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Asthma severity in school-children and the quality of life of their parents

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ASTHMA SEVERITY IN SCHOOL-
CHILDREN AND THE QUALITY
OF LIFE OF THEIR PARENTS

by

Noelle S. Cerdan

Bachelor of Science in Nursing
University of Nevada, Las Vegas
2005

A thesis submitted in partial fulfillment
of the requirements for the

**Master of Science Degree in Nursing
School of Nursing
Division of Health Sciences**

**Graduate College
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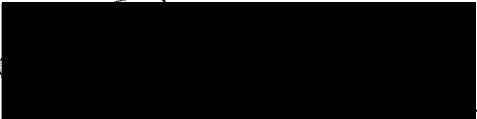
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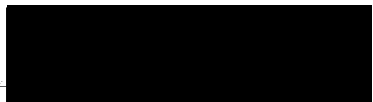
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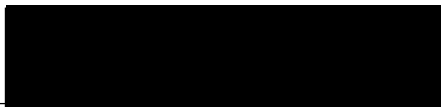
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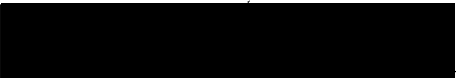
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ABSTRACT

**Asthma Severity in School-Children
And the Quality of Life of their Parents**

by

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Background: The everyday management of a child with asthma can affect the parent's quality of life. Past studies which examined the effects of asthma characteristics of the child on parental quality of life have not reached a consensus over findings. Few studies examine parent characteristics such as mental health and sociodemographics on the quality of life of parents of asthmatic children.

Purpose: To examine the effect of asthma severity of school-children and sociodemographic characteristics on the caregiver's quality of life. It also investigates whether agreement exists between the caregiver's perception of asthma severity and physician-diagnosed asthma severity.

Methodology: Parents of asthmatic children (n=101) were identified in the waiting room at an outpatient pediatric pulmonology clinic in Las Vegas and were given three questionnaires: (1) the Paediatric Caregiver's Quality of Life Questionnaire (PACQLQ), (2) asthma severity questionnaire, (3) sociodemographics questionnaire. Spearman's correlation (ρ), analysis of variance (ANOVA), linear and multivariate regression, Chi-

square, independent t-tests, Kendall tau rank correlation coefficient, and descriptive analyses were performed.

Results: A significant negative correlation was found between overall asthma severity, based on the 2007 NAEPP guidelines, and mean activity limitation scores ($\rho = .400, p < .001$), mean emotional function scores ($\rho = -.258, p < .001$), and mean total of PACQLQ scores ($\rho = -.342, p < .001$). A significant moderate, negative correlation was found between PACQLQ scores and asthma day symptoms, asthma night symptoms, and asthma exercise symptoms. No significant relationship was found between pulmonary function testing (PFT) scores and PACQLQ scores. Parents of children with mild intermittent asthma had higher mean PACQLQ scores, followed by those with mild persistent asthma, moderate persistent asthma, and lastly, severe persistent asthma who had the lowest PACQLQ scores. Predictors of better quality of life included increased income. Predictors of worse overall quality of life included increased hospitalization days, increased ER visits, increased school days missed, and increased work days missed. Using independent t-tests, better scores were found for those who were not of Black or African ethnicity, were able to pay for health costs, owned a home or a car, and perceived their child's asthma as under control.

Implications for Nursing: Measuring parental quality of life allows nurse researchers to measure the burden parents experience in caring for their child in order to develop more effective asthma programs that emphasize adherence to medical treatment. Other factors that can influence caregiver quality of life and other measurement tools for quality of life should be explored.

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CHAPTER 1

INTRODUCTION

Quality of life can be defined as general satisfaction with everyday living (Vila et al., 2003). Quality of life is related to health status which is defined by the World Health Organization (WHO) as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (2006, p. 1). In addition to asthma symptoms and other clinical indicators, measures of quality of life are important when assessing asthmatic children and their caregiver holistically. Asthma is known to have a significant impact on the quality of life of the child diagnosed as well as the caregiver (Juniper et al, 1996a; Juniper, Guyatt, Feeny, Ferrie, and Townsend, 1996b).

Problem Statement

Developed by Juniper and colleagues (1996a), the Paediatric Caregiver’s Quality of Life Questionnaire (PACQLQ) is a 13-item questionnaire measuring activity limitation and emotion that has been regularly utilized to measure the burden parents experience in caring for a child with asthma. Several studies have attempted to examine the relationship between asthma characteristics such as asthma severity, daily medication use, and daily symptoms and caregiver quality of life through the use of the PACQLQ but no agreement has been reached on whether the two variables do associate with each other (Halterman et al., 2004; Annett, Bender, DuHamel, & Lapidus, 2003). Examining urban cities such as New York City, several researchers have found that sociodemographic

factors such as location, age, family structure, income, education level, minority status, transportation availability, and other measures influence child and parental burden (Osman, Baxter-Jones, and Helms, 2001; Chen and Escarce, 2008; Claudio, Stingone, and Godbold, 2005). Specifically, minority families who live in low-income, inner-city neighborhoods experience more morbidity and mortality related to asthma (CDC, n.d.; Litonjua, Carey, Weiss, Gold, 1999). Researchers have also measured parent perception of asthma severity and control which can affect caregiver quality of life (Dozier, Aligne, & Schlabach, 2006; Moonie et al., 2005). More recent studies have suggested that psychological factors and mental health of the parents influence PACQLQ scores and health care utilization for their asthmatic children (Vila et al., 2004; Goldbeck, Koffmane, Lecheler, Thiessen, & Fegert, 2007).

