interactive capabilities to incorporate in *Okay with Asthma*™. Once the storywriter revised the story and incorporated the asthma curriculum, illustrators developed scenes that corresponded with the story. A paper version storyboard of the story, including colored graphics was evaluated by an instructional designer and a focus group of five children (F_1) with asthma aged 8-11 years. During the focus group, children were asked to review the story and answer questions pertaining to the story (see Appendix I). Children's responses to the questions were recorded individually. The collective responses were tabulated and ordered (see Appendix J) according to Nielsen's 10 usability heuristics (see Appendix K) and rating guidelines (see Appendix L).

Data from the children's group showed that overall, children were interested in the story and were able to report its purpose; they stated that the story was to 'help children feel better about having asthma". Participants easily understood the asthma content in the story and none of them reported discrepancies in the content. The children found the beginning and the end of the story captivating, but the middle section of the story needed more action to keep their attention. All the children in the focus group disliked one character, stating that, "he was mean." Since this was the intended purpose of the character, their responses showed that the character was accurately represented in the story. At this stage, experts offered minimal suggested revisions. One recommendation was to add interactive capability in the story to reinforce the material, as a way to maintain interest. Based on this recommendation, optional interactive scenes were added at various points in the story.

Animators and programmers developed prototype web pages or mockups for each of the various actions within the program. They included the introduction, instruction, and conclusion pages, one animated page with interactivity features from the story, and one animated page from the story writing section of the program. These web pages were evaluated by an instructional designer with expertise in web design and by a focus group of three children (F_2), aged 8-11 years. The children in this focus group did not have asthma since the purpose of this evaluation was to test the interface and navigation of the program, not the content. The feedback and comments made by the children were scored and ordered in priority (see Appendix M).

Findings from F_2 revealed that children were more attentive to the digital story if they could navigate through the story instead of having the story automatically advance

from one page to the next. F_2 children also desired more control, such as moving forward and backward in the story and replaying a scene, similar to the way they might choose to progress through a traditional book. F_2 children identified problems with the instructions: for example, some words in the instructions, such as the terms 'enter' and 'text', were difficult to understand. F_2 children were able to offer alternative wording for instructions throughout the program. F_2 children were also unable to read the instructions because they moved too rapidly across the screen. Slowing down the animated instructions and creating a loop animation so that the instructions continuously reappeared on the screen rectified this problem. The design expert reviewed the mockups and offered strategies for revising the navigation so that children would have more control during the program experience.

The usability of the program was tested using a heuristic method of evaluation (Nielsen, 1994). Heuristic evaluation identifies program usability problems though small group work. This method complements rapid prototyping since testing occurs during development, and feedback is obtained through the target audience. The best size groups include five to seven individuals; however, when working with children, it is best to consider a child's development and need for individualized attention. Focus groups with children are therefore most effective when limited to three to five participants (Kennedy, Kools & Krueger, 2001). The use of heuristic methods of evaluation and rapid prototyping ensured that the program was well designed for the intended audience, since modifications were made as the program was developed. This also prevented the need for extensive modifications when development was complete. For this program, three groups of children (n=11), aged 8-11, who were attending either the Albemarle County Extended

Day Care Program or Augusta County Summer Camp Program, reviewed portions of the project. Three instructional designers also reviewed the program while it was being developed and provided written feedback.

Based on recommendations by the instructional designers and evaluations by the focus groups, modifications were made to the mockup pages and the remaining scenes were developed. These modifications included changes in language or wording, navigation, voices for characters, and changes in interface. The entire program was then reviewed by an instructional designer and a third focus group (F_3) of three children aged 8-11 years with asthma. The purpose of this evaluation was to gain feedback on the interface, instructions, navigation through the site, interest in the story format, and knowledge gained from the program. Again, the focus group responses were recorded, scored, and ordered in priority (see Appendix N).

F_3 children were very interested in the animated story, but were particularly interested in the story writing component. Participants were eager to use the print feature to create their own certificate and printed version of the story that they had altered. This focus group identified several usability and design flaws, including the omission of an 'exit' or 'home' button in the program as well as the difficulty of the instructions in the story writing section. The participants in this group offered age appropriate instructions and terms that were adopted for use in the final program. Again, a design expert reviewed the program at this stage of development, provided written feedback about interface and instructions, and offered alternative ideas for resolving problematic design issues for children. The recommendations resulted in more prominent navigation buttons and page turn transitions from one scene to the next.

After *Okay with Asthma*™ was designed and tested, it was integrated with a database that stores responses to the knowledge and attitude measures used in the study. To ensure that data in the database were not manipulated and that subjects did not access the program at any time other than during the controlled treatment time, only the homepage of the *Okay with Asthma*™ web site was accessible without a password.

The MS-SQL 7 database that stored the responses to the attitude and knowledge measures in this study was accessed through the password protected *Okay with Asthma*™ web site. With this type of server, confidentiality of the participants was maintained. This database provided full security, including password-protection of data, and the ability to grant individual access to specific tables within the database and its data. The password-protected database was backed up daily. The data stored in the database tables were meaningless without the codebook, and the codebook was stored in a locked file cabinet in McLeod Hall, School of Nursing accessible only to the investigator. The online survey was tested at least twice a week to ensure the database was collecting the appropriate responses and storing the data.

Measures

The effectiveness of *Okay with Asthma*™ in influencing asthma knowledge and attitude toward having asthma was tested using the Asthma Information Quiz and the Child Attitude Toward Illness Scale. The Asthma Information Quiz (AIQ) developed by the National Cooperative Inner-City Asthma Study (NCICAS) staff is a 23-item true/false questionnaire testing a child's knowledge of asthma triggers, symptoms, medication management, and prevention (Appendix O). Nineteen of the items measure asthma knowledge and the remaining four are used to evaluate the measure. Three of the four

evaluative questions were used in this study. The fourth question was not applicable because the item assumes the questionnaire is administered via interview. This measure was modified in several ways. First, the language was simplified to reflect a Flesch-Kincaid Grade Level Score of 3.0. The double negative questions were changed to positive questions and two questions that required multiple responses were broken into individual questions requiring a true/false response. Four items (20-23) were added to the measure because the original knowledge scale did not contain items pertaining to the psychosocial management of asthma.

The AIQ was selected because it is the only known measure that distinguishes asthma knowledge from asthma behavior. The AIQ is scored by calculating the percent of items answered correctly. The mean score is 73.1%, (SD=12.1%) normed on a sample of 733 subjects with asthma aged 6-9. No other psychometric data about the questionnaire are published (Wade, et al, 1997). In the present study, the alpha reliability coefficient for the knowledge measure was .73. The inter-item correlation ranged from -.39 to .66 with a mean of .074 and a range of 1.05. The mean score on this measure during the present study was 78% (SD=10.36).

The Child Attitude toward Illness Scale (CATIS) was used to measure attitude toward having asthma (Appendix P). This 13-item, 5 point Likert scale instrument is a short self-report scale developed for children between the ages of 8-12 years. The CATIS is scored by summing the numerical responses and dividing by 13. High scores reflect positive attitudes. The instrument was tested on children with asthma and has been used in studies that evaluated asthma intervention effectiveness in changing attitude toward having asthma (Austin & Huberty, 1993; Austin, Smith, Risinger & McNelis, 1994). The

coefficient alpha for internal consistency reliability has been reported as .80, with item-total correlation ranging between .27 and .59, and test-retest reliability of .8 (Austin & Huberty, 1993). In this study, the alpha reliability coefficient for the attitude scale was .91. The inter-item correlation ranged from .04 to .71 with a mean of .44 and a range of .67.

Data Management and Analysis

Once data were collected from all participants, the database administrator retrieved the participants' responses from all evaluations stored in the MS SQL 7 database. The data were saved in tab-delimited format so that they could be exported into SPSS analytical software. Once data were made available in SPSS, the investigator added descriptive measures into the SPSS database, which was on a password-protected server owned and maintained by the University of Virginia School of Nursing. Data entered from the interview were verified twice to ensure accuracy in entry, scoring, and in calculation of the sum of measures. There were no missing data because data were collected by interview and through an online survey, which only advanced after a response was selected.

Descriptive Statistics

There were 14 descriptive variables collected including the demographics of each participant such as age, grade, gender, and ethnicity. Other descriptive data were collected to identify confounding variables influencing the knowledge and attitude scores. For example, the parent or guardian of each participant reported the length of time their child had asthma symptoms, measured in half year increments, and whether the

child had activity limitations (minimal, moderate, severe) as a result of their asthma. A child's previous involvement in asthma education programs and the type of health care provider that treated the child's asthma were recorded. It was anticipated that few children would have previously participated in asthma education programs, thus their asthma knowledge was likely gained from the provider and the family. Collecting information about the type of provider (asthma specialist, pediatrician, or family practice) determined patterns between knowledge and attitude scores by type of provider. Parents or guardians also reported the family structure such as the number of parents and siblings living in the household. They also reported the prevalence of a family history of asthma, which was recorded as either parent history of asthma and/or siblings with asthma. Parents or guardians reported the child's preferred learning style as either visual, auditory, or kinesthetic by responding to the following: "Would your child best learn about volcanoes by reading a book, watching a video or building a volcano for a science project?" Data on the participant's Internet and computer proficiency were analyzed to determine if these skills (novice, proficient, or advanced) were related to their scores on the knowledge and attitude measures.

Hypotheses and Analysis

The first study hypothesis was; in latency-aged children with moderate to severe asthma, 1 week after completing the *Okay with Asthma*™ program (T_2), participating children will have significantly higher post-treatment scores on both asthma knowledge and child attitude scales than at baseline (T_1). To test this hypothesis, scores on knowledge and attitude were calculated and subjected to t-tests pairing T_1 with T_2. The

alpha for significance was set at $p<.05$ and the hypothesis will be accepted if significance testing results in a p value below $<.05$.

