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DOES HEALTH HOOPS KENTUCKY IMPROVE THE HEALTH OF CHILDREN
WITH ASTHMA?

By

Yu-Ting Chen
B.S., China Medical University, 2005
M.P.H., University of Louisville, 2009

A Thesis
Submitted to the Faculty of the
Graduate School of the University of Louisville
in Partial Fulfillment of the Requirements
for the Degree of

Master of Science

Department of Bioinformatics and Biostatistics
School of Public Health and Information Sciences
University of Louisville
Louisville, Kentucky

December 2010

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A Thesis Approved on

November 12th, 2010

by the following Thesis Committee:

Thesis Director

DEDICATION

This thesis is dedicated to my parents

陳瑞欣 先生 (Mr. Zung-Sing Chen)

and

許寶桂 女士 (Mrs. Pao-Kuei Hsu)

who have given me invaluable educational opportunities.

ACKNOWLEDGMENTS

I would like to thank my academic advisor, Dr. John Myers, for his guidance and patience for the past three years. I would also like to thank the other committee members, Dr. Guy Brock and Dr. S. Lee Ridner, for their comments and assistance. I would also like to express my thanks to the members of my family in Taiwan: 陳維浩 (Wei-Hao Chen), 吳旻靚 (Min-Jing Wu), 陳昱志 (Yu-Chih Chen), and 陳妍閔 (Yan-Min Chen). They encouraged me and always stand up for me wherever I am. Also, many thanks to my friends in Louisville, Kentucky: Jeremy Skaggs, William Daep, Duke Appiah, Adell Mendes, 張偉伶 (Wei-Lin Chang), Ryan Steelman, 陳冠廷 (Kuan-Ting Chen), 吳品宜 (Pin-Yi Wu), 吳宜恬 (I-Tien Wu), 鄭旆欣 (Pei-Hsin Cheng), 張婕 (Jei Zhang), and 楊大可 (Dake Yang). Finally, I would like to give my especial thank to my grandmother, 陳李燭森 女士 (Mrs. Jhu-Sen Lee Chen) for her support.

ABSTRACT

DOES HEALTH HOOPS KENTUCKY IMPROVE THE HEALTH OF CHILDREN WITH ASTHMA?

Yu-Ting Chen, M.P.H.

November 12, 2010

Asthma is the most common chronic disease among children aged 7 to 17 years of age in the United States. An average, one of every ten school-aged children has asthma, and 13 million school days are missed each year due to asthma. Interventions to prevent or reduce the severity of asthma and to improve the quality of life among children and their families include the implementation of clinical practice guidelines, asthma care quality improvement programs, community preventive services, and other community-based approaches.

The Healthy Hoops platform was used to evaluate the quality of life of children with asthma. This was first time a Healthy Hoops event was held in Kentucky and the first time quality of life was assessed at a Healthy Hoops event. Children and their parents/guardians attended the Healthy Hoops Kentucky event, in which each child received an asthma action plan. In addition, unique to Healthy Hoops Kentucky event, the quality of life of the child and their parent/guardian was assessed using Juniper's valid and reliable instruments

The thesis had three distinct study aims (1) to examine the quality of life of children with asthma as well as their parents' quality of life via the healthy hoops platform,

(2) to investigate the feasibility of using the healthy hoops platform as a mechanism to assess the quality of life of children with asthma and their parents, and (3) to evaluate if the current advocated statistical techniques for analysis are most appropriate.

In addition, the thesis develops a study design that would allow us to compare Passport participants who took part in the 2008 event (cases) with Passport members in 2008 who did not participate in the 2008 event (controls) over time; testing for differences in changes in quality of life and level of health care utilization over time. Permission from Passport to obtain this data from non-attendees is still under review.

The results of the current study suggest that the Healthy Hoops platform is an efficient way in which to assess the quality of life of children with asthma and their parents and that the children's quality of life is significantly better when compared to their parents, which contradicts earlier studies. Lastly, it is suggested that the current advocated method for analysis is not appropriate.

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CHAPTER I

INTRODUCTION

Asthma as a Public Health Concern

Asthma is the most common chronic disease among children aged 7 to 17 years of age in the United States¹. An average, one of every ten school-aged children has asthma², and 13 million school days are missed each year due to asthma³. Interventions to prevent or reduce the severity of asthma and to improve the quality of life among children and their families include the implementation of clinical practice guidelines, asthma care quality improvement programs, community preventive services, and other community-based approaches.

It is estimated that 1 in every 11.24 (8.9%) children in the US have a diagnosis of asthma in 2005³; with asthma disproportionately affecting children in lower socioeconomic classes. In addition, Kentucky is similarly disproportionately affected by asthma. It is estimated that the prevalence rate of asthma among children in Kentucky is higher than the national average (10.4%, 1 out of 9.62 children)⁴; roughly 1.17 times higher than the national prevalence rate. Therefore, Kentucky is a fruitful area in which to perform research on asthma and asthma related interventions. Currently, asthma affects approximately 6.5 million children in the US³ with the CDC anticipating that this number

will continue to rise in the future. Therefore, establishing interventions that can effectively address and manage asthma and its effects is warranted and needed from both an individual as well as a public health level. Furthermore, Medicaid and others purchasers of health care (e.g., Passport Health Plan, Humana, United, Aetna) are interested in finding innovative ways to manage asthma; since a majority of their memberships are individuals in lower socioeconomic classes, which are disproportionately affected by asthma.

Asthma and Quality of Life

Children with Asthma. Asthma unfortunately is a disease that affects many domains of a child's life (e.g., school attendance, physical characteristics, sleep patterns, social stigma, etc.). Therefore, a child with asthma's quality of life is detrimentally affected by their asthma. In addition, asthma has an effect on education since children with asthma, on average, miss an additional 1.5 days of school, when compared with children without asthma in the U.S.⁵. Two thirds of children with asthma report that their asthma has prevented them from participating in sports and has limited their general activity level by decreasing the number of activities they participate in per day by two activities, when compared to children without asthma (2 activities per day compare to 4 activities per day)⁶. Clearly, this can lead to weight gain and increases in BMI further impacting a child's quality of life.

Parents of Children with Asthma. Similarly, parents of children with asthma, when compared to parents of children without asthma, report a decrease in their quality of life. This is routinely attributed to missed days at work, limited activities, inadequate sleep, frequent night awakenings, and decreased emotional health. Some other studies also show a negative relationship between a child's symptom frequency and parental QOL scores^{7,8}. That is, the worst the child's asthma the lower the parents' quality of life. Although asthma is a major cause of childhood disability^{9,10} (and in rare cases causes premature death), asthma related morbidity and mortality is largely preventable when patients and their families are adequately educated about the disease and have access to high quality health care^{11,12,13}.

A detailed asthma action plan has been well established as a mechanism in which to educate children with asthma and their parents, which allows for better self management of care. That is, an asthma action plan is a tailored regimen of medication and lifestyle changes that minimizes the effects of asthma. The use of an asthma action care plan has been associated with fewer emergency department visits, fewer hospitalizations, and decreased use of emergency/rescue medications. Therefore, mechanisms (i.e., Healthy Hoops Kentucky) that allow children with asthma to receive an asthma action plan is needed and warranted.

The health status outcomes of asthma are highly dependent on the control and management of the disease and its effect on the child as well as the family's life¹⁴. That is, chronic pediatric asthma can have a significant impact on not only the child experiencing the disease but also family functioning. Quality of life can be used to measure the patient's subjective experience with their disease. Several valid and reliable

disease-specific measures for asthma and quality of life are available¹⁵, some measuring the quality of life of the child and others measuring the quality of life of the parents. The Mini-Pediatric Asthma Quality of Life Questionnaire (mPAQLQ) and the Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) provide comparative information from the child and their caregiver about the impact of the child's asthma. Clearly, reducing severity of asthma symptoms can improve quality of life among children with asthma and their families.

Quality of life outcomes are increasingly being used to guide treatment and management strategies as well as monitor the effectiveness of health interventions. Particular to children with asthma it is hypothesized that a child's emotions, asthma severity/symptoms, visits to an emergency department, whether they missed school days, and whether their activity is limited significantly impacts the child's and their parent's quality of life¹⁶. All these attributes are measured and scored with the Juniper Pediatric Asthma Quality of Life Questionnaire.

Passport Health Plan and Asthma

The Passport Health Plan is the Medicaid payer for Jefferson County, Kentucky and the surrounding 16 counties. As such, their membership is largely comprised of individuals who are in lower socioeconomic classes. Therefore, the children who are members of the Passport Health Plan are subsequently disproportionately affected by asthma since it is well established that asthma is more prevalent in lower socioeconomic classes³. Therefore, Passport routinely and consistently seeks to identify innovative and

efficient ways in which to address asthma and its detrimental effects. One such initiative is ensuring all their members who suffer from asthma have a detailed and tailored Asthma Action Plan. One mechanism that has shown to increase the percentage of their pediatric membership (with asthma) who has an Asthma Action Plan is the Healthy Hoops Platform. In addition, the Healthy hoops platform has also been shown to decrease health care utilization in children with asthma. No previous study has investigated the influence Healthy Hoops has on quality of life of children with asthma.