The everyday management for a child with asthma can affect the parent's quality of life. The child is affected in his school attendance, physical activity choices, and other areas of life (Moonie, Sterling, Figgs, & Castro, 2006; Brook & Shemesh, 1991; Marsac, Funk, & Nelson, 2006). In caring for their sick child, caregivers are affected by loss of workdays, financial constraints, stress, and other factors (Laforest et al., 2004; Grineski, 2008). Caregivers are responsible for many aspects of the child's care including symptom observation, medication administration, transportation to health care services, and medical decision-making (Halterman et al., 2004). Many factors can influence the parent's perception of asthma severity and burden surrounding the care of their child including minimal knowledge or education on the disease process, low adherence to medications and not seeking health services to receive appropriate medications, and poor communication between health care providers and parents (Dozier et al., 2006; Moonie et

al., 2005). Additionally, other factors such as healthcare beliefs, perceived barriers to care, psychological issues, coping styles, and family and social environmental factors also influence caregiver quality of life (Grineski, 2008; Vila et al., 2004; Goldbeck et al., 2007; Chen & Escarce, 2008). Measuring caregiver quality of life and caregiver perceptions of asthma severity are important to develop a better understanding on how to create future interventions towards asthma management for both the child and parent. The gap that exists in the current knowledge base on childhood asthma and parental quality of life necessitates the reexamination of the influence of asthma severity and sociodemographic factors on caregiver quality of life and caregiver perceptions of asthma severity. This study examines the effect of the asthma severity of school-age children and sociodemographic factors on caregiver's quality of life measured by the PACQLQ and caregiver perception of asthma severity through an additional questionnaire. Using the Roy Adaptive Model (RAM), the effect of the child's asthma severity and sociodemographic factors on caregiver quality of life and caregiver perception will be explained through parent-environment interaction and adaptation.

Purpose of the Study

This descriptive correlational study examines the effect of asthma severity on caregiver's quality of life. In addition, it examines the relationship between caregiver's quality of life and caregiver sociodemographic characteristics. Lastly, it investigates whether agreement exists between the caregiver's perception of asthma severity and physician-diagnosed asthma severity. The Roy Adaptation Model (RAM) is used as a foundation to explain the study.

Significance to Nursing

This study is important to nursing study in that it provides a more holistic focus in reviewing the parent's quality of life, both in functional limitation and emotional dimensions. Using the RAM, the effect of environmental stimuli such as the child's asthma severity and sociodemographic factors on biophysiological responses such as parental quality of life and caregiver perception of asthma severity will be measured. This allows for further understanding in adaptation modes represented by separate questionnaires on quality of life and sociodemographics. Measuring parental quality of life will allow nurse researchers to measure the burden parents experience in caring for their child and can help to develop more effective asthma programs that take these experiences into consideration (Halterman et al., 2004). Quality of life is shown to be an important outcome measure and being aware of its effect on the individual is important for adherence to medical treatment (Mahajan, Pearlman, & Okamoto, 1998; Bender, Milgrom, Rand, & Ackerson, 1998). In addition, this study will stimulate future research on the topic.

CHAPTER 2

LITERATURE REVIEW

Asthma is one of the most common chronic diseases in the United States affecting about 22.2 million people, 6.5 million of which were children, in 2005 (NCHS, 2007). Asthma is a chronic respiratory disease triggered by allergens, infections, exercise, irritants, and various other exposures and can result in episodes of inflammation and narrowing of the lower airways. Symptoms experienced include shortness of breath, cough, wheezing, and chest pain or tightness (NCHS, 2007). School-age children with asthma are affected by the frequency and severity of episodes, hospital admissions, side-effects of medications, morbidity and mortality, and costs of hospitalization (CDC, n.d.; Vila et al., 2003). Asthma in school-age children affects not only health status but also other aspects of life such as school attendance, physical activities, family dynamics, coping styles, psychological functioning, and sleep (Moonie et al., 2006; Brook & Shemesh, 1991; Marsac et al., 2006). Depending on various factors, school-age children can experience a great burden on their quality of life. Asthma status in school-children can also influence the quality of life of their caregivers.