The second study hypothesis was; in latency-aged children with moderate to severe asthma, 2 weeks after completing *Okay with Asthma*™ (T_3), participating children will have significantly higher scores on both the asthma knowledge and child attitude scale than baseline scores (T_1). The second hypothesis was tested using the same statistical procedure as the first hypothesis. To evaluate the effect of *Okay with Asthma*™, scores for knowledge and attitude were calculated and subjected to t-tests pairing T_1 with T_3. The alpha for significance was set at $p<.05$ and the hypothesis will be accepted if significance testing results in a p value below $<.05$.

CHAPTER FOUR: RESULTS

In this chapter, the results of the data analysis are presented. Data collection occurred over a 10-week period. Since this study occurred during the spring season, all children in the sample reported asthma symptoms during the study. None of the children participated in other asthma intervention programs during the study. Descriptive data were examined for associations among variables and in particular with knowledge and attitude scores. Statistical procedures such as frequency, mean, median, mode, correlation, chi square and skewness were performed to identify the distribution of the sample, pinpoint outliers, and identify associated variables. Correlation analysis was performed on knowledge and attitude scores to determine associations and Independent t-tests were performed to determine the influence of descriptive variable on knowledge and attitude scores. The descriptive statistics were considered during the analysis and interpretation of the study results.

Sample Description

Twelve of the 16 elementary schools in Albemarle County were represented in the sample (see Appendix Q). One hundred sixty-nine letters requesting participation in this study were sent to families of children with asthma enrolled in these schools. Fifty-two families (30%) responded to the request to participate. Fifteen children were excluded because they did not meet inclusion criteria. Thirty-seven children enrolled in the study, but two children withdrew before completing the protocol due to scheduling conflicts. Data from the two children who withdrew were not included in the analyses.

Nearly half of the sample were girls (46%, N=16) and 7 (44%) of those girls were Asian or Black. Of the 19 boys, 8 (42%) were either Hispanic or Black (see Appendix B). This sample represents an over-sampling of Black and Hispanic children and an under-sampling of White children. In Albemarle County Public Schools, Blacks represent 12% of the student body, Hispanics and Asians both represent 3%, and Whites represent 82% of all children in Albemarle County public schools (National Center for Education Statistics, 2000).

Twenty-five (71%) children were categorized as having moderate asthma and 10 (29%) children had severe asthma. Their mean age was nine years (SD=1.1) with eight year-old children representing 42% of the sample. Twenty-four (69%) of the children in the study had a family history of asthma. Only four (11%) of the 35 participants received care from an asthma specialist; the remaining children received care from either a pediatrician or a family practice physician. Two children (6%) in the study had previously participated in an asthma education program; one child had attended a summer asthma camp and the other child had received asthma education from a nurse led program during day care. The largest number of the children (N=13) had been diagnosed with asthma three or more years before the study.

Findings Related to the Research Hypotheses

The first hypothesis states that 1-week after completing the *Okay with Asthma*™ program, (T_2), participating children will have significantly higher post-treatment scores on both the asthma knowledge and child attitude scale when compared to baseline (T_1). To test this hypothesis a paired t-test statistic on each of knowledge and attitude pretest and 1-week posttest scores was calculated. The pretest scores and the 1-week posttest

scores from the knowledge measure and the attitude measure were normally distributed. To determine equality of the groups, a test of homogeneity of variance was performed. The Levene statistic indicated that the groups were equal on both variables (p=.385, p=.682). The paired t-test statistic revealed significant differences between the knowledge pretest and 1-week posttest scores (t= 3.107, df=34, p=.004) but not between attitude pretest and 1-week posttest scores (t= 1.636, df=34, p=.111). The hypothesis was partially accepted because there were significant differences between pretest and 1-week posttest knowledge scores but no significant differences between pretest and 1-week posttest attitude scores.

A paired t-test on knowledge and attitude pretest and 2-week posttest scores was also planned to test the second hypothesis, which states that 2-weeks after completing the *Okay with Asthma*™ program, (T_3), participating children will have significantly higher scores on both the asthma knowledge and child attitude scale when compared to baseline scores (T_1). This was not performed because the assumptions of a paired t-test were not met. Neither the 2-week posttest knowledge scores nor the 2-week posttest attitude scores were normally distributed. Both knowledge and attitude 2-week posttest scores were negatively skewed at -2.53 and -2.51 respectively. Instead, a non-parametric Wilcoxon Signed Ranks test was performed. This hypothesis was accepted because children scored significantly higher on 2-week posttest knowledge scores than the pretest scores (z= 2.705, p=.007) and significantly higher on 2-week posttest attitude scores than pretest scores (z= 2.554, p=.011).

Overall, the attitude scores improved at either 1-week posttest or 2-week posttest, in 31 of 35 participants (highest possible score=5). Of those four participants who did not

improve their scores, two participants' scores remained constant. The knowledge scores improved at either 1-week posttest or 2-week posttest, when compared to pretest, in 30 of 35 participants (highest possible score=35). Of those 5 participants who did not improve their scores, 1 child's scores remained constant. See Table 3 for mean scores during each evaluation in both the knowledge and attitude measures.

TABLE 3 MEAN SCORES ON BOTH MEASURES DURING EACH EVALUATION

Measure	Mean Pretest Score (SD)	Mean 1-week Posttest Score (SD)	Mean 2-week Posttest Score (SD)
Knowledge Measure	26.3 (3.58)	27.8 (3.27)	28.1 (4.18)
Attitude Measure	3.58 (.74)	3.72 (.87)	3.80 (.82)

Descriptive Data Analysis

The descriptive data were examined to explore their effect on children's knowledge and attitude scores. Knowledge and attitude were not significantly correlated during all three evaluations indicating that these were independent constructs (see Table 4).

TABLE 4 ATTITUDE AND KNOWLEDGE SCORES CORRELATION

	Attitude (T_1)	Attitude (T_2)	Attitude (T_3)
Knowledge (T_1)	.025	-.003	-.070
Knowledge (T_2)	.049	-.055	-.022
Knowledge (T_3)	.060	.115	.079

Descriptive Variables and Knowledge Scores

Females consistently scored higher than males on the knowledge measure at each evaluation and their scores were significantly higher during the 1-week (T_2) evaluation ($t=2.74$, $p=.010$). The mean knowledge score of both males and females improved at each evaluation (see Table 5).

TABLE 5 MALE AND FEMALE KNOWLEDGE SCORES

	Knowledge T_1 (SD)		Knowledge T_2 (SD)		Knowledge T_3 (SD)	
Males	25.63 (3.4)	p=.244	26.53 (3.2)	p=.010	26.84 (4.7)	p=.053
Females	27.06 (3.7)		29.31 (2.8)		29.56 (2.9)	

The differences between the increase in knowledge scores at each evaluation for males and females were not significant when comparing pretest scores to 1-week posttest scores, (t=-1.405, p=.169), pretest scores to 2-week posttest scores, (t=-.995, p=.327), and 1-week posttest scores to 2-week posttest scores (t=.066, p=.947). The duration of a child's asthma diagnosis had no significance on knowledge pretest or 1-week posttest scores. Ten year-old participants scored significantly higher on knowledge pretest scores than any other age group (t=-2.351, p=.025). Table 6 summarizes mean knowledge scores at pretest, changes in mean knowledge scores between pretest (T_1) and 1-week posttest (T_2), and changes in mean knowledge scores between pretest (T_1) and 2-week posttest (T_3).

Descriptive Variables and Attitude Scores

Overall, mean attitude scores of both males and females improved at each evaluation but males scored consistently higher on the attitude measure than females (see Table 7). The highest possible attitude score was 5. The effects of descriptive variables on pretest attitude scores, differences in attitude scores from pretest to 1-week posttest, and differences in attitude scores between pretest and 2-week posttest scores are summarized in Table 8.