Healthy Hoops Platform

Healthy Hoops is an innovative health education and management program originally developed by AmeriHealth Mercy for children and their families. This National Committee for Quality Assurance (NCQA) recognized program uses basketball as a platform to teach kids how to manage asthma more effectively and efficiently (www.healthyhoopsprogram.com). However, the Health Hoops platform has never been used to measure QOL in children with asthma.

Healthy Hoops uses basketball (and local basketball stars) to address the needs of children with asthma. Under the guidance of celebrity basketball coaches and medical experts, children between the ages of 9 and 13 as well as their families, participate in a full day of health awareness, entertainment, asthma screenings, and basketball drills and skills workshops; with each child leaving with a personalized asthma action plan during the event. The program uses a coalition of local health care providers and community organizations. The program has resulted in improvements in health outcomes for

participants and decreased utilization and cost for the health organizations who have implemented the program (e.g. 10% increase in the use of preventive medication, 13% decrease in the use of rescue medication, a 67% decrease in ER visits, improvements in forced expiratory volume and forced vital capacity, a nearly 40% decrease in school absenteeism).

Healthy Hoops Kentucky

Healthy Hoops Kentucky (HHKY, <http://www.healthyhoopsky.com/>) was introduced in 2008 as an innovative program that uses basketball and local basketball stars to help children, as well as their families, successfully manage their disease. In particular, HHKY provides children with asthma with a detailed action plan and allows their parents/guardians to receive education; while using basketball drills and basketball stars as an incentive to attend the program. While HHKY was not exclusively designed for or served only Passport members, since the inception of the program, over 96% of attendees have been Passport members. Unfortunately, to date, no study has evaluated whether HHKY improves health outcomes, decreases health care utilization, or decreases associated costs for children with asthma who attend the event.

The Passport Health Plan held the first Kentucky Healthy Hoops event at Noe Middle school in September 2008. Since then it has been held twice at Louisville Male High School in September 2009 and September 2010.

At this free event held annually during the month of September (starting in 2008), participants register for mandatory health screenings, participate in basketball drills

conducted by professional basketball coaches, and learn health prevention and intervention techniques from health care experts including:

Asthma Screenings. All participants are required to undergo health screenings. The health screenings are used to assess each participant's health status, assess medications, review appropriate medication use, establish a personalized action plan, and evaluate results.

Parent Education. Parental/guardian participation is a vital component of HHKY. At each event, there are workshops for parents that provide management tips, prevention facts, and information about the importance of complying with the treatment plan(s) that their providers prescribe for their children.

Professional Development. An educational seminar developed by nationally recognized educators and based on national standards provides continuing education units for school nurses, recreational coaches, child care providers, day care staff, parents, community based organizations, and physical education teachers.

The HHKY program has received tremendous support from community members throughout the city, establishing a paradigm for performing community participatory research. In addition, the program, through the primary financial support of Passport, is soundly positioned to continue. However, Passport and all invested stakeholders are eager for empirical evidence demonstrating that the program is effective in improving health outcomes, decreasing health care utilization and decreasing health care

expenditures. Allowing decision-makers to be pragmatic in determining how resource intensive Passport should be in their support of HHKY.

While the national Healthy Hoops program suggests that the program is successful in achieving these objectives, no empirical evidence of its impact has been demonstrated. Their conclusions are based on anecdotal, unsubstantiated results. The current study provides the first empirical evidence of the significance of the Healthy Hoops platform.

Children and their parents were informed about the event through mailings, e-mails, TV commercials and print ads and were allowed to pre-register for the event. At the event the children and parents officially registered for the event. In the first half of the event the children were evaluated and received an asthma action plan from clinicians and nursing faculty as well as took part in health awareness activities. The health screenings are used to assess each participant's health status, assess medications, review appropriate medication use, establish a personalized action plan, and evaluate results. In addition, the quality of life of the children and their parents were assessed using the Juniper Pediatric Asthma Quality of Life Questionnaire and the Juniper Pediatric Caregiver Asthma Quality of Life Questionnaire. These qualities of life measurements are unique to Healthy Hoops Kentucky. That is, Healthy Hoops Kentucky was the first Healthy Hoops event to assess quality of life. Eight trained graduate students administered the instruments. Parents and children were separated while completing the surveys, to minimize the influence a parent may have on their child (the parents could always see their child). In the afternoon, children participated in basketball drills and skills workshops with local

basketball celebrities, while their parents participated in workshops about living with and managing their child's asthma.

Current Study

The current study had three distinct study aims (1) to examine the quality of life of children with asthma as well as their parents' quality of life via the healthy hoops platform, (2) to investigate the feasibility of using the healthy hoops platform as a mechanism to assess the quality of life of children with asthma and their parents, and (3) to evaluate if the current advocated statistical techniques for analysis are most appropriate.

In addition, the thesis develops a study design that would allow us to compare Passport participants who took part in the 2008 event (cases) with Passport members in 2008 who did not participate in the 2008 event (controls) over time; testing for differences in changes in quality of life and level of health care utilization over time. Permission from Passport to obtain this data from non-attendees is still under review.

The results of the current study suggest that the Healthy Hoops platform is an efficient way in which to assess the quality of life of children with asthma and their parents and that the children's quality of life is significantly better when compared to their parents, which contradicts earlier studies. Lastly, it is suggested that the current advocated method for analysis is not appropriate.

CHAPTER II

LITERATURE REVIEW

Asthma

Asthma is a chronic respiratory disease characterized by episodes or attacks of inflammation and narrowing of small airways. Asthma attacks can vary from mild to life threatening. Symptoms can include shortness of breath, cough, wheezing, and chest pain or tightness. Many things can trigger asthma attacks such as allergens (e.g., pollen), infections, exercise, changes in the weather, and exposure to airway irritants (e.g., tobacco smoke)¹⁷.

Asthma affects people of all ages, but it most often starts in childhood. From the National Health Interview Survey, an estimated 7.8% of people (23.3 million) had asthma in 2008. Nearly 7 million of these people were children. It is estimated that 1 in every 11 children have a diagnosis of asthma, which is 9.4% of children having asthma, compared to only 7.3% of adults (16.2 million) having asthma. Asthma prevalence increases with age, but health care use is highest among the youngest children. Boys (17%) have higher prevalence and death rates compared with girls (11%) throughout childhood. Non-Hispanic black children were more likely to have been diagnosed with asthma (21%) or to still have asthma (16%) than Hispanic children (11% and 7%) or non-Hispanic white

children (13% and 9%). Moreover, rates of adverse outcomes such as emergency department visits, hospitalizations, and deaths are substantially higher for black children. The disparity in asthma mortality between black and white children has increased in recent years. In addition, children in poor families were more likely to have been diagnosed with asthma (18%) or to still have asthma (12%) than children in families that were not poor (13% and 9%)³.

Asthma attack prevalence measures the percentage of children who had at least one attack over the past 12 months. It is a crude estimate of the percentage of symptomatic children who may have poorly controlled asthma, and thus are at risk of adverse outcomes such as emergency department visits or hospitalizations. In 2005, 5.2% of children had at least one asthma attack in the previous year (3.8 million children)³. Nearly two out of every three children, who currently have asthma, had at least one attack in the past 12 months.

In addition, Kentucky is similarly disproportionately affected by asthma with an asthma prevalence rate among children higher than the national average (10.4% vs. 8.9%). Therefore, establishing interventions that can effectively address and manage asthma and its related effects is warranted and needed from both an individual and public health approach. Furthermore, Medicaid and similar payers (e.g., Passport Health Plan) are interested in finding innovative ways to manage the disease since their membership is affected more dramatically with a majority of their members coming from lower socioeconomic classes.

Quality of Life

Quality of life (QOL) is defined by the individual and depends on many factors such as lifestyle, past experiences, hopes for the future, dreams and ambitions. Quality of life measures are increasingly becoming outcomes for comparing outcomes in clinical trials, evaluating interventions, commissioning programmes of care, assessing the outcomes of new treatments, and in audit work.

Issues about the definition and measurement of quality of life have been a matter of considerable debate. Three key ideas define the concept of quality of life: (1) individuals have their own unique perspective on quality of life, (2) quality of life is generally conceptualized as a multidimensional construct encompassing several domains (when used in a medical context), and (3) quality of life can include both objective and subjective perspectives in each domain¹⁸.

Asthma unfortunately is a disease that affects many domains of a child's life (e.g., physical, sleep patterns, social stigma). Therefore, a child with asthma's quality of life is detrimentally affected by their asthma. In addition, asthma has an effect on their education with children with asthma on average missing an additional 1.5 days of school, when compared with children without asthma in the U.S. Two thirds of children with asthma report that their asthma has prevented them from participating in sports and has limited their general activity level by decreasing the number of activities they participate in per day by two when compared to children without asthma (2 activities per day compare to 4 activities per day). Clearly, this causes that children with asthma had a higher mean BMI (20.78 vs 18.82) and higher rates of obesity (21.4% vs 6.6%) than children without asthma⁶.