Caregivers are responsible for many aspects of the child's care including symptom observation, medication administration, and transportation to health care services (Halterman et al., 2004). Because asthma is a chronic condition, this can lead to caregivers experiencing long-term stressors that impact work productivity and parenting

decision-making (Laforest et al., 2004). The caregiver's quality of life may also affect caring for and disciplining the child as well as making important medical decisions (Eiser, Eiser, Town, & Trip, 1991; Halterman et al., 2004). These decisions can be influenced by the caregiver's perception of barriers to asthma care including health insurance coverage, out-of-pocket costs for health services and daily needs, transportation, treatment delays, and inability to speak English (Grineski, 2008). Additionally, other sociodemographic factors such as marital status, smoking status, educational level and income, presence of family and support systems, presence of other children in the household, and the parents being diagnosed with asthma themselves can contribute to changes in caregiver quality of life. Many studies show childhood morbidity and mortality related to asthma is associated with low-income families, being a minority, and living in the inner-city (CDC, n.d.; Litonjua et al., 1999).

This study examines the effect of asthma severity of school-age children and sociodemographic factors on caregiver's quality of life measured through the PACQLQ. It also measures caregiver perception of asthma severity and compares it to medically-diagnosed asthma severity. The purpose of this literature review is to study the topics of caregiver's quality of life via the use of the PACQLQ, asthma severity of children, and caregiver sociodemographic factors. The literature review covered a time period of 18 years, ranging from 1990 to 2008. The sources used to retrieve the documents include the UNLV subscribed research databases Scopus, Medline, and CINAHL. The following words, both individually and together, were typed into the search engines to retrieve articles: child, asthma, caregiver, parent, guardian, physician, medical, quality of life, perception, control, severity, sociodemographic, socioeconomic, diagnosis, and

Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ). Inclusion criteria to the literature review included peer-reviewed, empirical studies dating from 1990 which addressed children diagnosed with asthma and the caregiver's quality of life measured through a form of the questionnaire PACQLQ. Exclusion criteria included letters to the editor, policy statements, program statements, non-empirical studies, and studies written in a foreign language, and any form of intervention (i.e., education and medication) to have been administered to the participants.

PACQLQ and General Use

Juniper and colleagues (1996a) developed the Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) to measure the daily parental physical and emotional quality of life factors impacted by their asthmatic children. Their disease-specific instrument has been shown to be both responsive and reliable. To test for responsiveness, the PACQLQ was used to measure longitudinal change in the parents and longitudinal construct validity. To test for reliability, the PACQLQ was used to measure the ratio of differences between subjects to difference within subjects and also tested for cross-sectional construct validity. Results showed that the PACQLQ was able to detect quality of life changes in caregivers over time ($p < .001$) and detect stability in those who did not change ($p < .0001$). The PACQLQ is reproducible in stable subjects (intraclass correlation coefficient = .84). Providing moderate validity, they also showed high-range correlation between the PACQLQ and the Impact on Family Scale and a low-range correlation between the PACQLQ and asthma severity (Juniper et al., 1996a).

Several studies have tested the responsiveness and reliability of the PACQLQ. Though originally tested for children within the age range of seven through seventeen

(Juniper et al., 1996), Osman, Baxter-Jones, and Helms (2001) tested the PACQLQ on parents with children under the age of seven and they recommend its use to measure clinical outcomes on preschool children with varying degrees of asthma severity. Annett and colleagues (2003) state that the PACQLQ has a high level of internal reliability when measuring parental feelings of distress and parental worry. The PACQLQ has also been studied in other countries such as Sweden and Mexico (Reichenberg & Broberg, 2001; Sienra-Monge, Río-Navarro, Álvarez-Amador, Blandon-Vijil, & Chico-Velasco, 2003).

Several studies were performed testing quality of life differences between children and their parents as well as differences between parents within the same family and gender. Annett and colleagues (2003) found a strong correlation between parents' PACQLQ scores and scores of children between the ages of 12-13 years in the Paediatric Asthma Quality of Life Questionnaire (PAQLQ). Dalheim-Englund, Rydstrom, Rasmussen, Moller, & Sandman (2004) found no significant differences in overall PACQLQ scores and individual scores for emotion and activity limitation among Swedish parents. They state that due to developmental differences in younger children, scores on asthma perception at the younger (6-11 years of age) would differ (2004; Bibace & Walsh, 1980). Hederos, Janson, & Hedlin (2008) showed that though there were differences in how mothers and fathers answered the PACQLQ, there were no significant differences in their overall score. Using the Paediatric Asthma Quality of Life Questionnaire (PAQLQ) and PACQLQ, Williams and colleagues (2000) found a statistically significant correlation between the quality of life of children with asthma and the quality of life of their caregivers ($r = .64, P < .001$). Because the PAQLQ and

PACQLQ were both filled out by the parents, caution should be used when interpreting the findings.