TABLE 6 MEAN KNOWLEDGE SCORES AND CHANGES IN SCORES

Variable	Mean T_1 (SD)			Δ Mean T_1 & T_2 (SD)			Δ Mean T_1 & T_3 (SD)		
Gender									
Male (n=19)	25.63	(3.40)	p=.244	.89	(2.87)	p=.169	1.21	(4.05)	p=.327
Female (n=16)	27.06	(3.73)		2.25	(2.82)		2.50	(3.52)	
Age									
8 years (n=15)	25.60	(3.18)	p=.061	1.60	(3.96)	p=.892	1.80	(5.21)	p=.937
9 years (n=7)	26.57	(2.57)		2.0	(2.31)		2.57	(3.96)	
10 years (n=9)	28.56	(4.2)		.89	(1.62)		1.33	(1.58)	
11 years (n=4)	23.25	(2.63)		1.75	(1.26)		1.50	(2.38)	
Ethnicity									
White (n=20)	27.10	(3.77)	p=.122	1.15	(2.91)	p=.006	1.10	(3.64)	p=.005
Black (n=12)	25.75	(2.77)		1.33	(1.23)		1.42	(2.61)	
Hispanic (n=2)	25.00	(2.83)		1.50	(3.54)		5.50	(2.12)	
Asian (n=1)	19.00	-		11. 0	-		13.0	-	
Asthma Severity									
Moderate (n=25)	26.04	(3.62)	p=.529	1.72	(3.06)	p=.513	1.44	(4.25)	p=.474
Severe (n=10)	26.90	(3.57)		1.00	(2.45)		2.70	(2.36)	
Limitations in Activity									
Minimal (n=18)	25.78	(3.32)	P=.529	1.39	(3.33)	p=.558	1.11	(4.63)	p=.710
Moderate (n=12)	27.25	(3.86)		2.00	(2.56)		2.58	(2.79)	
Severe (n=5)	25.80	(4.09)		.8	(2.05)		2.40	(2.70)	
Asthma Duration									
< 1 year (n=5)	27.80	(3.56)	p=.268	.60	(2.19)	p=.092	.40	(2.61)	p=.446
1.5-3 years (n=10)	24.30	(3.27)		2.5	(1.89)		1.10	(4.38)	
> 3.5 yrs. (n=20)	26.90	(3.49)		1.25	(3.39)		2.5	(3.78)	
Family Structure									
2 adult (n=26)	26.12	(3.73)	p=.639	1.92	(2.91)	p=.157	2.04	(3.40)	p=.538
1 adult (n=9)	26.78	(3.23)		.33	(2.6)		1.11	(3.37)	
Siblings (n=26)	26.12	(3.73)	p=.639	1.92	(2.91)	p=.157	2.04	(4.0)	p=.538
No siblings (n=9)	26.78	(3.23)		.33	(2.6)		1.11	(3.37)	
Family History of Asthma									
Asthma hx (n=24)	26.33	(3.82)	p=.909	1.63	(3.19)	p=.743	1.92	(4.23)	p=.794
No hx (n=11)	26.18	(3.16)		1.27	(2.2)		1.55	(2.87)	
Previous Asthma Programs									
camp (n=1)	29.00	-	p=.714	-1.0	-	p=.675	5.0	-	p=.670
Dr. office (n=33)	26.24	(3.65)		1.61	(2.94)		1.67	(3.89)	
school (n=1)	25.00	-		1.0	-		3.0	-	
Type of Provider									
Specialist (n=4)	27.25	(1.71)	p=.699	.00	(2.94)	p=.429	1.25	(2.3)	p=.644
Pediatrician (n-27)	26.24	(3.65)		1.85	(3.0)		2.11	(3.83)	
Family Prac (n=4)	25.00	-		.75	(2.22)		.25	(5.0)	
Learning Style									
Auditory (n=12)	25.75	(4.09)	p=.667	1.83	(3.94)	p=.351	1.67	(3.75)	p=.930
Visual (n=10)	26.00	(3.53)		2.30	(3.86)		2.20	(4.98)	
Kinesthetic (n=13)	27.00	(3.27)		.62	(2.5)		1.62	(3.1)	
Computer Proficiency									
Novice (n=12)	25.85	(2.91)	p=.484	1.31	(3.23)	p=.759	1.31	(4.46)	p=.750
Proficient (n=20)	26.55	(3.96)		1.64	(2.74)		2.09	(3.46)	
Advanced (n=3)	24.00	(6.1)		2.67	(.578)		3.33	(1.53)	
Internet Proficiency									
Novice (n=13)	26.17	(2.79)	p=.584	1.25	(3.36)	p=.750	1.42	(4.64)	p=.565
Proficient (n=22)	26.70	(3.67)		1.50	(2.84)		1.80	(3.59)	

TABLE 7 MALE AND FEMALE ATTITUDE SCORES

	Attitude T_1 (SD)	Attitude T_2 (SD)	Attitude T_3 (SD)
Males	3.67 (.92)	3.91 (.95)	3.99 (.92)
Females	3.47 (.46)	3.49 (.72)	3.57 (.65)

Participants with severe asthma had significantly greater change in attitude scores from pretest to 1-week posttest compared to children with moderate asthma (t=2.13, p=.041). Children from 2 parent/guardian households, significantly improved their attitude scores at 1-week posttests (t=2.42, p=.021) and 2-week posttests (t=2.23, p=.031) when compared to pretest scores of children from 1 parent/guardian families. Children with siblings also significantly improved 1-week attitude posttest scores (t=2.42, p=.021) and 2-week attitude posttest scores (t=2.25, p=.031) compared to children without siblings. Lastly, novice Internet and computer users had significantly greater increase in attitude scores between pretest and 2-week posttest scores than proficient Internet users (t=2.74, p=.010) and proficient or advanced computer users (t=2.41, p=.021).

Table 8 Mean Attitude Scores and Changes in Scores

Variable	Mean T_1 (SD)		Δ Mean T_1 & T_2 (SD)		Δ Mean T_1 & T_3 (SD)	
Gender						
Male (n=19)	3.66 (.918)	p=.451	.247 (.554)	p=.198	.324 (.518)	p=.177
Female (n=16)	3.47 (.46)		.019 (.454)		.106 (.396)	
Age						
8 years (n=15)	3.60 (.722)	p=.527	.195 (.477)	p=.682	.421 (.436)	p=.031
9 years (n=7)	3.40 (.549)		.066 (.605)		.308 (.596)	
10 years (n=9)	3.45 (.918)		.017 (.186)		-1.5 (.256)	
11 years (n=4)	4.1 (.714)		.365 (.316)		.173 (.368)	
Ethnicity						
White (n=20)	3.52 (.782)	p=.228	.069 (.413)	p=.002	.165 (.413)	p=.005
Black (n=12)	3.78 (.608)		.083 (.419)		.135 (.396)	
Hispanic (n=2)	2.69 (.762)		1.38 (.761)		1.31 (.326)	
Asian (n=1)	4.08 -		-.15 -		.308 -	
Asthma Severity						
Moderate (n=25)	3.66 (.749)	p=.268	.031 (.446)	p=.041	.209 (.434)	p=.082
Severe (n=10)	3.35 (.708)		.423 (.596)		.262 (.583)	
Limitations in Activity						
Minimal (n=18)	3.73 (.668)	p=.276	.214 (.499)	p=.357	.231 (.438)	p=.939
Moderate (n=12)	3.29 (.838)		.250 (.586)		.244 (.540)	
Severe (n=5)	3.71 (.689)		.323 (.354)		.154 (.235)	
Asthma Duration						
< 1 year (n=5)	3.68 (.733)	p=.641	.154 (.188)	p=.170	.108 (.215)	p=.295
1.5 – 3 years (n=10)	3.38 (.879)		.015 (.518)		.139 (.526)	
> 3.5 yrs. (n=20)	3.65 (.688)		.204 (.575)		.296 (.496)	
Family Structure						
2 adult (n=26)	3.65 (.730)	p=.335	.027 (.423)	p=.021	.124 (.418)	p=.031
1 adult (n=9)	3.37 (.774)		.479 (.636)		.513 (.526)	
Siblings (n=26)	3.65 (.730)	p=.335	.027 (.423)	p=.021	.124 (.418)	p=.031
No siblings (n=9)	3.37 (.775)		.479 (.636)		.513 (.526)	
Family History of Asthma						
Asthma hx (n=24)	3.89 (.736)	p=.177	.189 (.577)	p=.442	.266 (.523)	p=.447
No hx (n=11)	3.12 (.054)		.042 (.353)		.133 (.341)	
Previous Asthma Programs						
Camp (n=1)	3.85 -	p=.689	-.77 -	p=.187	-.54 -	p=.167
Dr. office (n=33)	3.55 (.755)		.163 (.505)		.233 (.461)	
school (n=1)	4.15 -		.385 -		.692 -	
Type of Provider						
Specialist (n=4)	3.67 (1.05)	p=.175	-.05 (.254)	p=.127	.020 (.357)	p=.144
Pediatrician (n=27)	3.66 (.70)		.103 (.455)		.194 (.084)	
Family Prac (n=4)	2.92 (.533)		.615 (.895)		.171 (.424)	
Learning Style						
Auditory (n=12)	3.67 (.93)	p=.709	.135 (.385)	p=.099	.109 (.414)	p=.234
Visual (n=10)	3.65 (.69)		-.12 (.484)		.131 (.492)	
Kinesthetic (n=13)	3.44 (.613)		.349 (.586)		.402 (.489)	
Computer Proficiency						
Novice (n=12)	3.52 (.57)	p=.477	.122 (.407)	p=.970	.474 (.400)	p=.029
Proficient (n=20)	3.61 (.867)		.146 (.608)		.142 (.474)	
Advanced (n=3)	3.13 (1.58)		.205 (.320)		-.23 (.154)	
Internet Proficiency						
Novice (n=13)	3.56 (.561)	p=.906	.172 (.430)	p=.805	.485 (.385)	p=.010
Proficient (n=22)	3.59 (.841)		.126 (.571)		.070 (.458)	

CHAPTER FIVE: DISCUSSION OF RESULTS

Okay with Asthma™ is an intervention designed to improve children's knowledge about asthma and attitude toward having asthma, therefore, it was predicted that mean knowledge and attitude scores would improve when compared to their baseline. *Okay with Asthma*™ used digital story to deliver psychosocial asthma management strategies, which until now had never been done, therefore, the effect size of the intervention was unknown. Because data were not available on similar studies, a pilot study was appropriate to understand these relationships.

Children's knowledge about asthma was significantly improved at both 1-week posttest and 2-week posttest when compared to pretest. Children's attitude toward having asthma also improved at 2-week posttest when compared to pretest, but there were no significant differences in attitude between pretest and 1-week posttest scores in this pilot study. Overall, the mean scores on both asthma knowledge and attitude toward having asthma improved at each evaluation. The results of this pilot study indicate *Okay with Asthma*™ is useful for improving asthma knowledge and attitude toward having asthma.

These findings are exciting for several reasons. Literature supported the use of story for learning and the presence of psychosocial stressors in children with asthma, but it was unknown if delivering psychosocial content through story would effect asthma knowledge or attitude toward having asthma. Despite the small sample size, knowledge scores improved and were sustained for 2 weeks. Eighteen (51%) of the children scored higher on the knowledge pretest (a score of 75% or higher) than children's post-intervention scores in another study that used the same knowledge measure (Wade, et al,

1997). Even though the participants in this sample had higher pretest knowledge scores, their scores significantly improved at each evaluation. None of the children in the study received a perfect score on either the pretest or the 2 posttests.

Attitude, which is widely documented as more difficult to change due to the complexity of the construct, was significantly improved in as little as 2 weeks. The mean attitude pretest scores in this sample were only slightly higher (3.6) than mean attitude scores (3.4) in previous studies using the same measure (Austin & Huberty, 1993). The greatest change in attitude scores occurred in children with severe asthma and children 8 years of age. Presumably, children with severe asthma would have lower attitude scores, and greatest change in scores than children with moderate asthma, as was the case in this sample. Children with fewer computer and Internet skills scored better on attitude measures than children with more computer skills indicating *Okay with Asthma*™ is useful regardless of computer skills, and in fact, may be suitable for younger children with less computer skills.