Similarly, parents of children with asthma, when compared to parents of children without asthma, report lower quality of life assessments, which is attributed to missed workdays, limited activities, inadequate sleep, frequent night awakenings, and decreased emotional health. Some other studies also show a negative relationship between their child's symptom frequency and parental quality of life scores. That is, the worse the child's asthma is the lower the parents' quality of life. Although asthma is a major cause of childhood disability (and in rare cases causes premature death), asthma related morbidity and mortality fortunately is largely preventable when patients and their families are adequately educated about the disease and have access to high quality health care. An asthma action plan has well established as a mechanism in which to educate children with asthma and their parents as well as allow for self management of care. The use of an asthma action care plan has been associated with fewer emergency department visits, hospitalizations, and use emergency/rescue medications.

Healthy Hoops and Healthy Hoops Kentucky

The health status outcomes of asthma are highly dependent on the control of the disease and its effect on the child's and the family's life. Quality of life can be used to measure the patient's subjective experience with their disease. Some researchers use several domains of life (i.e. functional abilities, physical status, social interactions, etc.) to define QOL. As such, researchers have developed generic (e.g., SF-36, EuroQoL 5-D, HUI3) as well as disease specific scientific instruments (e.g., Juniper Mini Paediatric Asthma Quality of Life Questionnaire) to quantify a child's QOL. QOL outcomes are

increasingly being used to guide treatment and management strategies as well as monitor their effectiveness.

Particular to children with asthma it is hypothesized that a child's emotions, asthma severity/symptoms, whether they visit an emergency department, whether they miss school days, and whether their activity is limited, significantly impacts their QOL, which are all measured and scored with the Juniper Mini Paediatric Asthma Quality of Life Questionnaire. Previous literature has shown that the child's QOL is quantified differently than their parents. As such, Juniper developed the Juniper Paediatric Asthma Caregiver's Quality of Life Questionnaire, which evaluates the quality of life of parents of children with asthma.

The Passport Health Plan is the Medicaid payer for Jefferson County, Kentucky and the surrounding 16 counties. As such, their membership is largely comprised of individuals who are in the lower socioeconomic classes. Therefore, the children who are members of Passport Health Plan are disproportionately affected by asthma since asthma is more prevalent in lower socioeconomic classes. It has become increasingly apparent that Passport identifies innovative and efficient ways in which to address asthma; in particular ensuring all their members (with Asthma) have an Asthma Action Plan. One way in which to maximize the percentage of their pediatric membership who has an Asthma Action Plan is to use the Healthy Hoops Platform, which has been shown to decrease health care utilization in children with asthma; although no previous study has investigated the influence Healthy Hoops has on quality of life of children with asthma.

Healthy Hoops is an innovative health education and management program originally developed by AmeriHealth Mercy for children and their families. This

National Committee for Quality Assurance (NCQA) recognized program uses basketball as a platform to teach kids how to manage asthma more effectively and efficiently (www.healthyhoopsprogram.com). However, the Health Hoops platform has never been used to measure QOL in children with asthma.

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In 2005, a research team in Baltimore used the Health Hoops platform in a rural area¹⁹. They reported that the mean total quality of life scores for parents/caregivers were higher at baseline and follow-up compared with child's total quality of life scores. Rural parents also reported higher emotional and activity quality of life subscale scores than did children at both baseline and follow-up. In contrast to the scores of the parents/caregivers, children's total quality of life scores decreased from baseline to follow-up in both groups; however, there was no statistically significant difference in

total quality of life scores between time periods. No statistically significant correlations existed between any of the parents'/caregivers' quality of life scores and quality of life scores for the children. Whether this finding holds consistent in our sample in an urban setting is evaluated and discussed.

There is a clear connection between asthma and quality of life; the more severe the asthma the lower the quality of life. In addition, it is well established that an asthma action plan minimizes the detrimental effects of asthma. The Healthy Hoops Kentucky program clearly increases the probability a child with asthma will have a detailed asthma action plan. The question that remains unanswered is whether Healthy Hoops Kentucky improves the health of children with asthma who attend the event. In addition, what is the quality of life of children with asthma as well as the parents' quality of life. The current project aims to address these gaps in the current knowledge base.

CHAPTER III

MATERIALS AND METHODS

General Overview

The Healthy Hoops platform was used to evaluate the quality of life of children with asthma. This was first time a Healthy Hoops event was held in Kentucky and the first time quality of life was assessed at a Healthy Hoops event. Children and their parents/guardians attended the Healthy Hoops Kentucky event, in which each child received an asthma action plan. In addition, unique to Healthy Hoops Kentucky event, the quality of life of the child and their parent/guardian was assessed using Juniper's valid and reliable instruments (discussed in detail below).

As a result, the research team has designed a retrospective, observational study design to evaluate if the Healthy Hoops Kentucky event has had an impact on health care utilization (ER visits, hospitalizations, rescue medications used, etc.) by testing for difference between children in the Passport Health Plan who attended the event and comparable children in the Passport Health plan who did not attend the event.

Study Population and Exclusion/Inclusion Criteria

Invitations to attend Healthy Hoops Kentucky were sent out to all children who have a diagnosis with asthma who were members of the Passport Health Plan. In addition, children with asthma who were not members of the Passport Health Plan were invited through TV commercials, print ads in the newspaper, and via print ads distributed by Kroger grocery stores.

To be eligible for the study, children had to be between the ages 9 – 13 at the time of recruitment, have an asthma diagnosis from a qualified health professional (physician or nurse practitioner), been prescribed asthma medication, and have at least one of the following symptoms in the past 12 months: wheezing, shortness of breath, nighttime cough, daytime cough, and wheezing with exercise or colds. If the child's parents reported that they were developmentally delayed, the child was excluded because of the need for the child to understand the educational component of the intervention. As a result, annually nearly 200 children and their parents/guardians accepted have accepted the invitation and agreed to participate by pre-registering for the event.

Response Rate

During the 2008 Healthy Hoops Kentucky event 72 children and their parents/guardians attended the event, which established the baseline database for future comparisons. This represented a 36% response rate, which is consistent for studies following similar recruitment strategies and was similar to previous Health Hoops events held in other locations. In 2009 and 2010, we achieved a similar response rate. Therefore,

the research team believed their results were generalizable and was not threatened by a low response rate. A comparison between attendees and non-attendees was not performed since the needed data to perform the analysis has not been made available by Passport Health Plan.

Quality of Life Instrument

Two quality of life instruments were required for this study; one instrument to evaluate the quality of life of the child and one instrument to evaluate the quality of life of the parent/guardian. The research team chose to use the disease specific instrument developed by Juniper; which has repeatedly been demonstrated to be valid and reliable.

Pediatric Asthma Quality of Life Questionnaire. The Juniper's Pediatric Asthma Quality of Life Questionnaire (PAQLQ) is a survey that consists of 23 questions concerning the quality of life of a child and issues that impact the child's daily activities. The questionnaire is designed to measure the child's perception of their QOL. The responses for each question range from 1-7, one representing severe impairment in the child's QOL and seven representing no impairment in the child's QOL. The instrument can be divided into subgroups that measure: activity limitation (5 items), symptoms (10 items), and emotional function (8 items). All items are equally weighted and averaged. The responses from each subcategory are then combined and calculated for the overall QOL score. The intra-class correlation coefficients for children ages 7 to 10 years were 0.89 for overall QOL and 0.68, 0.83, and 0.87, respectively, for the subscales emotional function, activity

limitations, and symptoms. The cross-sectional correlation between asthma QOL and clinical asthma control for symptoms subscales was respectively 0.61, for activity subscales was 0.62, and for emotions subscales was 0.37²⁰.

Mini Pediatric Asthma Quality of Life Questionnaire. To lessen the burden on our study population the research team chose to use the Mini Pediatric Asthma Quality of Life Questionnaire (Appendix A). The Mini Pediatric Asthma Quality of Life Questionnaire is a self-administered 13 item instrument. Similar to the full instrument three subscales are evaluated: activity limitations (3 items), emotional function (4 items), and symptoms (6 items). The shorter and simpler MiniPAQLQ, with 13 questions, was developed to meet the need for greater efficiency in large clinical trials, group patient monitoring and large surveys. Responses to each item in the Mini Paediatric Asthma Quality of Life Questionnaire are given on a 7-point scale where 1 represents severe impairment and 7 represents no impairment. Individual items are weighted within the questionnaire equally and express the results as the mean score per item for each of the domains (emotional function, symptoms and activity limitation) as well as for overall quality of life. Therefore, both the domain and overall scores range from 1-7.

Caregiver Quality of Life Questionnaire. The Juniper's Pediatric Caregiver Quality of Life Questionnaire (PCQLQ) is a survey that consists of 13 questions concerning subjects whose child has asthma and the impact on their quality of life (Appendix B). The questionnaire is designed to measure the caregiver's quality of life. The responses for the question ranged 1-7, lower numbers representing severe impairment and higher numbers

little to no impairment in QOL. The PCQLQ includes the subcategories of activity limitation and emotional function, but fails to evaluate symptoms. The responses of the two subcategories are combined and totaled in order to calculate the overall QOL of the caregiver. The intra-class correlation coefficients for the total PCQLQ score and the emotional and the activity domains were 0.80 to 0.85. The cross-sectional correlation between caregiver QOL and clinical asthma control for activity limitations subscale was 0.30 and 0.29 for emotional functioning subscale²¹.