Asthma Characteristics of School-Children and PACQLQ

Several studies have not shown consensus on whether asthma characteristics including clinical measures and symptoms do influence PACQLQ. Juniper and colleagues (1996a) showed acceptable levels of correlation between asthma status and parent's quality of life. Results showed that the PACQLQ was able to detect quality of life changes in caregivers over time ($p < .001$) and detect stability in those who did not change ($p < .0001$). The PACQLQ is also reproducible in stable subjects (intraclass correlation coefficient = .84) (Juniper, 1996a). Following schoolchildren through the school year, Halterman and colleagues (2004) showed baseline children's asthma severity as measured by daytime symptoms, nighttime symptoms, the need for rescue inhaler use, and the number of symptom-free days had a significant correlation with PACQLQ (range $r = .23-.51$, all $p < .1$). The highest correlation was between symptom-free days and parental quality of life ($r = .51$, $p < .001$). At the end of the school year, significant correlations were found with all measures of asthma severity except for rescue inhaler use. An increase in symptom-free days over time correlated with an improvement in PACQLQ scores ($r = .30$, $p < .001$). An increase in symptom days ($r = -.27$, $p < .001$) and symptom nights ($r = -.22$, $p = .005$) correlated with lower PACQLQ scores.

In a study of children and parents over the course of three months, Osman and colleagues (2001) showed a significant correlation between a change in children's asthma symptoms and PACQLQ scores ($r = .54-.57$, $p < .001$). However, there was a difference in the amount of change in PACQLQ scores between parents. Some score changes did not

meet Juniper and colleague's minimum change score of .5 which indicates clinically significant change (Juniper et al., 1996a; Juniper, Guyatt, Willan, Griffith, 1994). This suggests other social factors such as family and friend support may influence the PACQLQ scores. Williams and colleagues (2000) found a negative correlation between quality of life scores for both caregivers and children and the children's asthma severity scores using 7-item questionnaire on wheezing frequency, day and night symptoms, and other measures in the past four months ($r = -.39$ and $r = -.47$, respectively, $P < .001$ for both). Reichenberg and Broberg (2001) found a negative correlation between asthmatic symptoms as recorded by a parental diary and PACQLQ scores (overall $\rho = -.637$, $p < .001$) but found no correlation between PACQLQ scores and peak expiratory flow rate (PEFR).

Annett and colleagues (2003) state burden of illness experienced by the parent and other factors such as social or economic variables, not daily asthma symptoms and family characteristics as measured through the Family Environment Scale (FES) and Impact on Family Scale (IOF), contribute to quality of life outcome scores. Juniper (1998) states that previous studies (Juniper et al., 1995; Rutten-van Molken et al., 1995; Rowe & Oxman, 1993; Leidy & Coughlin, 1998) using the quality of life questionnaire (AQLQ) have shown only weak to moderate correlations between clinical measures such as incentive spirometry and patient quality of life. For example, Leidy and Coughlin (1998) showed no relationship between FEV1% (forced expiratory volume in one second) and patient quality of life. Row & Oxman (1993) demonstrated low correlations between pulmonary function results and AQLQ domains, except activity limitations ($r = .44$; $p < .001$). However, high correlations were found between symptoms or global assessments

and AQLQ ($r > .6$; $p < .0001$). Clinical measures are useful to provide information regarding airway status but do not explain the functional and emotional status of the patient in their daily routine (Juniper, 1998).

Studying the number of caregiver visits to preventive care services, Butz and colleagues (2004) reported that caregivers in the 0-1 visit group had higher PACQLQ scores than caregivers in the 2 or more visit group (mean scores: 0–1 visits: 16.1, SD= 3.7; 2 or more visits: 15.1, SD =4.0 and $p = .001$). An association was found between a higher burden on the caregiver's quality of life and more preventive asthma care visits which was confirmed by nonparametric analysis (Kruskal-Wallis $\chi^2 = 4.43$, $df = 1$, $p = .04$). The researchers suggest that the caregiver's decision to attend preventive care visits is based more on asthma burden on the caregiver rather than the child's asthma symptoms (Butz et al., 2004). A factor analysis performed by Juniper and colleagues (2004) showed weak correlations between clinical measures such as airway caliber and quality of life. The analysis concludes that a child's quality of life cannot be obtained from measures of asthma status. Quality of life of asthma patients and asthma status must be measured and analyzed separately (Juniper et al., 2004). Some researchers have suggested that psychological factors rather than asthma severity greatly influence quality of life scores (Vila et al., 2004; Goldbeck et al., 2007).

Sociodemographic Characteristics of Caregivers and PACQLQ

Many studies were performed that connect asthma prevalence in children to sociodemographic characteristics such as being associated with minority families living in urban, low-income neighborhoods (Akinbami & Schoendorf, 2002; Crain et al., 1994; Lang & Polansky, 1994; Litonjua et al., 1999; Aligne, Auinger, Byrd, Weitzman, 2000).