Theoretical Models and Results

Gagne's conditions of learning theory and Egan's learning through story model guided the testing of *Okay with Asthma*™. Specifically, Gagne describes two conditions that influence the learning process; external factors, such as the arrangement and timing of the instruction, and internal factors, such as the learner's self-perception and attitude. Using Gagne's 9 instructional events and Egan's story model to develop the stories in the program, the arrangement of the instruction (external) and the psychosocial content in *Okay with Asthma*™ influenced the learner's self-perception and attitude (internal) so that a change occurred in asthma knowledge and attitude toward having asthma. Further,

according to Egan, (1986) using story for instruction influences retention of content since individuals learn and process through story construction. Egan also proposes that story influences attitude, therefore, embedding psychosocial content in a story format should influence attitude, as was the case in this pilot study.

The program *Okay with Asthma*™ was developed using several guiding models; namely, Austin's child and family adaptation model and Miller and Wood's model of interaction with family, school, and peer systems. Austin's focus on attitude in a child's adaptation to illness was of particular interest. The program incorporated psychosocial management strategies and medical management skills (e.g. using peak flow meters and inhalers) with the goal of helping children adjust to asthma. This in turn influences a child's attitude toward having asthma and according to Gagne's concepts of internal factors, may improve the learning process.

Okay with Asthma™ not only focused on psychosocial strategies to adjust to asthma, but it also focused on school personnel and peers and their role in helping a child adjust to asthma as described by Miller and Wood. The program reinforced family, peer, and school involvement in managing asthma by role-modeling effective strategies such as eliciting help from others and talking with friends about feelings associated with asthma.

Literature and Results

Knowledge and attitude have been examined in numerous asthma studies and some studies found a correlation between the two variables (Brooks & Kishon, 1993; Gibson et al, 1995), but in this study, knowledge and attitude were not correlated. Similar to previous results reported by Brook and Kishon, (1993), attitude scores were higher in older children. Beginning knowledge scores in this study were lowest in the 11 year-old

group, unlike previous studies (Brook & Kishon, 1993; Gibson, et al., 1995; Pinto et al., 1999, Hazzard & Angert, 1986). In this study, the 11 year-old group also had the greatest improvement in scores as well as the highest knowledge scores at the end of the study, but these findings may not fairly represent the 11 year-old group since there were only 4 participants in this age group.

In the review of literature, summer camps and traditional asthma programs found in schools and clinics were effective in improving knowledge and attitude (Colland, 1993; Honer, 1998; Briery & Rabian, 1999; Hazzard & Angert, 1986), similar to the results of this study. This study demonstrated that *Okay with Asthma*™ may offer the similar benefits to summer camps and traditional asthma programs in a feasible and accessible self-guided program available on the Internet.

Several multimedia based asthma programs claim to be effective in improving asthma knowledge and behavior but the evidence to support these claims is not available (MindJourney, 1999; ARCV, 1999). *Okay with Asthma*™, on the other hand, was tested to determine the feasibility and accessibility of using the program. The results of this pilot study will guide revisions and improvements in the program and future research to examine its effects on self-efficacy and behavior.

Many studies that examined attitude measured it once and compared children's' attitude toward asthma to children with other chronic diseases, or to attitudes of others involved in the child's care, such as parents and teachers (Brook and Kishon, 1993; Gibson et al., 1995; McNelis et al., 2000; Pinto et al., 1999& Van Sciver, 1995). Measuring attitude once may not be effective since measuring one's attitude is, at best, a measurement of values and beliefs within a social and personal context at a fixed point in

time. This distinction is important because attitude will change depending on an individual's personal experiences or context at the moment of measurement. Since attitude is subjective and dependent on personal context, changes in attitude must occur over time and the length of time will vary among individuals. For this reason, it is noteworthy that in this pilot study, mean attitude scores improved at each evaluation with 2-week posttest scores reflecting significant differences from pretest scores. This delay in attitude response is to be expected since change in attitude occurs over time (Ajzen & Fishbein,1980). This trend further supports the need for additional research examining the length of time that knowledge improvement and attitude change is sustained.

Interpreting the Results

The average pretest knowledge score for this study was 75%. The possibility of a ceiling effect on the knowledge scores is minimal because 49% of the sample scored below the mean at pretest, 34% of the sample scored below the 25th percentile and the pretest scores were normally distributed. Further, some children's knowledge scores did not improve at all. The attitude scores were also slightly higher than scores reported in previous studies. Children in this study had pretest attitude scores of 3.6 compared to attitude scores of 3.4 in a study comparing children with asthma to children with epilepsy (Austin & Huberty, 1993).

In several circumstances parents declined enrollment because although their child was diagnosed with moderate to severe asthma, families were concerned that their child would be alarmed at the prospect of engaging in an asthma study. This observation suggests those families who agreed to participate in the study may have been information-seekers, families who perceived their children were lacking asthma

management skills, or families who offer support and help the child manage their asthma, especially since participation was not influenced by the gift certificate incentive. Pediatric asthma studies consistently report children manage asthma better when families offer support to children (Austin, 1990; Kieckhefer, 1988; Donnelly, Donnelly, & Thong, 1987). Children who successfully manage their asthma have higher asthma knowledge and attitude scores (Brazil et al, 1997). If the sample represented children with supportive families, this may also account for higher pretest knowledge and attitude scores.

Higher pretest scores in the study may also have occurred because only one child in the study reported unfamiliarity with two major components in *Okay with Asthma*™; namely content on action plans and peak flow meters. It can thus be assumed the program was a review of content for most participants explaining the slight increase of 5% between the pretest and posttest knowledge scores.

This study also found that computer and Internet proficiency had no influence on knowledge scores, but children with fewer computer and Internet skills scored significantly higher on attitude posttests than children with more advanced computer skills. This is an important finding because the measures were converted from a paper and pencil survey to an on-line questionnaire. It used common buttons and navigation design, such as radio buttons, 'next' and 'back' buttons. Many on-line surveys require the user to answer a list of questions before advancing to a new web page, which may cause confusion and lead to omission of responses. Because the participants in this study were children, the survey was limited to one question per web page that did not advance after the 'next' button was clicked unless a response was provided. This design was established to reduce confusion and overwhelming children with a scrolling web page of

numerous items. The 'back' button allowed participants to review and change responses. The on-line survey format, which was uniquely tailored for children, was easy to use and may be well suited for children with fewer computer skills.

All of the children in this study had home computers, however, 34% of the participants were ranked as novice computer users and 37% were novice Internet users. Despite the novice user's inexperience with computers and the Internet, all participants in the study easily navigated through the on-line survey and *Okay with Asthma*™. In fact, at no time did participants ask questions regarding how to proceed or what actions to take in the program. Regardless of a child's computer skills, the on-line survey designed for this study and *Okay with Asthma*™ was easy to use.

The child's learning style; auditory, visual, and kinesthetic, was not related to scores on either the knowledge measure or the attitude measure. Therefore, learning styles had no influence on the learning process that occurred with each child while participating in the program and the measure scores were not dependent on learning styles. As an educational tool for psychosocial management of asthma, *Okay with Asthma*™ is not sensitive to various learning styles and can be used by all types of learners and with learners of varying computer skills.

Of particular interest is the significant change in attitude two weeks after completing *Okay with Asthma*™ one time. While this finding is promising, it is premature to assume *Okay with Asthma*™ improves attitude toward asthma in as little as two weeks. *Okay with Asthma*™ is a self-guided program with limited features that has undergone preliminary testing that showed a significant change in knowledge and attitude scores. With additional psychosocial asthma management content, a greater selection of

stories, and advanced interactive features, children may re-visit *Okay with Asthma*™ more frequently. With frequent visits to the site, psychosocial content would be reinforced. This may lead to sustained improvement in both asthma knowledge and attitude toward having asthma, which, in part, may contribute to effective asthma management behavior. Testing the effects of *Okay with Asthma*™ on attitude and knowledge over time will lead to a better understanding of its effect on knowledge and attitude retention. This would be followed by an examination of the effects of *Okay with Asthma*™ on asthma management behaviors.

Limitations

The study was susceptible to several internal validity threats; threat of history, testing, instrumentation, and selection process. Other limitations of this study include the small sample size and the potential for emotional disturbance from misinterpreting information in the program. The threat of history leads to participant mortality and/or altered posttest scores. Some children became uninterested in the study after the first week since they were only completing measures during the 1-week evaluation and the 2-week evaluation but none of the participants withdrew from the study for this reason. There were two children who withdrew from the study and both withdrew due to scheduling conflicts.

Children may have improved their test scores as a result of repeating the same measures since the study occurred weekly over a 3-week period. Recall of measure items is more likely to occur when measures are repeated in a shorter period of time. To address this limitation, responses to the knowledge and attitude measures were not discussed with the child. But children may have responded to the attitude measure during

posttest evaluations that reflected the attitude toward having asthma they perceived to be the correct response instead of their actual attitude.

The threat of interaction between testing and treatment was present in this design because all participants completed a pretest before the treatment. Pretests condition the participants to the experimental stimulus. It was necessary to administer a pretest and obtain baseline scores in order determine the influence of the program on asthma knowledge and attitude because the participants act as their own control group in a one-group pretest-posttest design.

The tool used to measure knowledge in the study was problematic for some participants. It was selected because it had been used in previous pediatric asthma studies (Wade, et al, 1997) and no other tools were available that specifically examined asthma knowledge. Other knowledge measures included constructs such as attitude, behavior, and self-efficacy and it was not the goal of this pilot study to measure other constructs. The tool was developed for the National Cooperative Inner-city asthma study and was to be administered through an interview. Despite the modifications to the tool, discussed in Chapter 3, children often struggled with the concepts in the questions and the language was challenging for some participants. In some cases, it was necessary for the investigator to read items aloud and explain questions or concepts so the child could respond to the item.