The QOL questionnaires were administered by trained data collectors to 72 children and their respective caregivers in 2008, 70 children and their respective caregivers in 2009, and 165 children and their respective caregivers in 2010, each at separate stations to minimize interactions between child and caregiver during the collection of responses. Cue cards with a list of response options were provided to each participant. Four caregivers did not fully complete all items on the questionnaire in 2008, providing an analytic cohort of 68 child-caregiver dyads in 2008. *The Institutional Review Board at UofL provided an exemption for this project, as all data were de-identified.*

Data Analysis

For Aim #1, the feasibility and acceptability of the instruments were evaluated using tradition techniques that evaluates feasibility and acceptability (e.g, face validity, construct validity, etc.).

For Aim #2, the scores on the two quality of life instruments were calculated for both the children and their parent/guardian; using the scoring system developed and advocated by Juniper. The quality of life scores were stratified by domains of life; as defined by the authors of the instruments (activity limitations, emotional function, symptoms). All scores were based on a 1-7 scales. To test for differences between the children and their parent/guardians Paired-samples t-tests were performed. Statistical significance was set at the 0.05 level. All analyses were performed utilizing the SAS statistical software package version 9.2 (Appendix C).

For Aim #3, Juniper and associates advocate using paired t-tests to examine differences in overall quality of life and subscale scores between children and their caregivers. The Shapiro-Wilks test was used to determine if the quality of life outcome variables were normally distributed. Subsequently, the differences between scores from the child and their caregiver were analyzed using the non-parametric approach (Wilcoxon signed rank test). The test is indicated for matched-pairs, when data is non-normally distributed and the level of the data is ordinal or higher. Finally, we evaluated whether the different statistical approaches produced similar or different results with the same data. If the results from parametric methods were different from those with non-parametric approaches, then a change in the currently advocated approach for evaluating data from mPAQLQ and PACQLQ may be indicated.

Factor Analysis: To assess how the children and parents viewed the multiple items concerning the effects of asthma on their QOL, we performed a confirmatory factor analysis on responses to the PAQLQ and PACQLQ. Factor analysis is a data reduction statistical technique designed to delineate a hypothesized underlying structure of large

data sets represented by numerous variables. Our data set meets an important guideline for factor analysis; that the minimum number of subjects in a sample must be 5 times the number of variables being analyzed. In our 2008 sample 72 childish participants responded to 13 variables and also 68 adult participants responded to 13 variables. We also had 70 children with asthma and 68 caregivers in 2009 event and 165 children with asthma and 153 caregivers in 2010 event.

Factors are assumed responsible for the covariation between two or more observed variables. Based on either correlation or covariance matrices, factor analysis extracts factors representing shared variance. In this thesis, factors were extracted using maximum likelihood estimations, which permits hypothesis testing for the best number of factors to be retained. Extracted factors were then rotated, that is; a linear transformation was performed on the factor solution for easier interpretation, via the VARIMAX option, rendering the extracted factors correlated or “oblique”. Individual variables were considered to “strongly load” on each factor if they possessed factor loading scores equal to or above 0.40. Variables which did not achieve this level (known as lowloading) were removed from subsequent analysis.

To determine the number of factors to be retained in the model, variables with eigenvalues (interpreted as the amount of variance accounted for by each factor) greater than 1.0 remained. This point separates factors with large eigenvalues from those with relatively small eigenvalues.

CHAPTER IV

RESULTS

Overall Results

Results were calculated and stratified by year of the event. Differences between parents and their children's quality of life scores were tested for to evaluate if asthma affects parents' or their children quality of life differently. All results are presented as means and standard deviations as well as in graphical representation.

Caregiver and Child Quality of Life Assessments for 2008

Study Sample.

Prior to the event nearly 200 children and their parents pre-registered for the Healthy Hoops Kentucky event. However, a total sample of n=72 children actually attended the event in 2008. The MiniPAQLQ and the PACQLQ was administered to all n=72 children and their parent/guardian, respectively. All 72 MiniPAQLQ instruments were completed properly (100% response rate), while only n=68 PACQLQ were completely properly (95% response rate). The PAQLQ instruments (in the 2008 edition)

had two pages with two questions on the second page. As such, the 5% of the PAQLQ instruments that were not completely properly had blank second pages. Therefore, the analyses were performed on data collected from n=72 MiniPAQLQ instruments and n=68 PACQLQ instruments.

Acceptability/Feasibility.

One objective in determining the feasibility of using the Healthy Hoops platform to assess the quality of life of children with asthma; and their parents/guardians, is to demonstrate the efficiency of administering the instruments. On average, it took each parent/guardian less than 3 minutes time to complete the PACQLQ instrument. Similarly, on average, it took the children took less than 5 minutes time to complete the MiniPAQLQ instrument. All responders felt the instruments were easy to understand, read and complete.

Quality of Life Assessments.

Statistically significant results were present in the analysis of differences in overall quality of life scores between mPAQLQ and PACQLQ by paired t-tests (5.24 vs. 4.79; $p_{\text{Paired t-tests}}=0.013$), as well as for differences between child's and caregiver's scores for "Activities Limitation" ($p\leq 0.0001$). (See Table 3) However, the Shapiro-Wilks tests indicate the scores for subscales and overall quality of life for the mPAQLQ are not normally distributed, whereas PACQLQ scores are. Therefore, the Wilcoxon signed rank test is indicated as a preferred test in this situation. (See Table 2)

Results for the differences between mPAQLQ and PACQLQ scores for overall quality of life by Wilcoxon signed rank test were not statistically significant ($p_{\text{Wilcoxon}}=0.150$), although statistically significant differences remained for “Activities Limitation” ($p_{\text{Wilcoxon}}\leq 0.0001$). Differences in subscale scores “Emotional Function” did not reach statistical significance by either method ($p_{\text{Paired t-tests}}=0.093$; $p_{\text{Wilcoxon}}=0.142$).

The results using Wilcoxon signed rank method and paired t-tests provided different levels of statistical significance for the differences in overall quality of life scores between the mPAQLQ and PACQLQ. Despite lack of statistical significance, estimates of achieved statistical power for the Wilcoxon method were 94% for all subscales examined (effect size = 0.18 [emotional functioning] and 0.27 [activity limitations]) and 92% for overall quality of life (effect size = 0.18). This indicates that insufficient statistical power of the study does not threaten the statistically significant differences with non-parametric methods.

Measures of internal consistency measured by Cronbach’s alpha, were excellent for overall QoL assessments on both mPAQLQ ($\alpha=0.88$) and PACQLQ ($\alpha=0.89$). Reliability coefficients for the subscales ranged from $\alpha=0.66$ for emotional subscales for the child, to $\alpha=0.82$ for emotional subscales from the caregivers. (See Table 1)

Factor Analysis:

Children with asthma. Factor analysis proceeded in a two-step manner. First, all thirteen variables were included in the analysis, and the results examined for low-loading variables. Accordingly, in the second step these variables were removed and the analysis repeated. This revealed a steep drop-off in eigenvalues after the first factor, which had an eigenvalue of 5.434. The second factor featured an eigenvalue of 1.298, the third factor’s

eigenvalue was 1.143 and the fourth factor's eigenvalue was 1.012. Examination of the variable loadings, representing standardized regression coefficients, for each of the four factors is shown in Table 4. These data support our initial supposition of four distinct factors. The first factor, accounts for over 41% of the total variance and is represented by all 13 manifest variables; the remaining three factors contributes another 26.6% of the total variance.

Parents. Similarly, factor analysis proceeded in a two-step manner. First, all thirteen variables were included in the analysis, and the results examined for low-loading variables. Accordingly, in the second step these variables were removed and the analysis repeated. This revealed a steep drop-off in eigenvalues after the first factor, which had an eigenvalue of 5.823, the second factor featured an eigenvalue of 1.214, and the third factor's eigenvalue was 1.214. Examination of the variable loadings, representing standardized regression coefficients, for each of the two factors is shown in Table 5. These data support our initial supposition of two distinct factors. The first factor, accounts for nearly 45% of the total variance and is represented by all 13 manifest variables; the remaining two factors contributes another nearly 25% of the total variance.

QUESTIONNAIRE	Reliability Coefficients (Cronbach's Alpha)	
	mPAQLQ	PACQLQ
Overall QoL	0.879	0.889
SUB-SCALE	mPAQLQ	PACQLQ
"Activity Limitations"	0.729	0.768
"Symptoms"	0.756	N/A
"Emotional Function"	0.662	0.826

Table 1: Comparing Cronbach's Alpha Coefficients for mPAQLQ and PACQLQ for the 2008 event.