Several studies have suggested prevalence and severity of asthma are associated with the African American and Hispanic population as well as poverty-related factors such as young maternal age, maternal cigarette smoking, low birth weight, and living in crowded conditions in the inner-city (Schwartz, Gold, Dockery, Weiss, & Speizer, 1990; Weitzman, Gortmaker, & Sobol, 1990; Coultas et al., 1994). Through a review of articles, Erickson and colleagues (2002) stated other variables related to increased asthma prevalence, severity, and use of health resources include limited access to care, poor patient-physician relationship, lower income and educational level, lack of social support, and lack of asthma-specific education leading to ineffective medication use and noncompliance (Murray, Stang, & Tierney, 1997; Weiss & Wagener, 1990; Lozano, Connell, & Koepsell, 1995; Schwartz et al., 1990; Mitchell et al., 1989).

Mansour, Lanphear, and DeWitt (2000) state in their study many barriers existed for urban, minority, low-income parents that prevent them from giving their asthmatic child adequate care: Parental adherence to asthma management care was related to parental personal and cultural beliefs regarding medicine usage. Limitation of their child's physical activity was related to lack of education by physicians regarding exercise and fear of exacerbation of symptoms. Parental quality of life was related to psychological burden and fear for their child's safety. School issues were related to the parents perceiving that school health services were insufficient. Other barriers identified include education regarding asthma care; the relationship between physician, patient, and parent; the availability of the physician and services; financial barriers including insurance status; and environmental barriers including lack of transportation and social support. In a study assessing demands and resources between African American (AA) parents and

European American (EA) parents, both groups with asthmatic children, Lee, Parker, DuBose, Gwinn, & Logan (2006) state that AA parents had more difficulty performing and balancing tasks such as managing work schedules, home finances, and scheduling and transporting to the clinic while EA parents had more difficulty performing child care tasks such as providing emotional support and managing asthma warning signs and exacerbations. The AA parents studied by Lee and colleagues (2006) were twice as likely to be employed and less likely to be married compared to EA parents.

Other studies exist that examine caregiver quality of life via the PACQLQ and sociodemographic characteristics. Using Carstairs deprivation scores to describe sociodemographics of the families in their studies, Osman and colleagues (2001) found that younger mothers, less affluent families, and those with greater social deprivation had lower PACQLQ scores. Halterman and colleagues (2004) predicted better quality of life to include symptom-free days and parent perception that their child's asthma is under control. Predictors of poor quality of life included Hispanic ethnicity, daily use of medication, and secondhand smoke exposure in the home. Erickson and colleagues (2002) showed that household income and lower perceived asthma severity were a statistically significant predictor of quality of life in relation to both PACQLQ and (Paediatric Asthma Quality of Life Questionnaire) PAQLQ. Longer length of time diagnosed with asthma, longer length of time enrolled in a specialty clinic, less siblings living in the household, and greater convenience of seeing the physician were all related to higher quality of life. Chen & Escarce (2008) found that asthmatic children in families with a single mother as the head of the household or families with three or more children had fewer office visits for asthma and filled fewer prescriptions for controller

medications than children with two parents and children living with no other children, respectively. Caregiver absenteeism is significantly correlated with the level of a child's asthma control which can have financial and economical implications for the parents and society (Laforest et al., 2004). In a study of New York City children, Claudio and colleagues (2005) found children living in low-socioeconomic status neighborhood had a ≥ 70 percent increased risk of current asthma versus children of the same ethnicity and income level living in neighborhoods with greater economic status.

Physician-Diagnosed Asthma Severity and Parental Perceptions

Few studies have been performed that compare physician-based diagnosis of asthma severity to parent or patient perception of asthma severity. Examining patient self-reported and physician-diagnosed asthma severity, Moonie and colleagues (2005) found a moderate measure of agreement between the two ($k = .48$; $p < .001$). However, as the level of asthma severity increased, the correlation between the two decreased. The researchers found that at higher severity levels based on the patient's self-reported symptoms, primary care physicians underrated asthma severity (Moonie, 2005). Hammer and colleagues (2008) showed that patient's perception of asthma control was significantly better than of doctor-diagnosed asthma control. The researchers found a low correlation between the pediatrician and patient's perception of asthma control. However, in patients with poor asthma control, the agreement between doctors and patients increased ($\rho = .484$, $p = .001$) (2008).