On average, older children in the sample (10 and 11 years of age) asked fewer questions regarding knowledge measure items. There were two exceptions to this generalization. Two males, both 11year-old children, had difficulty with the knowledge measure and both were reported by teachers to read below grade level. Those children in

the sample who were in second grade had some difficulty reading items but more often needed clarification about words such as "mucus" and "wheezing." It took younger children more time to respond to the items in the measure.

Inter-item correlation and participant responses were examined thoroughly but no items were omitted from the analysis because the program *Okay with Asthma*™ was carefully designed to include all content that was included in the measure. Despite concerns with the knowledge measure, mean knowledge scores improved at 1-week post intervention and the scores were sustained at 2-week posttest.

The final threat to internal validity in this study is the selection process or the convenience sample that was collected. There were fewer children in Albemarle County public school systems with moderate to severe asthma than anticipated. Many of the children with asthma inhalers in the school system were diagnosed with either reactive airway disease or reactive bronchitis. It was only after meeting with school nurses to discuss each case that decisions were made to invite participation in the study. The sample in this study represented more children with moderate asthma than severe asthma. The decision to invite participation in the study was based on the child's asthma severity and age because this study targeted children 8-11 years with moderate to severe asthma. Further, children were targeted based on their ethnicity since the sample represented all ethnic groups in Albemarle County public schools. Because children were recruited for the study based on the school nurse's impression of the child's asthma, selection bias may be present in this sample. School nurses may have inadvertently selected children who not only met the inclusion criteria, but children they believed would benefit from the

program or children they believed would perform well in the study. This may explain the high mean pretest scores of the sample.

Okay with Asthma™ is an innovative program using techniques never used before in asthma education, therefore no previous research was available to draw upon to determine the effect size of the program and sample size. In such cases, pilot studies are performed. Although this sample of 35 children represented the ethnic population of children with asthma in Albemarle County, the sample was small and skewed with respect to age, asthma severity, and duration of asthma. Fifteen (43%) of the children were eight years of age, 25 (71%) children were categorized as having moderate asthma, and 20 (57%) children had been diagnosed with asthma for more than three years. Asians and Hispanics represented only 3% of the population in Albmarle County public schools. In fact, only one participant was Asian and two children were Hispanic. Ethnicity was significantly related to several variables such as asthma duration, knowledge and attitude scores, and family structure. A closer examination reveals the three children representing the Asian and Hispanic population scored higher than the mean scores on both knowledge and attitudes measures, and all three children were diagnosed with asthma for longer than 3 years. Because of the limited sample size with respect to the Asian population and Hispanics, it can be concluded that there were no differences in scores between Blacks and Whites. The sample in this study was small and specific to the population of students in Albemarle County, but this study was necessary to determine the research questions, effect size and power for future research related to the use of digital story to deliver psychosocial content for children with chronic diseases.

Content in *Okay with Asthma*™ may evoke negative feelings or be misunderstood by some children. One child reported, to his parents, confusion and concerns about the size of lungs in a child with asthma. The participant's parents reviewed the multimedia program with the child to clarify misconceptions. At the request of the parents and the child, he remained enrolled in the study. As a result of this occurrence, the procedures for the study were revised and included a debriefing session that allowed children to express feelings and concerns and ask for clarification about information in the program.

Future Research

Pilot testing *Okay with Asthma*™ over a 3-week period indicates the program is a feasible and acceptable intervention for asthma management. More research is needed to determine its efficacy and retention of changes in knowledge and attitude using larger samples of children with asthma. Further, to generalize these findings and determine efficacy of *Okay with Asthma*™ the intervention must be tested with larger samples of children. The testing must also occur over a longer period of time to determine the retention of changes in asthma knowledge and attitude toward having asthma.

To sustain a child's interest, the program must also be modified to include more interactive features that allow a user to better personalize stories. This is based on observations during pilot testing. Overall, children appeared to prefer the story writing component to the storytelling section of the program. This was evidenced by their remarks, interests in using the keyboard, and the number of participants who printed a copy of their written story. The story writing section may have been preferred by some children because it resembled a comic strip with text bubbles over characters. The comic

strip style story also responded to a child's entered text by animating the scene for which they entered text. The animation reinforced the content from the scene (i.e., avoid your triggers, express your feelings). For older children, the stories must include action with an element of interactive gaming to peak their interest (Street, Gold & Manning, 1997). All modifications in the program must undergo additional usability testing during the development to ensure the tool is usable and engaging to a child with asthma.

Future research must also include investigating the effects of *Okay with Asthma*™ on asthma management behaviors and health outcomes. This is important for several reasons. First, if *Okay with Asthma*™ influences asthma management behaviors, then the research may further support a relationship between knowledge, attitude and behaviors. Second, *Okay with Asthma*™ uses two unique features, digital story and the addition of psychosocial asthma management skills to influence knowledge and attitude. These two methods must be examined separately to determine the contribution of each in influencing asthma related health behavior. Lastly, if a digital story and story writing program that includes psychosocial management strategies, such as *Okay with Asthma*™, effects knowledge, attitude, and behavior in children with asthma, then similar programs could be developed and evaluated to determine if similar effects occur in children with other chronic diseases.

Conclusion

The contributions of the pilot study described in this dissertation were twofold. First, it established preliminary work for future research related to the effects of: (1) asthma knowledge and attitude toward asthma on behavior (2) using digital story on knowledge and attitude, (3) psychosocial asthma

management content on attitude toward having asthma. Second, participation in this pilot study had potential benefits for children. Two families of children who participated in the program contacted the investigator after data collection. One parent of an 11 year-old female was interested in exploring further her child's feelings associated with asthma. The parent reviewed the printed version of the story her child wrote and learned of feelings that the child had never expressed. The parent wished to discuss the content of the story and learn of additional feelings that the participant may have shared while writing the story so the family could attend to the feelings expressed in the story. The second parent who contacted the investigator reported that her 9 year-old son was able to recite new facts that he had learned from the *Okay with Asthma*™ program and that the child "enjoyed" the program.

Okay with Asthma™ has promise for children with asthma. The methods used to influence children's knowledge and attitude may have implications for children with other chronic diseases. The use of stories as an instructional method has long been used in education, and the use of interactive technologies in patient education is emerging. Asthma summer camps are successful in affecting children's self-esteem and coping because summer camps focus on the psychological aspects of asthma. Prior interventions have not incorporated story and psychosocial asthma management strategies using interactive technologies in a self-guided Internet-based program. This pilot study provides information about an innovative computer-based program using novel health education strategies. It

contributes to knowledge in health care research by suggesting innovations that have promise in promoting health in children with chronic illnesses.

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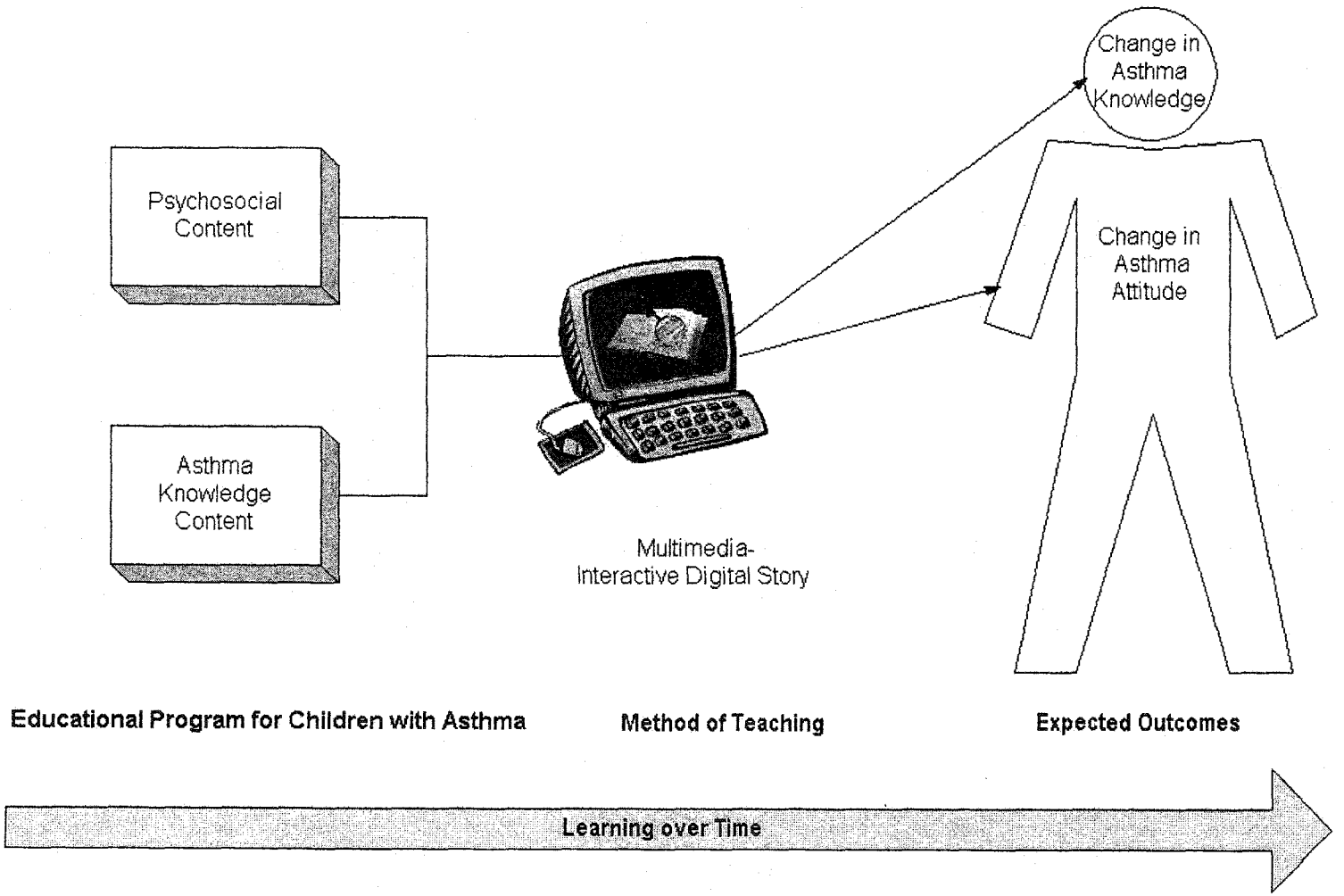
APPENDIX A: Model for Pilot Testing *Okay with Asthma*™