Quality of Life Measure	mPAQLQ Scores Child	Distribution For Child	PACQLQ Scores Caregiver	Distribution For Caregiver
	N=72	Shapiro-Wilks	N=68	Shapiro-Wilks
	Mean (SD) [Median]	p-value	Mean (SD) [Median]	p-value
Overall Quality of Life	5.24 (1.23) [5.50]	0.0026***	4.79 (1.19) [4.92]	0.1244
Subscale "Activity Limitation"	5.30 (1.54) [6.00]	<0.0001***	4.40 (1.49) [4.50]	0.1181
Subscale "Symptoms"	5.17 (1.42) [5.50]	0.0005***	N/A	N/A
Subscale "Emotional Function"	5.29 (1.25) [5.50]	0.0014***	4.97 (1.19) [5.11]	0.1611

*** $\leq$ significance at the 0.05 level or less.

Table 2: Quality of life scores for subscale and overall quality of life, for mPAQLQ scores for children and PACQLQ scores for their caregivers for the 2008 event. The Shapiro-Wilks tests indicate if the scores for subscales and overall quality of life for the mPAQLQ and PACQLQ are normally distributed.

Figure 1: A histogram of activity limitation score differences between children with asthma and their caregivers from the 2008 event.

Figure 2: A histogram of emotional function score differences between children with asthma and their caregivers from the 2008 event.

Figure 3: A histogram of overall quality of life score differences between children with asthma and their caregivers from the 2008 event.

Quality of Life Measures	mPAQLQ Scores Child N=72 Mean (SD) [Median]	PACQLQ Scores Caregiver N=68 Mean (SD) [Median]	Difference in QoL Scores N=68 Mean Difference [Median Difference]	Parametric Statistics Paired t-Test p-value	Non-Parametric Statistics Wilcoxon Signed Rank Test p-value
Overall Quality of Life	5.24 (1.23) [5.50]	4.79 (1.19) [4.92]	0.45 [0.58]	0.013***	0.150
Subscale "Activity Limitation"	5.30 (1.54) [6.00]	4.40 (1.49) [4.50]	0.90 [1.50]	<0.001***	<0.001***
Subscale "Symptoms"	5.17 (1.42) [5.50]	N/A	N/A	N/A	N/A
Subscale "Emotional Function"	5.29 (1.25) [5.50]	4.97 (1.19) [5.11]	0.32 [0.39]	0.093	0.142

*** ≤ significance at the 0.05 level or less.

Table 3: Quality of life scores for subscale and overall quality of life, for mPAQLQ scores for children and PACQLQ scores for their caregivers from the 2008 event. All scores were based on a 1-7 ordinal scale, with "1" representing maximal limitations, and "7" representing no limitations. Differences between scores from a child and their caregiver were tested using paired t-tests, Wilcoxon signed rank and difference in median test. The significance level was set at $p \leq 0.05$.

Component	Eigenvalue	Percent of Variance Explained	Total Variance Explained
1	5.434	41.798%	41.798%
2	1.298	9.982%	51.781%
3	1.143	8.790%	60.570%
4	1.012	7.788%	68.358%

Table 4: Results from the factor analysis for the children from the 2008 event.

Component	Eigenvalue	Percent of Variance Explained	Total Variance Explained
1	5.823	44.794%	44.794%
2	2.010	15.458%	60.252%
3	1.214	9.340%	69.591%

Table 5: Results from the factor analysis for the parents from the 2008 event.

Caregiver and Child Quality of Life Assessments for 2009

Study Sample.

In 2009 there was a total sample of $n=70$ children and their parents who attended the Healthy Hoops Kentucky event. Similar to 2008, all $n=70$ children completed the MiniPAQLQ properly (100% response rate). In 2009, only $n=68$ parents completed the PACQLQ properly (97% response rate). Although in the 2009 edition of the PACQLQ all questions appeared on one-page, $n=2$ parents failed to answer one question. Investigation into why they failed to answer the (same) one question was not performed.

Acceptability/Feasibility.

Similar to 2008, administering the instruments proved to be very efficient. On average, it took each parent less than 3 minutes time to complete the PACQLQ instrument, while the children took less than 5 minutes time to complete the MiniPAQLQ instrument.

Quality of Life Assessments.

Measures of internal consistency measured by Cronbach's alpha, were excellent for overall QoL assessments on both mPAQLQ ($\alpha=0.86$) and PACQLQ ($\alpha=0.91$) in 2009. Reliability coefficients for the subscales ranged from $\alpha=0.62$ for activity limitation subscales for the child, to $\alpha=0.88$ for emotional subscales from the caregivers. (See Table 6)

The Shapiro-Wilks tests indicate the scores for subscales and overall quality of life for the mPAQLQ and the PACQLQ are not normally distributed. Therefore, the Wilcoxon signed rank test is indicated as a preferred test in this situation. (See Table 7)

As seen in Table 8, in 2009, mean activity limitations scores for children with asthma was 5.44 (SD = 1.43), while it was 5.11 (SD=1.39) for parents of children with asthma suggesting no difference in activity limitations scores ($p_{\text{Paired t-tests}}=0.1068$; $p_{\text{Wilcoxon}}=0.0578$). Correspondingly, in 2009, the mean emotional function scores for children with asthma [5.60 (SD = 1.28)] and parents of children with asthma [5.29 (SD=1.34)] were not significantly different ($p_{\text{Paired t-tests}}=0.1739$; $p_{\text{Wilcoxon}}=0.1755$); as well as overall quality of life scores for children with asthma [5.36 (SD = 1.17)] and parents of children with asthma [5.23 (SD=1.30)], $p_{\text{Paired t-tests}}=0.3795$ and $p_{\text{Wilcoxon}}=0.3599$. Mean symptoms scores for children with asthma was 5.17 (SD = 1.40).

Factor Analysis:

Children with asthma. Factor analysis proceeded in a two-step manner. First, all thirteen variables were included in the analysis, and the results examined for low-loading variables. Accordingly, in the second step these variables were removed and the analysis repeated. This revealed a steep drop-off in eigenvalues after the first factor, which had an eigenvalue of 4.942. The second factor featured an eigenvalue of 1.473, the third factor's eigenvalue was 1.253 and the fourth factor's eigenvalue was 1.037. Examination of the variable loadings, representing standardized regression coefficients, for each of the four factors is shown in Table 9. These data support our initial supposition of four distinct factors. The first factor, accounts for over 38% of the total variance and is represented by

all 13 manifest variables; the remaining three factors contributes another 29% of the total variance.

Parents. Similarly, factor analysis proceeded in a two-step manner. First, all thirteen variables were included in the analysis, and the results examined for low-loading variables. Accordingly, in the second step these variables were removed and the analysis repeated. This revealed a steep drop-off in eigenvalues after the first factor, which had an eigenvalue of 6.352 and the second factor featured an eigenvalue of 1.678. Examination of the variable loadings, representing standardized regression coefficients, for each of the two factors is shown in Table 10. These data support our initial supposition of two distinct factors. The first factor, accounts for nearly 49% of the total variance and is represented by all 13 manifest variables; the remaining factor contributes another nearly 13% of the total variance.

Reliability Coefficients (Cronbach's Alpha)		
QUESTIONNAIRE	mPAQLQ	PACQLQ
Overall QoL	0.860	0.910
SUB-SCALE	mPAQLQ	PACQLQ
"Activity Limitations"	0.623	0.775
"Symptoms"	0.781	N/A
"Emotional Function"	0.687	0.879

Table 6: Comparing Cronbach's Alpha Coefficients for mPAQLQ and PACQLQ for the 2009 event.

Quality of Life Measure	mPAQLQ Scores Child	Distribution For Child	PACQLQ Scores Caregiver	Distribution For Caregiver
	N=70	Shapiro-Wilks	N=68	Shapiro-Wilks
	Mean (SD) [Median]	p-value	Mean (SD) [Median]	p-value
Overall Quality of Life	5.36(1.17) [5.69]	0.0005***	5.23(1.30) [5.38]	0.0039***
Subscale "Activity Limitation"	5.44(1.43) [6.00]	<0.0001***	5.11(1.39) [5.25]	0.0035***
Subscale "Symptoms"	5.17(1.40) [5.58]	0.0004***	N/A	N/A
Subscale "Emotional Function"	5.60(1.28) [6.00]	<0.0001***	5.29(1.34) [5.67]	0.0021***

*** ≤ significance at the 0.05 level or less.

Table 7: Quality of life scores for subscale and overall quality of life, for mPAQLQ scores for children and PACQLQ scores for their caregivers from the 2009 event. The Shapiro-Wilks tests indicate if the scores for subscales and overall quality of life for the mPAQLQ and PACQLQ are normally distributed.

Figure 4: A histogram of activity limitation score differences between children with asthma and their caregivers from the 2009 event.

Figure 5: A histogram of emotional function score differences between children with asthma and their caregivers from the 2009 event.

Figure 6: A histogram of overall quality of life score differences between children with asthma and their caregivers from the 2009 event.