Other studies have shown that perception of asthma severity both by the patient and physician are influenced by awareness diagnosis- and treatment-based national asthma guidelines. Dozier and colleagues (2006) found a significant difference between parental

perceptions of their children's asthma control and their reports of asthma morbidity. With a sample of over 300 school-aged children with asthma, many parents reported their child's asthma as being under good control. However, only 58 percent of parents' responses were consistent between their assessment of control and the reported symptoms. Children with uncontrolled asthma which was perceived as "well controlled" by parents were at particularly high risk for asthma morbidity. About 40 percent of parents (n =138) reported well- or completely controlled asthma even though the children had increased use of health services, rescue medications, absenteeism, or presence of symptoms. Dozier and colleagues found that parental perception of asthma severity and control is different than the definition of severity and control used by physicians and other health care professionals (2006). Wolfenden (2003) and colleagues found that physicians' estimate of asthma severity, not patient symptoms of asthma, was a strong predictor of asthma care, including use of inhaled corticosteroids, owning a peak flow meter, allergy testing, and self-management care. This finding indicates that patients with moderate or severe asthma could receive insufficient care if the physician labeled them as having mild asthma (2003). Both of these studies suggest that education for the parent, patient, and physician on updated national asthma guidelines for diagnosis and treatment are necessary to prevent asthma-related morbidity and mortality (Dozier et al., 2006; Wolfenden et al., 2003).

Roy Adaptation Model: Application in Asthma and Caregiver Quality of Life

Several studies exist that use RAM as a model for examining chronic diseases such as cancer and quality of life. For example, Nuamah, Cooley, Fawcett, and McCorkle (1999) used RAM to study environmental stimuli and biophysical responses in patients with

newly diagnosed cancer. The environmental stimuli included race, age, income, marital status, cancer treatment, and illness severity. The biophysical responses included physiologic (physical symptoms), self-concept (affective status), interdependence (social support), and role function (functional support). Results showed that illness severity and cancer treatment had the strongest association with the biophysical response. Wright (1993) used RAM to study parent's perceptions of their own quality of life before and after their child was diagnosed with cancer.

Few studies exist that use RAM in the case of pediatric asthma and quality of life. For example, Buckner and colleagues (2006) studied adolescent adaptation in the four RAM modes (i.e., physiologic-physical, self-concept-group identity, role function, and interdependence modes) on those attending the Youth Asthma Camp. The physiologic mode was measured through peak expiratory flow measures, self-concept and role function measured through the General Self-Efficacy Scale and Social Self-Efficacy Scale, and interdependence mode through the Asthma Responsibility Questionnaire. Through the use of individual Asthma Action Plans and educational sessions, results showed that there were improvements in the self-concept, role function, and interdependence modes. The author is not aware of any studies that use RAM to describe childhood asthma and caregiver quality of life.

Other Models: Application in Asthma and Caregiver Quality of Life

Very few studies regarding this topic use theory to explain their reasoning. In a study by Lee and colleagues (2006) to compare the demand and resources utilized by African Americana and European families with asthmatic children, the Resiliency Model of Family Stress, Adjustment, and Adaptation by McCubbin and McCubbin (1996) was

used as a guide to determine which families would experience a crisis caused by stress in caring for an asthmatic child. According to theory, the level of resiliency of the family which is based on an individual family's use of resources, appraisal, and problem solving leads to adaptation of this crisis. In a study of socioeconomic variables and quality of life of both asthmatic children and their parents, Erickson and colleagues (2002) used the Behavior Model of Health Services to describe predisposing (i.e., age, gender, race, length of time diagnosed with asthma), enabling (i.e., family income, health insurance coverage, family structure), and need variables (i.e., perceived and evaluated asthma severity) related to health care service use and health-related outcomes such as quality of life (Andersen, 1995)

Summary

The PACQLQ, developed by Juniper and colleagues (1996a), has been used in many studies to test its reliability and its responsiveness. Many studies have been performed that examine the relationship between asthma characteristics in children and caregiver quality of life through use of the PACQLQ but results vary among the studies.

Sociodemographic factors have shown to have an impact on the quality of life of asthmatic children and their parents. Few studies have used RAM to describe the topics of childhood asthma and quality of life. The author is not aware of any studies that use RAM to describe childhood asthma and caregiver quality of life. Very few models such as the Resiliency Model of Family Stress, Adjustment, and Adaptation and the Behavior Model of Health Services have been utilized to explain childhood asthma and caregiver quality of life. This literature review reinforces the need to examine the relationship between asthma severity and sociodemographic factors on caregiver quality of life.

CHAPTER 3

CONCEPTUAL FRAMEWORK

The theoretical framework for this study is the Roy Adaptation Model (RAM). It is a systematic theory which describes the interaction between person and environment in order to achieve adaptation. RAM defines adaptation as “the process and outcome by which the thinking and feeling person uses conscious awareness and choice to create human and environmental integration” (Roy and Andrews, 1999, p. 30). The person is portrayed as a holistic, adaptive system that is a “whole with parts that function as unity for some purpose” (Roy and Andrews, 1999, p. 31).

The person has control of adaptation through the use of subsystems used in response to the environment including focal, contextual, and residual stimuli. Focal stimuli represent stimuli of immediate importance to the person while contextual stimuli represent other stimuli within that situation. Residual stimuli are other environmental factors in which its influence of that situation remain unclear (Roy & Andrews, 1999).