APPENDIX B: Sample Representation of Gender and Ethnic groups

	American Indian or Alaskan	Asian or Pacific Islander	Black, not Hispanic origin	Hispanic	White, not Hispanic origin	Total
Female	0 (0%)	1 (3%)	6 (20%)	0 (0%)	9(26%)	16
Male	0 (0%)	0 (0%)	6 (20%)	2 (6%)	11 (31%)	19
Subtotal	**0 (0%)**	**1 (3%)**	**12(34%)**	**2 (6%)**	**20(57%)**	**35**

(Note: figures in the table represent over sampling of minority groups when compared to percentages in Albemarle County Public Schools)

APPENDIX C: Cover Letter

Tami H. Wyatt, RN

Email: tamiwyatt@virginia.edu

Dear Parent or Guardian:

Hello. My name is Tami Wyatt and I am a registered nurse and a student at the University of Virginia. The staff at **[name of elementary school]** are working with me on a multimedia project. Your child is one of the few selected to play with a computer story that I developed and answer questions to determine if the computer story teaches children about asthma and if the computer story makes children feel better about having asthma.

Why was your child selected?

The story program is about children who have asthma. The stories do not require that your child tell a personal story. The stories are about fictitious characters that have asthma but your child will have an opportunity to add words to a story making it more personal. At the end of the story, your child can print the story and keep it.

Although I am sending you this letter, I do not know who is receiving it to protect the privacy of you and your child and so that your child does not feel obligated to talk with me about the computer story. If your child decides that he/she would like to play with this story and answer questions and you agree, **please complete and return the attached postcard by [date].**

What will you do?

Once I receive a postcard from you, I will contact you to set up a 20-minute meeting so that I can explain the study and answer any questions. When we meet, I will also ask questions such as how often your child has asthma symptoms and where your child receives asthma care.

What will your child do?

Your child will meet with me three times while at school but the activity will not interfere with learning because we will only meet before or after school and during free time. The first time I meet with your child, he or she will answer questions about asthma and how it feels to have asthma. Then your child will look at the computer story. The second and third time we meet, your child will not look at the computer story but will answer

questions about asthma and how it feels to have asthma so that I can determine if the computer story was effective in teaching about asthma.

The computer story will probably be fun for your child since it is similar to a cartoon. Your child may also learn about his or her asthma. Participation in this computer story is completely voluntary. If you have any questions, please do not hesitate to contact me. I look forward to showing my computer story to your child and getting feedback from him/her so that I can improve it before giving it to school health nurses in your county.

Respectfully,

Tami H. Wyatt, PhD(c), RN, MEd

APPENDIX D: Parental Consent Form

Pilot testing *Okay with Asthma*™: A digital story for psychosocial asthma management

Please read this carefully before you allow your child to participate in this study. Your child will also sign a form like this one. A copy of their form is attached for you to look at and discuss with your child.

Purpose of the research study:
This study will test *Okay with Asthma* to see if children learn about asthma self-care and to see if it influences their attitude about having asthma. *Okay with Asthma* is a digital story web site that tells children how to manage asthma. The program can be used in classrooms, by the school nurse, or in asthma clinics to learn about asthma. Children who do not have asthma can also use the digital story program so that they can learn how to help other children with asthma.
How your child scores on the knowledge test and the attitude test will help us makes it better for future users.

What you and your child will do in the study:
First, the parent(s) will answer questions during an interview such as where your child receives asthma care and how many asthma attacks your child has in a week. This interview should take approximately 15 minutes. Next, your child will answer questions on the computer about asthma and how he or she feels about having asthma. This will take about 15 minutes. Then your child will go to the *Okay with Asthma* web site and watch/listen and interact with the story. Your child can also write a story, print it and print a certificate of completion. Even though your child can print the story, the words that he or she adds to the story are not stored on the web site. One week later, your child will answer the same questions and then three weeks later, your child will answer these questions one last time.

Time required of the parent:
It will take you approximately 15-20 minutes to review and sign this form and answer questions about your child's asthma.

Time required of your child:
Your child will spend 10-15 minutes each time that he or she answers the questions. The Okay with Asthma site takes an additional 30 minutes. The first time that we meet will take about an hour. The second time that we meet will take 15 minutes and the third time will take 15 minutes. Total, your child will be involved in this study about 1 and ½ hours.

Risks:
There are no risks associated with this study. The content of the digital story informs children about how to manage asthma and cope with having asthma.

Benefits: There are no direct benefits to your child for participating in this research study. But, your child may better understand his or her own asthma or how to help friends who have asthma.

Confidentiality:
The information that your child gives in this study will be handled confidentially. Your child's information is protected in a secure database that requires a password. The information that you give me about your family will be kept in a locked file. When the study is completed and the data have been analyzed, this information will be destroyed. Your child's name will not be used in any report.

Voluntary participation:

Your child's participation in the study is completely voluntary.

Right to withdraw from the study:
You have the right to withdraw your child from the study at any time without penalty. Your child may withdraw from this study at any time without penalty.

How to withdraw from the study:
If your child wants to withdraw from the study at any time, they can tell me, "I don't want to do this anymore." Their responses and the information that you give me about your child will be destroyed.

Payment: Your child will receive a $10.00 certificate to a music store after he or she completes the entire study.

Who to contact if you have questions about the study:
Tami H. Wyatt, MEd, MSN, RN
School of Nursing, McLeod Hall
University of Virginia, Charlottesville, VA 22903
Telephone: (434) 924-1982

Faculty Advisor's Name
Emily Hauenstein, Ph.D., RN
University of Virginia, School of Nursing
Charlottesville, VA 22903
Telephone: (434) 243-2915

Who to contact about your rights in the study:
Luke Kelly, Chairman, Institutional Review Board for the Social and Behavioral Sciences , 2400 Old Ivy Road, Suite C141, Room 156, University of Virginia, P.O. Box 800392, Charlottesville, VA 22908-0392.
Telephone: (434) 243-2915

Agreement:
I agree to allow my child to participate in the research study described above.

Child's Name:_____

Signature: _____ **Date:** _____

You will receive a copy of this form for your records.

APPENDIX E: Child's Assent Form

Pilot testing *Okay with Asthma*™: A digital story for psychosocial asthma management

People who write stories and create web sites at the University of Virginia are trying to learn more about how to make a story on a web site better. It is called *Okay with Asthma*. We need help from children so that we know if the story helped you learn about your asthma and made you feel better about having asthma.

You are being asked to test this story because the story was created for kids like you who have asthma.

The people in charge of this study are Tami Wyatt and Emily Hauenstein. You or your parents can contact them by email at tamiwyatt@virginia.edu and ejh7m@virginia.edu or by phone at (434) 924-1982 and (434) 924-0093.

We will have you answer questions to see how much you know about asthma and to see how you feel about having asthma. Then, you will go to the web site and watch the story and then you can write your own story. After a week, you will answer questions again to see if *Okay with Asthma* taught you anything. Then, in three weeks, you will answer questions again to see if you remember what you learned from *Okay with Asthma*.

Sometimes things happen to people in research studies that may make them feel bad. These are called risks. If you feel sad or unhappy tell Tami Wyatt or an adult in the room.

People also may have things happen to them because they are in research studies. These are called benefits. This study may have some benefits: you may learn more about asthma and the way to cope with asthma, and you might also learn how to help others who have asthma.

You do not have to do this testing if you do not want to. You can stop at any time by telling an adult "I don't want to do this anymore." If you decide to stop, no one will be angry or upset with you.

If you want to look at *Okay with Asthma*™ and answer questions about asthma, please sign your name, and write today's date below.

Name: _____ **Date:** _____

Your parents have been given a copy of this form to keep.

APPENDIX F: Interview Data Form

First Name: _____

Age: _____ Gender: _____ Grade: _____

Race: _____ School: _____

Length of time with asthma? _____

Setting where asthma care received: _____

Prior asthma education: _____

How does your child prefer to learn material (i.e., observing, watching, hands on, games, reading)?

_____

_____

_____

Limitations in play and functioning due to asthma: _____

Household Income: _____

Family Structure (step-parent, single parent): _____

Transportation to school: _____ Time arrive: _____

Special activities during school (clubs, music) _____

Transportation from school: _____ Time leave: _____

Attend After School Program: _____

Computer in home: _____

Uses the Internet? _____

APPENDIX G: Asthma Severity Scale[3]

To be completed by the investigator during the interview. Fill in the blanks and check by the correct severity rating.