Quality of Life Measures	mPAQLQ Scores Child N=70 Mean (SD) [Median]	PACQLQ Scores Caregiver N=68 Mean (SD) [Median]	Difference in QoL Scores N=68 Mean Difference [Median Difference]	Parametric Statistics Paired t-Test p-value	Non-Parametric Statistics Wilcoxon Signed Rank Test p-value
Overall Quality of Life Subscale	5.36(1.17) [5.69]	5.23(1.30) [5.38]	0.13 [0.31]	0.3795	0.3599
Subscale "Activity Limitation"	5.44(1.43) [6.00]	5.11(1.39) [5.25]	0.33 [0.75]	0.1068	0.0578
Subscale "Symptoms"	5.17(1.40) [5.58]	N/A	N/A	N/A	N/A
Subscale "Emotional Function"	5.60(1.28) [6.00]	5.29(1.34) [5.67]	0.31 [0.33]	0.1739	0.1755

*** ≤ significance at the 0.05 level or less.

Table 8: Quality of life scores for subscale and overall quality of life, for mPAQLQ scores for children and PACQLQ scores for their caregivers from the 2009 event. All scores were based on a 1-7 ordinal scale, with "1" representing maximal limitations, and "7" representing no limitations. Differences between scores from a child and their caregiver were tested using paired t-tests, Wilcoxon signed rank and difference in median test. The significance level was set at $p \leq 0.05$.

Component	Eigenvalue	Percent of Variance Explained	Total Variance Explained
1	4.942	38.018%	38.018%
2	1.473	11.331%	49.349%
3	1.253	9.641%	58.990%
4	1.037	7.973%	66.963%

Table 9: Results from the factor analysis for the children from the 2009 event.

Component	Eigenvalue	Percent of Variance Explained	Total Variance Explained
1	6.352	48.864%	48.864%
2	1.678	12.908%	61.772%

Table 10: Results from the factor analysis for the parents from the 2009 event.

Caregiver and Child Quality of Life Assessments for 2010

Study Sample.

In 2010 there was a total sample of $n=165$ children and their parents who attended the Healthy Hoops Kentucky event. Similar to 2008 and 2009, all $n=165$ children completed the MiniPAQLQ properly (100% response rate). In 2010, only $n=153$ parents completed the PACQLQ properly (93% response rate). Although in the 2010 edition of the PACQLQ all questions appeared on one-page, $n=12$ parents failed to answer one question. Investigation into why they failed to answer the (same) one question was not performed.

Acceptability/Feasibility.

Similar to 2008 and 2009, administering the instruments proved to be very efficient. On average, it took each parent less than 3 minutes time to complete the PACQLQ instrument, while the children took less than 5 minutes time to complete the MiniPAQLQ instrument.

Quality of Life Assessments.

Measures of internal consistency measured by Cronbach's alpha, were excellent for overall QoL assessments on both mPAQLQ ($\alpha=0.87$) and PACQLQ ($\alpha=0.93$) in 2010. Reliability coefficients for the subscales ranged from $\alpha=0.54$ for activity limitation subscales for the child, to $\alpha=0.91$ for activity limitation subscales from the caregivers. (See Table 11)

The Shapiro-Wilks tests indicate the scores for subscales and overall quality of life for the mPAQLQ and the PACQLQ are not normally distributed. Therefore, the Wilcoxon signed rank test is indicated as a preferred test in this situation. (See Table 12)

As seen in Table 13, in 2010, mean activity limitations scores for children with asthma was 5.31 (SD = 1.36), while it was 5.01 (SD=1.68) for parents of children with asthma suggesting no difference in activity limitations scores ($p_{\text{Paired t-tests}}=0.0762$; $p_{\text{Wilcoxon}}=0.1842$). Correspondingly, in 2010, the mean emotional function scores for children with asthma [5.44 (SD = 1.40)] and parents of children with asthma [5.29 (SD=1.41)] were not significantly different ($p_{\text{Paired t-tests}}=0.2064$; $p_{\text{Wilcoxon}}=0.1599$); as well as overall quality of life scores for children with asthma [5.30 (SD = 1.21)] and parents of children with asthma [5.24 (SD=1.40)], $p_{\text{Paired t-tests}}=0.5269$ and $p_{\text{Wilcoxon}}=0.6118$. Mean symptoms scores for children with asthma was 5.18 (SD = 1.34).

Factor Analysis:

Children with asthma. Factor analysis proceeded in a two-step manner. First, all thirteen variables were included in the analysis, and the results examined for low-loading variables. Accordingly, in the second step these variables were removed and the analysis repeated. This revealed a steep drop-off in eigenvalues after the first factor, which had an eigenvalue of 5.184, and the second factor featured an eigenvalue of 1.093. Examination of the variable loadings, representing standardized regression coefficients, for each of the four factors is shown in Table 14. These data support our initial supposition of four distinct factors. The first factor, accounts for almost 40% of the total variance and is represented by all 13 manifest variables; the remaining factor contributes another 8% of the total variance.

Parents. Similarly, factor analysis proceeded in a two-step manner. First, all thirteen variables were included in the analysis, and the results examined for low-loading variables. Accordingly, in the second step these variables were removed and the analysis repeated. This revealed a steep drop-off in eigenvalues after the first factor, which had an eigenvalue of 7.250 and the second factor featured an eigenvalue of 1.241. Examination of the variable loadings, representing standardized regression coefficients, for each of the two factors is shown in Table 15. These data support our initial supposition of two distinct factors. The first factor, accounts for nearly 56% of the total variance and is represented by all 13 manifest variables; the remaining factor contributes another nearly 10% of the total variance.

QUESTIONNAIRE	Reliability Coefficients (Cronbach's Alpha)	
	mPAQLQ	PACQLQ
Overall QoL	0.870	0.933
SUB-SCALE	mPAQLQ	
	PACQLQ	
	0.544	0.914
	0.765	N/A
"Emotional Function"	0.706	0.901

Table 11: Comparing Cronbach's Alpha Coefficients for mPAQLQ and PACQLQ from the 2010 event.

Quality of Life Measure	mPAQLQ Scores Child	Distribution For Child	PACQLQ Scores Caregiver	Distribution For Caregiver
	N=165	Shapiro-Wilks	N=153	Shapiro-Wilks
	Mean (SD) [Median]	p-value	Mean (SD) [Median]	p-value
Overall Quality of Life	5.30(1.21) [5.62]	<0.0001***	5.24(1.40) [5.46]	<0.0001***
Subscale "Activity Limitation"	5.31(1.36) [5.67]	<0.0001***	5.01(1.68) [5.25]	<0.0001***
Subscale "Symptoms"	5.18(1.34) [5.50]	<0.0001***	N/A	N/A
Subscale "Emotional Function"	5.44(1.40) [5.75]	<0.0001***	5.29(1.41) [5.56]	<0.0001***

*** ≤ significance at the 0.05 level or less.

Table 12: Quality of life scores for subscale and overall quality of life, for mPAQLQ scores for children and PACQLQ scores for their caregivers from the 2010 event. The Shapiro-Wilks tests indicate if the scores for subscales and overall quality of life for the mPAQLQ and PACQLQ are normally distributed.

Figure 7: A histogram of activity limitation score differences between children with asthma and their caregivers from 2010 event.

Figure 8: A histogram of emotional function score differences between children with asthma and their caregivers from 2010 event

Figure 9: A histogram of overall quality of life score differences between children with asthma and their caregivers from 2010 event.

Quality of Life Measures	mPAQLQ Scores Child N=165 Mean (SD) [Median]	PACQLQ Scores Caregiver N=153 Mean (SD) [Median]	Difference in QoL Scores N=153 Mean Difference [Median Difference]	Parametric Statistics Paired t-Test p-value	Non-Parametric Statistics Wilcoxon Signed Rank Test p-value
Overall Quality of Life	5.30(1.21) [5.62]	5.24(1.40) [5.46]	0.06 [0.16]	0.5269	0.6118
Subscale "Activity Limitation"	5.31(1.36) [5.67]	5.01(1.68) [5.25]	0.30 [0.42]	0.0762	0.1842
Subscale "Symptoms"	5.18(1.34) [5.50]	N/A	N/A	N/A	N/A
Subscale "Emotional Function"	5.44(1.40) [5.75]	5.29(1.41) [5.56]	0.15 [0.19]	0.2064	0.1599

*** ≤ significance at the 0.05 level or less.

Table 13: Quality of life scores for subscale and overall quality of life, for mPAQLQ scores for children and PACQLQ scores for their caregivers from the 2010 event. All scores were based on a 1-7 ordinal scale, with "1" representing maximal limitations, and "7" representing no limitations. Differences between scores from a child and their caregiver were tested using paired t-tests, Wilcoxon signed rank and difference in median test. The significance level was set at $p \leq 0.05$.

Component	Eigenvalue	Percent of Variance Explained	Total Variance Explained
1	5.184	39.874%	39.874%
2	1.093	8.406%	48.280%

Table 14: Results from the factor analysis for the children from the 2010 event.

Component	Eigenvalue	Percent of Variance Explained	Total Variance Explained
1	7.250	55.770%	55.770%
2	1.241	9.544%	65.313%

Table 15: Results from the factor analysis for the parents from the 2010 event.