Two primary subsystems which describe forms of coping include: the regulator which is the physiologic coping subsystem and the cognator which is the cognitive-emotive coping subsystem. The regulator involves neural, chemical, and endocrine systems. The cognator subsystem involves perceptual and information processing, learning, judgment, and emotion. Through the relationship of four secondary modes (i.e., physiologic-physical, self-concept-group identity, role function, and interdependence modes)

representing the response to stimuli, the client and environment interact as manifested through cognator and regulator activities and adaptation is observed. The subsystems allow the person to adapt and make changes in response to stress. One of the benefits of adaptation is the person being able to cope and being satisfied with health status (Roy & Andrews, 1999).

Physiologic-physical Mode

This mode is defined as the physical health of the person as a result of physical and physiological responses to stimuli such as illness or change in health status. In this mode, five needs are recognized including: oxygenation, nutrition, elimination, activity and rest, and protection. Using the regulator and cognator subsystems to cope, the goal is operational integrity, or maintaining physical and physiological wholeness by adapting to changes in needs (Roy & Andrews, 1999). The PACQLQ has measures of physical limitations in caregivers (Juniper et al., 1996a). An additional questionnaire will measure asthma severity and perception of asthma severity by the parents.

Self-concept-group Identity Mode

This is defined as the psychological and spiritual health of the person. Emphasis is placed on a sense of unity, understanding, purpose, and meaning. Self-concept represents one's beliefs and feelings about self as formed by self-perception and perception of others. It consists of two components: the physical self which involves self-image and the personal and moral-ethical-spiritual self which involves self-expectancy. The mode is defined as the perception of groups based on environment and is comprised of relationships, group image, social interactions, and culture. Using the regulator and cognator subsystems, adaptation in this mode is through identity integrity (Roy &

Andrews, 1999). The PACQLQ has questions regarding emotional health of the caregiver (Juniper et al., 1996a).

Role Function Mode

This is defined as functional status and emphasizes the role or position that the person performs in society. Using the regulator and cognator subsystems, social integrity is achieved through the formation of expectations of self and expectations of behavior towards people in other positions. Primary, secondary, and tertiary roles are observed through instrumental and expressive behavior. The primary role determines the behavior of the person during a time period and is influenced by age, sex, and developmental stage such as being an adult female. The secondary role is an extension of the primary role and is associated with task completion such as being a wife, mother, and registered nurse. The tertiary role is an extension of the secondary role and is associated with meeting role obligations during a temporary time such as being part of an organization (Roy & Andrews, 1991; Roy & Andrews, 1999). The sociodemographic questionnaire will inquire about parenting role, family role, and job role.

Interdependence Mode

This is defined as the development and maintenance of significant relationships and support system of the person. Using the regulator and cognator subsystems, relational integrity is achieved through receptive and contributive behavior such as giving and receiving love, respect, knowledge, time, and other variables (Roy & Andrews, 1999). The sociodemographic questionnaire will inquire about family and social support as well as possibly coping.

Used in the context of asthma in school-children, this theory describes the children and their caregivers as holistic, biopsychosocial persons who are required to adapt to environmental stimuli such as asthma severity and sociodemographic factors (Roy & Andrews, 1999). Focal stimuli are represented by the child's asthma and asthma characteristics. Contextual stimuli are represented by sociodemographic factors such as location of home, health care access, and social support. Residual stimuli are represented by other unknown factors such as level of cognitive development and mental health of the caregiver. The caregivers use cognator and regulator activities to adapt through each of the four modes. Adaptation through the physiologic-physical, self-concept-group identity, role function, and interdependence modes will be represented in Juniper's PACQLQ (1996a) and the sociodemographic questionnaire. The goal in this study is to understand adaptation through the parent's point of view via a questionnaire and to observe the interlacing of the four modes as shown through quality of life (Roy & Andrews, 1999).

Assumptions of This Study

Using Roy's Adaptation Model to guide this study, the following assumptions were made:

1. Environmental stimuli (e.g., severity of illness, sociodemographic characteristics) influence biopsychosocial responses (e.g., caregiver quality of life, caregiver perception of asthma severity).
2. The four adaptive modes are interrelated.

Research Questions

1. What is the relationship between asthma severity and caregiver's quality of life?

2. What sociodemographic factors influence caregiver's quality of life?
3. Does physician-diagnosed asthma severity differ from parental perception of asthma severity?

CHAPTER 4

METHODOLOGY

This study examines the effects of the child's asthma severity and parental sociodemographic factors on parental quality of life and parental perception of asthma severity. With the data, three relationships were examined: (1) the child's asthma severity and parental quality of life and (2) parental sociodemographic factors and parental quality of life, and (3) physician-diagnosed asthma severity and parental perception of asthma severity. This chapter discusses the topics of research design, sample, data collection, and data analysis used in this study.

Research Design

This is a descriptive, cross-sectional study. Independent variables include asthma severity and sociodemographic factors. Dependent variables include the parent's quality of life and parent perception of asthma severity. The data will be collected through three self-report questionnaires at one time period in the study using a convenience sample.