Name: _____ Age: _____

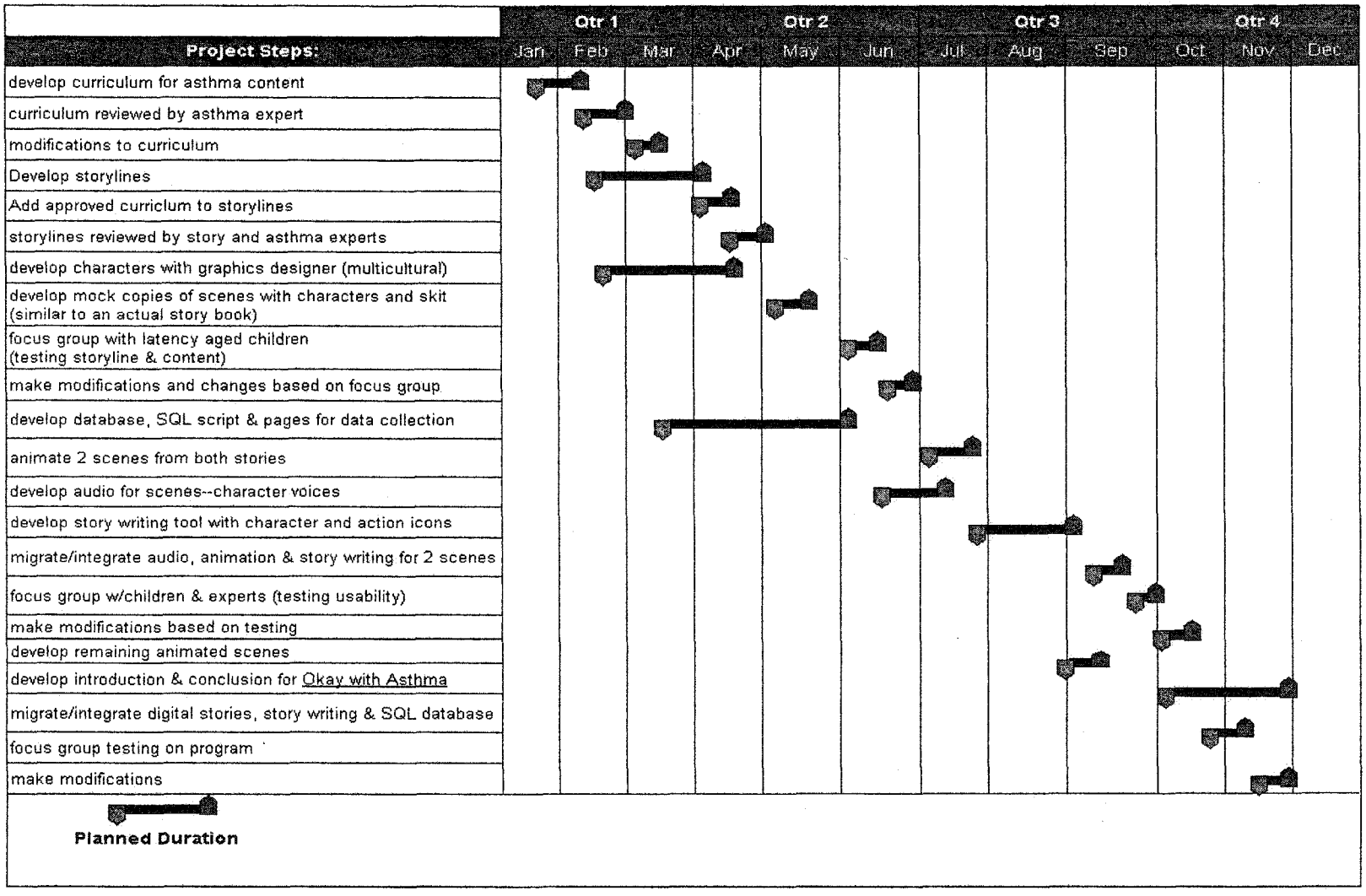
School: _____

Please tell me how often your child has asthma symptoms.

_____	At least two asthma symptoms every week	Mild Intermittent
_____	At least two asthma symptoms every week but less than 1 a day.	Mild Persistent
_____	Asthma symptoms every day.	Moderate Persistent
_____	Asthma symptoms continuously.	Severe Persistent

[3] Developed by the National Heart, Lung and Blood Institute (1997). National Asthma Education and Prevention Program. National Institutes of Health.

APPENDIX H: *Okay with Asthma*™ Development Schedule



APPENDIX I: Sample Questions During Usability Testing

Group		Evaluations	Interview Questions
Focus Group 1	Paper Version of Story	What are the facial expressions of the child while reading the stories?	What do you think was the purpose of the story?
		How long does the child study the illustrations?	Did reading this story make you think about your asthma?
		Where, if ever, does the child appear to lose interest in the stories?	Did you understand the information about asthma? What did you learn?
		What nonverbal communications are present while reading the stories?	What was your favorite part or character in the stories?
Focus Group 2	Mock-ups & portions of animation	Did the child explore the screen with the mouse?	Did this story make you feel different or the same about asthma?
		Did the child go directly to the navigation buttons?	Which do you like better, listening and watching a story on the computer or reading a story in a book?
		Did the child read the instructions?	Did you find any screen in the story confusing?
		Was the child attentive to the animated story?	Was there something you saw that didn't make sense?
Focus Group 3	Entire Okay with Asthma™ program	What did the child attend to first on the home page?	What did you learn about asthma?
		Did the child use the mouse to explore the page? If so, what?	Did you understand what to do?
		How did the child navigate through the site?	Do you like the characters? What did you not like in the story?
		Was the child attending to the story? How do I know?	Did you find any screen in the story confusing?
		What did the child want to do at the end of the program?	Do you know how to advance through the book?
		List questions child asked while using the site.	Did you understand the instructions?

APPENDIX J: Heuristic Evaluation Focus Group 1

FOCUS GROUP 1		IMPORTANCE	EASE of ACHIEVEMENT	PRODUCT
***Okay with Asthma*™ site**	Based on Heuristic?	Low .....High 1 2 3 4 5	Difficult.....Easy 1 2 3 4 5	
Story				
Change the word wheeze to cough throughout the story.	☒	☐ ☐ ☐ ☒ ☐	☐ ☐ ☐ ☐ ☒	20
Introduce action plan concept better.	☐	☐ ☐ ☐ ☒ ☐	☐ ☐ ☒ ☐ ☐	12
Children tire of the scene (clinic) but like the quick read and quick action of the tips.	☒	☐ ☐ ☐ ☐ ☒	☐ ☐ ☒ ☐ ☐	15
Change lung looker concept	☒	☐ ☐ ☐ ☐ ☒	☐ ☐ ☒ ☐ ☐	15
No window for the dog to jump out of.	☐	☐ ☐ ☐ ☒ ☐	☐ ☐ ☐ ☐ ☒	20
Controlling emotions is the wrong message. "the idea is affective regulation through specific strategies while appreciating the emotion for what it is telling us".	☒	☐ ☐ ☐ ☐ ☒	☐ ☐ ☐ ☒ ☐	20
'these airways' to 'this tube', change the reference to Matthew's healthy lungs; implies that Gina's lungs are not healthy. Change word inflamed to red.	☒	☐ ☐ ☐ ☒ ☒	☐ ☐ ☐ ☐ ☒	23
First tip same name as the story (confusing).	☒	☐ ☐ ☐ ☒ ☐	☐ ☐ ☐ ☒ ☐	16

APPENDIX K: Nielsen's Ten Usability Heuristics

1. *Visibility of System Status:* The system should always keep users informed about what is going on, through appropriate feedback within reasonable time.
2. *Match between system and the real world:* The system should speak the users' language, with words, phrases and concepts familiar to the user, rather than system-oriented terms. Follow real-world conventions, making information appear in a natural and logical order.
3. *User control and freedom:* Users often choose system functions by mistake and will need a clearly marked "emergency exit" to leave the unwanted state without having to go through an extended dialogue. Support undo and redo.
4. *Consistency and standards:* Users should not have to wonder whether different words, situations, or actions mean the same thing. Follow platform conventions.
5. *Error prevention:* Even better than good error messages is a careful design, which prevents problems from occurring in the first place.
6. *Recognition rather than recall:* Make objects, actions, and options visible. The user should not have to remember information from one part of the dialogue to another. Instructions for use of the system should be visible or easily retrievable whenever appropriate.
7. *Flexibility and efficiency of use:* Accelerators—unseen by the novice user—may often speed up the interaction for the expert user such that the system can cater to both inexperienced and experienced users. Allow users to tailor frequent actions.

APPRENDIX K: Continued

8. *Aesthetic and minimalist design:* Dialogues should not contain information, which is irrelevant or rarely needed. Every extra unit of information in a dialogue competes with the relevant units of information and diminishes their relative visibility.
9. *Help users recognize, diagnose, and recover from errors:* Error messages should be express in plain language (no codes), precisely indicate the problem, and constructively suggest a solution.
10. *Help and documentation:* Even though it is better if the system can be used without documentation, it may be necessary to provide help and documentation. Any such information should be easy to search, focused on the user's task, list concrete steps to be carried out, and not be too large. [4]

[4] Molich, R. & Nielsen, J. (1990). Improving a human-computer dialogue, Communications of the ACM 33, 3 (March); excerpt [available online] http://www.useit.com/papers/heuristic/heuristic_list.html Accessed: November 23, 2002.

APPENDIX L: Nielsen's Rating Guidelines

The severity of a usability problem is a combination of three factors:

1. The **frequency** with which the problem occurs: Is it common or rare?
2. The **impact** of the problem if it occurs: Will it be easy or difficult for the users to overcome?
3. The **persistence** of the problem: Is it a one-time problem that users can overcome once they know about it or will users repeatedly be bothered by the problem?