Synopsis of Results

In our sample, the results suggest that children with asthma have higher quality of life scores when compared to their parents; in those years the healthy hoops event was held. This finding contradicts the only other study that investigated the quality of life of children with asthma using the same instruments, but conducted in a rural setting. Our hypotheses for the differences are discussed below in the discussion.

The non-parametric approach using the Wilcoxon signed rank test to analyze differences in quality of life scores from dyads of asthmatic children with mPAQLQ scores and caregivers with PACQLQ scores is supported by the current results. Analyses of differences in quality of life scores from mPAQLQ and PACQLQ may best be accomplished using non-parametric methods, such as the Wilcoxon signed rank test, instead of the currently recommended paired t-tests. Further research on additional datasets with concurrent mPAQLQ and PACQLQ scores using both parametric and non-parametric methods for analyses is suggested to replicate the findings of this report.

CHAPTER V

DISSCUSSION AND CONCLUSION

The current study aimed to evaluate the feasibility of using the Health Hoops platform to examine the quality of life of children with asthma, as well as their parents' quality of life. Therefore, the current study allowed for (1) an investigation of the feasibility of using the healthy hoops platform as a mechanism to assess the quality of life of children with asthma and their parents, (2) whether quality of life assessment were different between the children and their parent, and (3) whether the data from these instrument should be analyzed using non-parametric techniques.

As such, the Healthy Hoops platform was used to evaluate the quality of life of children with asthma. This was first time a Healthy Hoops event was held in Kentucky. Children and their parents/guardians attended the Healthy Hoops Kentucky event where the child received a detailed asthma action plan. In addition, Healthy Hoops Kentucky was the first Healthy Hoops event, to assess the quality of life of the child and their parent/guardian using Juniper's valid and reliable instruments.

Discussion

In previous studies, parents of children with asthma reported significantly higher emotional functioning and fewer activity limitations in contrast to the child's perceptions of their quality of life. However there was no significant difference between the overall quality of life of parents and children. In our study, children with asthma tended to report higher quality of life than their parents in 2008, 2009, and 2010. However, the previous findings were seen in a non-urban setting. Urban parents tend to have double-incomes to support their household, which dictates that both parents have a job outside the home. If their child's asthma becomes severe, it not only causes the child to miss school in order to see a doctor or stay home, but the asthma exacerbation also affects the parents. Parents would need to take care of their sick child, including missing work to take the sick child to seek medical care or to stay home to be with the sick child. However, it is assumed that children in urban settings tend to have a higher quality of life because there are more medical resources in urban areas. The previous study also showed that the number of school days missed was significantly associated with the child's emotional quality of life for all children¹. Compared to rural children, urban children get their asthma under control quicker because of greater access to more medical resources.

The results of this study suggest that the Healthy Hoops platform is an efficient way in which to assess the quality of life of children with asthma and their parents. The results also suggest that the children's quality of life is significantly better when compared to their parents, which contradicts earlier studies.

Administering the survey was an effective mechanism to assess the quality of life of children with asthma at a Healthy Hoops event (98% of participants completed

questionnaires properly). Parents consistently scored their quality of life (overall as well as in specific domains) lower when compared their child's assessment of their quality of life. Previous findings suggest that adults experiencing a disease assess their own quality of life higher when compared to surrogates assessment of their quality of life. Our results suggest this phenomenon may hold in a population of children with asthma.

Limitations

This study was unique in that it presented the impact of asthma on urban families from the viewpoint of both parent and child. Some study limitations existed. The study findings may not be generalizable beyond the urban sample. Lost to follow-up is a limitation for this study to gain more information of changes over time.

Future Work

Baseline estimates were obtained during this event that will be available for future more sophisticated longitudinal analyses involving Healthy Hoops Kentucky. In the future, we hope to compare Passport participants who took part in the 2008, 2009 or 2010 events (cases) with Passport members in 2008, 2009, or 2010 who did not participate in the event (controls) over time and test for differences in change in quality of life and level of health care utilization. We would like to see if there are changes over time between baseline and follow-up, so it would be beneficial to be able to follow individuals over

time as well. Below is a study design was developed as part of this thesis that is currently under review:

Basic Study Design and Methodology

The primary goal of the current study is to determine if we can improve health outcomes, decrease health care utilization, and decrease costs among children with persistent asthma who are members of Passport by using the HHKY program; while adjusting for traditional risk factors. As a result, children with asthma who are members of Passport will be divided into two groups: *(1) those who are attended HHKY 2008 and (2) those who did not attend HHKY 2008*. A comparison of the two groups will allow us to investigate the influence HHKY has on health outcomes, health care utilization, and costs.

Group 1: 50 children with asthma who are members of Passport who attended the Healthy Hoops 2008 event.

Group 2: Two years of follow-up data are available on nearly 600 children with asthma who are members of Passport who did not attend the HHKY 2008 event. We will match on age, gender and ethnicity to construct a sample of 100 children (using a 2:1 allocation rate) who did not attend Healthy Hoops 2008.

Power and Sample Size Justification.

Power calculations were based on the anticipated total sample size (from both groups) using an unbalanced design (n=150); that will be available for complete analysis. We will develop separate mixed-effects general linear models for each of the four outcomes. From the anticipated sample size (n=150) **the study has 88% power to detect a 10% main effect** of each treatment for each of the four outcomes. *Therefore, we have more than sufficient numbers of participants in each comparison group to detect main effects.*

H1: Healthy Hoops will significantly improve peak expiratory flow rate (PEF), forced expiratory volume one second (FEV₁), forced vital capacity (FVC), and FEV₁/FVC in children with asthma over time.

Baseline demographics, risk behaviors for asthma, and markers of asthma progression will be compared among the two study groups. First we will start with straightforward tests for differences among individuals who attended Healthy Hoops and comparable individuals in the control group. Analysis of Variance (ANOVA) techniques will be used to test for differences among continuous variables, while Kruskal-Wallis, Fischer's Exact Tests and Wilcoxon methods (when appropriate) will be used to test for differences among categorical variables.

PEF, FEV1 and FVC values are obtained from Passport. To examine the outcomes (1) PEF, (2) FEV1, (3) FVC (4) FEV1/FVC separate mixed-effects general linear models will be developed for each outcome. That is, four separate models will be

developed. The two groups (the Healthy Hoops group and the control group), will be analyzed as fixed effects and time (month since the event) will be analyzed as a repeated measures effect. Traditional risk factors (e.g. age, gender, and ethnicity) and the mediating factors being studied (residence, school, change in medication, etc.) will be incorporated as covariates during secondary analyses. All main effects and all two-way interaction effects will be investigated for significance from the mixed-effects models developed.

H2: Individuals who attended Healthy Hoops 2008 will exhibit fewer unscheduled health care visits over time, when compared to the control group.

Similar to aim #1 above, a mixed-effects general linear model will be developed for the outcome unscheduled health care visit (e.g., ER visit, rescue medication used, etc.). The two groups will be analyzed as fixed effects and time (month since event) will be analyzed as a repeated measures effect. In addition, negative binomial regression techniques will be used to evaluate the number of unscheduled health care visits over the two follow-up period. Life table analysis and Kaplan-Meier techniques will initially be used to analyze the time until the first unscheduled visit. The Log-rank test will be used to test for differences among survival curves. In addition, Cox (proportional hazards) regression techniques will be developed to test for differences among groups as well as allow for adjustment for additional covariates, risk factors, and the mediating factors being studied. Cox regression will allow us to investigate all potential main effects and

interaction effects. Differences between median times will be tested using traditional Wilcoxon methods.

Since the frequency (and rate) of unscheduled health care visits may be nominal, an individual's frequency of unscheduled health visits over time may need to be collapsed into logical time frames (i.e. monthly, quarterly). As such, repeated measures ANOVA will be used to examine differences in frequency of unscheduled health care visits among groups. However, if pooling all unscheduled health visits over the entire time-frame is necessary; two-sample t-tests will be performed to test for differences in frequencies. In addition, Poisson regression techniques may be used to test for differences in rates of unscheduled health care visits.

H3: *The cost of hosting Healthy Hoops Kentucky will be offset by the decreased costs associated with fewer health care visits and fewer rescue medications being prescribed for those members who attend the event.*

Economic Evaluation: Adoption of a new intervention requires knowledge of both its effectiveness and costs. Also, since the financial feasibility of using the Healthy Hoops platform is unclear, the current study will investigate the costs associated with its implementation. Therefore, we will perform a cost-effective analysis evaluating the cost-effectiveness of Healthy hoops Kentucky, potentially indicating a cost-savings approach for passport Health Plan.

Financial Feasibility: Initially we will perform a cost-minimization analysis. We will calculate all costs associated with Healthy Hoops Kentucky allowing us to investigate the distribution of costs. Results will be expressed as average cost per ER visit averted, cost per rescue medication use averted, and cost per quality of life year gained.

Cost Effectiveness: The primary goal of the cost-effectiveness analysis will be to estimate the incremental cost-effectiveness of the Healthy Hoops program approach when compared with the standard treatment approach. Our effectiveness will be measured as the number of health care utilizations (ER visits, rescue medications used) averted as well as quality adjusted life years gained.

We will measure all costs associated with hosting HHKY. Combined with the within-trial data an estimate of the incremental cost-effectiveness ratio according to a traditional decision analytic model will be calculated. Estimation of cost will adhere to current standards. Rates of ER visits and rescue medications used will be obtained from the Passport Health plan.

The incremental cost of HHKY versus control will be measured as the additional costs of implementing the HHKY program compared with the (potential) cost-savings of decreasing ER visits and rescue medications used. Then incremental cost-effectiveness will be measured as the ratio of incremental costs to incremental effectiveness. Costs and effects will be expressed per ER visit averted, rescue medication use avert and quality adjusted life year gained. Results will be expressed as means, ratios of mean incremental cost-effectiveness, and medians since the ratio of means is not always normally distributed. Sensitivity analysis will adopt the perspective of the provider. All costs will be converted to 2010 US dollars. Future costs and effects will be discounted at a rate of

3% per annum. A cost-effectiveness acceptability curve will be developed, so decision-makers can interpret the data relative to their threshold willingness to pay for the incremental health outcome.

The effect of uncertainty in clinical and economic data will be assessed by following the techniques outlined in Briggs et al. For threshold analyses, variables will be considered sensitive if the incremental cost per clinical failure averted exceeds \$100,000, which is the advocated threshold value to establish cost-effectiveness. The discount rate will be varied from 0% to 10% since the true discount rate is unknown.

Feasibility and Potential Pitfalls

This project is extremely feasible given the time frame and the funding level. The research is qualified to successfully accomplish all of aspects of the research planned. In addition, the team has demonstrated commitment for and has been involved with the Healthy Hoops program since its inception. The major potential pitfall is having incomplete data on all 50 attendees. Preliminary analysis has shown this not to be the case. The study will be adequately powered to observe a main effect even if the sample size (per group) is 34.

Future Directions

If the results of the current study support our hypotheses, the future plans will be to demonstrate how resource intensive Passport could be concerning HHKY and still achieve cost-savings. In addition, the research team will explore other diseases and disorders in which the Healthy Hoops platform may be beneficial. A distinct advantage will be enroll future participants before subjecting them to the HHKY program; so a hypothesis-driven prospective study using a pre-port time-series analysis design can be performed.

Conclusion

This thesis provides the results of quality of life assessments of children with asthma as well as their parents. The results suggest differences among parents and their children. The report also suggests that the advocated way in which to analyze the quality of life data may need to be reconsidered. Finally the report provides a study design that will allow for comparisons for individuals who did and did not attend the Healthy Hoops Kentucky events.

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APPENDIX A

NAME: _____ ID #: _____ DATE: ____/____/____

MINI PEDIATRIC ASTHMA QUALITY OF LIFE QUESTIONNAIRE

INTERVIEWER-ADMINISTERED

I want you to tell me how much you have been bothered by your asthma during the past week. I will tell you which card to use. Pick the number that best describes how much you were bothered by your asthma during the past week.

SCORE:

- ____ 1. How much did **COUGHING** bother you in the past week? **[BLUE CARD]**
- ____ 2. How much did **WHEEZING** bother you during the past week? **[BLUE CARD]**
- ____ 3. How much did **TIGHTNESS IN YOUR CHEST** bother you during the past week? **[BLUE CARD]**
- ____ 4. How often did you feel **OUT OF BREATH** during the past week? **[GREEN CARD]**
- ____ 5. How often did your asthma make you feel **TIRED** during the past week? **[GREEN CARD]**
- ____ 6. How often did you have trouble **SLEEPING AT NIGHT**, because of your asthma, during the past week? **[GREEN CARD]**
- ____ 7. How often did you feel **FRUSTRATED** because of your asthma during the past week? **[GREEN CARD]**
- ____ 8. How often did you feel **FRIGHTENED OR WORRIED** because of your asthma during the past week? **[GREEN CARD]**
- ____ 9. How often did your asthma make you feel **IRRITABLE (grumpy*)** during the past week? **[GREEN CARD]**
- ____ 10. How often did you feel **DIFFERENT OR LEFT OUT** because of your asthma during the past week? **[GREEN CARD]**
- ____ 11. How much have you been bothered by your asthma in **PHYSICAL ACTIVITIES** (such as running, swimming, sports, walking uphill/upstairs and bicycling) during the past week? **[BLUE CARD]**
- ____ 12. How much have you been bothered by your asthma in **BEING WITH ANIMALS** (such as playing with pets and looking after animals) during the past week? **[BLUE CARD]**
- ____ 13. How much have you been bothered by your asthma in **ACTIVITIES WITH FRIENDS AND FAMILY** (such as playing during school break and doing things with your friends and family) during the past week? **[BLUE CARD]**

APPENDIX B

NAME: _____ ID #: _____

RELATIONSHIP TO CHILD: _____ DATE: ____/____/____

PEDIATRIC ASTHMA CAREGIVER'S QUALITY OF LIFE QUESTIONNAIRE

This questionnaire is designed to find out how you have been during the last week. We want to know about the ways in which your child's asthma has interfered with your normal daily activities and how this has made you feel. Please answer each question by placing a check mark in the appropriate box. Check only one box per question.

DURING THE PAST WEEK, **HOW OFTEN**:

	All Of The Time	Most Of The Time	Quite Often	Some of The Time	Once in A While	Hardly Any Of The Time	None Of The Time
	1	2	3	4	5	6	7
1. Did you feel helpless or frightened when your child experienced cough, wheeze or breathlessness?							
2. Did your family need to change plans because of your child's asthma?							
3. Did you feel frustrated or impatient because your child was irritable due to asthma?							
4. Did your child's asthma interfere with your job or work around the house?							
5. Did you feel upset because of your child's cough wheeze or breathlessness?							
6. Did you have sleepless nights because of your child's asthma?							
7. Were you bothered because your child's asthma interfered with family relationships?							
8. Were you awakened during the night because of your child's asthma?							
9. Did you feel angry that your child has asthma?							

DURING THE PAST WEEK, **HOW WORRIED OR CONCERNED** WERE YOU:

	Very, Very Worried/ Concerned	Very Worried/ Concerned	Fairly Worried/ Concerned	Somewhat Worried/ Concerned	A Little Worried/ Concerned	Hardly Worried/ Concerned	Not Worried/ Concerned
	1	2	3	4	5	6	7
10. About your child's performance of normal daily activities?							
11. About your child's asthma medications and side effects?							
12. About being over-protective of your child?							
13. About your child being able to lead a normal life?							

APPENDIX C

```
data HHK;
    set sasuser.HHK10;
    keep caseid c1 c2 c3 c4 c5 c6 c7 c8 c9 c10 c11 c12 c13
        p1 p2 p3 p4 p5 p6 p7 p8 p9 p10 p11 p12 p13;
    if caseid = 166 then delete;
    else if caseid = 167 then delete;

proc print data = HHK;
run;

data HHK1;
    set HHK;
    CAL = (c1 + c2 + c3)/3;
    CSM = (c4 + c5 + c6 + c7 + c8 + c9)/6;
    CEF = (c10 + c11 + c12 + c13)/4;
    CA = (c1 + c2 + c3 + c4 + c5 + c6 + c7 + c8 + c9 + c10 + c11 + c12
+ c13)/13;

    PAL = (p2 + p4 + p6 + p8)/4;
    PEF = (p1 + p3 + p5 + p7 + p9 + p10 + p11 + p12 + p13)/9;
    PA = (p1 + p2 + p3 + p4 + p5 + p6 + p7 + p8 + p9 + p10 + p11 + p12
+ p13)/13;

    ALDIFF = CAL - PAL;
    EFDIFF = CEF - PEF;
    ADIFF = CA - PA;
run;

proc means data = HHK1 n mean median std;
    var CAL CSM CEF CA PAL PEF PA ALDIFF EFDIFF ADIFF;
run;

proc univariate data = HHK1 NORMALTEST;
    var CA CAL CSM CEF PA PAL PEF;
run;

proc univariate normal data = HHK1;
    var ALDIFF EFDIFF ADIFF;
run;

proc ttest data = HHK1;
    paired CAL*PAL CEF*PEF CA*PA;
run;
```

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- Thesis: Does the Healthy Hoops Kentucky Program Improve the Health of Children with Asthma?
- Practicum: “Using Healthy Hoops Kentucky to Develop Interventions to Increase the Quality of Life of Kids with Asthma”
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PRESENTATION/MANUSCRIPTS:

- Chen, Y., Mendes, A.M., (2008, September). Evaluating the performance of diagnostic and screening tools used in public health. Paper presented at the 65th Kentucky Public Health Annual conference in Louisville, Kentucky.
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- John A. Myers, Robert William Prasaad Steiner, James Legleiter, Yu-Ting Chen, Robert Esterhay. Appropriate Statistical Testing of Quality of Life Scores from Children with Asthma and Their Caregivers. August 4, 2010

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