The following 0 to 4 rating scale can be used to rate the severity of usability problems:

0 = I don't agree that this is a usability problem at all

1 = Cosmetic problem only: need not be fixed unless extra time is available on project

2 = Minor usability problem: fixing this should be given low priority

3 = Major usability problem: important to fix, so should be given high priority

4 = Usability catastrophe: imperative to fix this before product can be released

APPENDIX M: Heuristic Evaluation Focus Group 2

FOCUS GROUP 2		IMPORTANCE	EASE of ACHIEVEMENT	PRODUCT
***Okay with Asthma*™ site**	Based on Heuristic?	Low .....High 1 2 3 4 5	Difficult .....Easy 1 2 3 4 5	
Story				
The story needs a next button on the last frame of each scene instead of automatically animating from one scene to the next.	☐	☐ ☐ ☒ ☐ ☐	☐ ☐ ☐ ☒ ☐	12
How can I replay the scene?	☒	☐ ☐ ☐ ☒ ☐	☐ ☐ ☐ ☒ ☐	16
I don't like the bully-I don't like his voice.	☐	☐ ☐ ☒ ☐ ☐	☐ ☐ ☐ ☐ ☒	15
There is no back button.	☒	☐ ☐ ☐ ☐ ☒	☐ ☐ ☐ ☐ ☒	25
Instructions Page				
I don't know what 'text' means.	☒	☐ ☐ ☐ ☐ ☒	☐ ☐ ☐ ☐ ☒	25
Story Writing				
I didn't have time to read the instructions. I don't know what to do.	☒	☐ ☐ ☐ ☐ ☒	☐ ☐ ☒ ☐ ☐	15
How come the words are not going into the bubble?	☒	☐ ☐ ☐ ☐ ☒	☐ ☒ ☐ ☐ ☐	10

APPENDIX M: Continued

I didn't see the instructions.	☒	☐ ☐ ☐ ☐ ☒	☐ ☐ ☐ ☐ ☒	25
Where is the ON button for the TV?	☒	☐ ☐ ☐ ☒ ☐	☐ ☐ ☐ ☐ ☒	20
Matthew's jersey numbers are backward on all of the scenes.	☐	☐ ☐ ☐ ☐ ☒	☐ ☐ ☐ ☐ ☒	25
User didn't know which bubble to click and thought that she needed to click on the Cole bubble.	☒	☐ ☐ ☐ ☒ ☐	☐ ☒ ☐ ☐ ☐	10
Text is small, needs to be bigger.	☒	☐ ☐ ☐ ☒ ☐	☐ ☐ ☐ ☒ ☐	16

APPENDIX N: Heuristic Evaluation Focus Group 3

FOCUS GROUP 3		IMPORTANCE	EASE of ACHIEVEMENT	PRODUCT
***Okay with Asthma*™ site**	Based on Heuristic?	Low .....High 1 2 3 4 5	Difficult .....Easy 1 2 3 4 5	
Overall Site				
There is no way for me to get out.	☒	☐ ☐ ☐ ☐ ☒	☐ ☐ ☒ ☐ ☐	15
Do I push the start button now?	☒	☐ ☐ ☒ ☐ ☐	☐ ☐ ☐ ☐ ☒	15
Introduction/Home Page				
What does "contain" mean?	☒	☐ ☐ ☐ ☒ ☐	☐ ☐ ☐ ☐ ☒	20
The words are too small on the introduction/home page.	☐	☐ ☐ ☐ ☒ ☐	☐ ☐ ☐ ☐ ☒	20
Story				
What does afar mean?	☒	☐ ☐ ☒ ☐ ☐	☐ ☐ ☒ ☐ ☐	9
Tip # 6 is too loud and scratchy!	☒	☐ ☐ ☒ ☐ ☐	☐ ☐ ☐ ☒ ☐	12
The words disappeared before I could read them.	☒	☐ ☐ ☐ ☐ ☒	☐ ☐ ☒ ☐ ☐	15
Load time after the laughing interactive scene is still very long. Seems out of place since it is right during the middle of the story.	☒	☐ ☐ ☐ ☒ ☐	☐ ☒ ☐ ☐ ☐	8

APPENDIX N: Continued

Story Writing				
The printed story in the writing section, prints the words "Scene 1, 2, 3, & 4" respectively but not on any other pages.	☐	☐ ☐ ☒ ☐ ☐	☐ ☒ ☐ ☐ ☐	6
Scene 1, Mrs. Koogler's bubble statement is missing a period at the end of the sentence.	☐	☐ ☐ ☒ ☐ ☐	☐ ☐ ☐ ☐ ☒	15
Is this my story?	☒	☐ ☐ ☒ ☐ ☐	☒ ☐ ☐ ☐ ☐	3
Why is car exhaust at motorcross racing? Why does it say Vroom, Vroom?	☐	☐ ☐ ☒ ☐ ☐	☐ ☐ ☐ ☐ ☒	15
If I push the finish button, does that mean the story ends?	☐	☐ ☐ ☒ ☐ ☐	☐ ☐ ☐ ☐ ☒	15
It takes over 4 minutes to load the story writing section.	☒	☐ ☐ ☐ ☒ ☐	☐ ☒ ☐ ☐ ☐	8
What does "view the story so far mean"? (no children in any focus group have used this feature)	☒	☐ ☐ ☒ ☐ ☐	☐ ☐ ☐ ☐ ☒	15
Users cannot get the cursor in the bubble box to type. Users don't realize that they must click in the bubble again to get the cursor in the bubble.	☒	☐ ☐ ☐ ☐ ☒	☐ ☒ ☐ ☐ ☐	10
Take a puff of what?	☐	☐ ☐ ☐ ☒ ☐	☐ ☐ ☐ ☐ ☒	20
What does this say (in reference to Home button)?	☒	☐ ☐ ☒ ☐ ☐	☐ ☐ ☐ ☐ ☒	15

APPENDIX O: NCICAS Asthma Information Quiz for Children

Answer True or False: T = True and F = False

1. _____ Coughing is often a warning sign of asthma.

2. _____ There are usually other signs of an asthma attack before you can hear wheezing.

3. _____ Asthma medicine only works after warning signs like coughing or wheezing have started.

4. _____ Being unable to breathe or short of breath may be a sign of an asthma attack.

5. _____ All kids grow out of asthma by the time they are 18 years old.

6. _____ Allergies can start or set off an asthma attack.

7. _____ Eating fatty foods can make asthma worse.

8. _____ Kids don't need to stay away from people who smoke because smoke cannot start asthma.

9. _____ Some asthma medicines are used only when you need them, not all the time.

10. _____ Kids with asthma should not play sports.

11. _____ Taking medicine regularly is supposed to help keep asthma problems from happening.

12. _____ If you are getting tired or having trouble keeping up with your friends you should stop and rest.

13. _____ Staying away from certain things will help keep an attack from starting.

14. _____ Coughing to clear mucus out of the lungs is not a good idea if you are having asthma symptoms.

15. _____ If you have not had any problems with asthma for more than a month, you can stop taking your medicine.

16. _____ Some things around the house can start asthma attacks.

17. _____ Changes in the weather can start an asthma attack.

APPENDIX O: Continued

18. It is OK to use medicine that should be used only when you need it:

_____ a. before you play outside or play sports
_____ b. when you are overtired or tired out
_____ c. when you have a cold or are sick
_____ d. when the weather is cold
_____ e. before you are around
_____ f. something
_____ g. when you are coughing
_____ h. when you have trouble breathing
_____ i. when you have pain or tightness in your chest

19. Some should call the doctor or take you to the hospital when:

_____ a. wheezing lasts 1 to 3 hours after you have taken medicine.
_____ b. You have problems breathing.
_____ c. You stop playing or being active and can't start again.
_____ d. You have trouble walking or talking
_____ e. You have blue/purple lips or fingernails

20. _____ I should share my feelings and talk to people I trust about having asthma.

21. _____ I don't ask my friends to help me when I am having trouble breathing because it might scare them.

22. _____ Having an asthma action plan can help me stay calm during an attack.

23. _____ I should tell my teachers, friends, counselors, and anyone who takes care of me that I have asthma.

APPENDIX P: Child Attitude Toward Illness Scale (CATIS)

Here are 13 questions that ask about you and your feelings. Read each one carefully. If there is anything that you do not understand, please ask us about it. For each question, put a check mark √ above the response that best describes your feelings. Answer EVERY question even if some are hard to decided, but check only one answer. There are no right or wrong answers. Only YOU can tell us how you feel so we hope that you will mark the way you REALLY feel inside.

1. How good or bad do you feel it is that you have asthma?

Very Good	A Little Good	Not Sure	A Little Bad	Very Bad

2. How fair is it that you have asthma?

Very Fair	A Little Fair	Not Sure	A Little Unfair	Very Unfair

3. How happy or sad is it for you to have asthma?

Very Sad	A Little Sad	Not Sure	A Little Happy	Very Happy

4. How bad or good do you feel it is to have asthma?

Very Good	A Little Good	Not Sure	A Little Bad	Very Bad

5. How often do you feel that your asthma is your fault?

Never	Not Often	Sometimes	Often	Very Often

6. How often do you feel that your asthma keeps you from doing things you like to do?

Very Often	Often	Sometimes	Not Often	Never

7. How often do you feel that you will always be sick?

Never	Not Often	Sometimes	Often	Very Often

8. How often do you feel that your asthma keeps you from starting new things?

Very Often	Often	Sometimes	Not Often	Never

APPENDIX P: Continued

9. How often do you feel different from others because of your asthma?

Never	Not Often	Sometimes	Often	Very Often

10. How often do you feed bad because you have asthma?

Very Often	Often	Sometimes	Not Often	Never

11. How often do you feed sad about being sick?

Never	Not Often	Sometimes	Often	Very Often

12. How often do you feel happy even though you have asthma?

Never	Not Often	Sometimes	Often	Very Often

13. How often do you feel just as good as other kids your age even though you have asthma?

Very Often	Often	Sometimes	Not Often	Never

Appendix Q: Schools Represented in the Sample

School (# of recruitment letters sent)	Male	Female	Total
Agnor-Hurt (33)	6	4	10
Baker-Butler (7)	0	3	3
Broadus-Wood (15)	0	1	1
Brownsville (8)	3	1	4
Cale (17)	3	1	4
Crozet (7)	0	1	1
Greer (5)	1	0	1
Hollymead (11)	3	0	3
Meriwether-Lewis (12)	0	0	0
Murray (7)	1	0	1
Red Hill (6)	0	0	0
Scottsville (7)	0	0	0
Stone Robinson (17)	1	0	1
Stony Point (7)	0	2	2
Woodbrook (10)	1	3	4
Yancey (0)	0	0	0
Totals (169)	**19**	**16**	**35**