Definition of Terms

Asthma Severity

Asthma severity in this study is classified according to the National Asthma Education and Prevention Program guidelines and categories include intermittent asthma, mild persistent asthma, moderate persistent asthma, and severe persistent asthma (2007). According to the NAEPP, asthma severity is defined as the intrinsic intensity of asthma

in those not using long-term asthma medications. This is differentiated from asthma control which is defined as the degree of asthma manifestations that are minimized through the use of an asthma management plan. The program categorizes patients based on impairments such as symptoms, nighttime awakenings, short acting beta2-agonist use for symptom control, interference with normal activity, and lung function. The categories are further divided into the following age ranges: 0-4 years, 5-11 years, and 12 years of age and above (NAEPP, 2007). Since this study involves the parents of children ages 7 to 17 with asthma, the last two age categories (i.e., 5-11 years and 12 years and above) will be described. Lung function via the use of spirometry and physician-diagnosed asthma severity will be utilized in this study as made available by the clinic medical records. In this study, asthma severity as described by the parents through symptom complaints will be measured by an NAEPP-based questionnaire.

Intermittent Asthma

Children ages 5-11 years with intermittent asthma experience symptoms ≤ 2 days a week, nighttime awakenings ≤ 2 times a month, no interference with normal activity, and short-acting beta2-agonist use for symptom control ≤ 2 days a week. Lung function shows normal FEV1 (forced expiratory volume in one second) between exacerbations, $FEV1 > 80$ percent predicted, and $FEV1/FVC$ (forced expiratory volume in one second/forced vital capacity) > 85 percent. Children 12 years of age and above with intermittent asthma experience symptoms ≤ 2 days a week, nighttime awakenings ≤ 2 times a month, no interference with normal activity, and short-acting beta2-agonist use for symptom control ≤ 2 days a week. Lung function shows normal FEV1 between exacerbations, $FEV1 > 80$ percent predicted, and normal FEV1/FVC (NAEPP, 2007).

Mild Persistent Asthma

Children ages 5-11 years with mild persistent asthma experience symptoms >2 days a week but not daily, nighttime awakenings 3-4 times a month, minor interference with normal activity, and short-acting beta2-agonist use for symptom control > 2 days a week but not daily. Lung function shows FEV1 > 80 percent predicted and FEV1/FVC > 80 percent. Children 12 years of age and above with mild persistent asthma experience symptoms > 2 days a week but not daily, nighttime awakenings 3-4 times a month, minor interference with normal activity, and short-acting beta2-agonist use for symptom control > 2 days a week but not > 1 time daily. Lung function shows FEV1 > 80 percent predicted and normal FEV1/FVC (NAEPP, 2007).

Moderate Persistent Asthma

Children ages 5-11 years with moderate persistent asthma experience symptoms daily, nighttime awakenings > 1 each week but not nightly, some interference with normal activity, and daily short-acting beta2-agonist use for symptom control. Lung function shows FEV1 > 60-80 percent predicted and FEV1/FVC > 75-80 percent. Children 12 years of age and above with mild persistent asthma experience symptoms daily, nighttime awakenings > 1 each week but not nightly, some interference with normal activity, and daily short-acting beta2-agonist use for symptom control. Lung function shows FEV1 > 60 percent but < 80 percent predicted and FEV1/FVC > reduced 5 percent (NAEPP, 2007).

Severe Persistent Asthma

Children ages 5-11 years with severe persistent asthma experience symptoms throughout the day, nighttime awakenings 7 times per week, extremely limited activity,

and short-acting beta2-agonist use for symptom control several times per day. Lung function shows FEV1 < 60 percent predicted and FEV1/FVC < 75 percent. Severe persistent asthma experience symptoms throughout the day, nighttime awakenings 7 times per week, extremely limited activity, and short-acting beta2-agonist use for symptom control several times per day. Lung function shows FEV1 < 60 percent predicted and FEV1/FVC reduced > 5 percent (NAEPP, 2007).

Quality of Life

Quality of life can be defined as general satisfaction with everyday living (Vila et al., 2003). Quality of life is related to health status which is defined by the World Health Organization (WHO) as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (2006, p. 1). In this study, caregiver quality of life was measured by the PACQLQ which consists of 13 items which represent activity limitations and emotional burden in response to caring for a child with asthma.

Sociodemographic Factors

Sociodemographic factors include variables that identify the person as belonging to a particular social or demographic group. Examples include age, sex, race, education level, annual income, marital status, health insurance coverage, and other factors. In this study, sociodemographic factors were measured in a questionnaire.

Parent or Caregiver

The parent or caregiver is the biological parent, adoptive parent, stepparent, legal guardian, foster parent, or adult who lives with the child and provides physical (i.e., food, water, shelter, and transportation) and emotional support (i.e. love and comfort) to the child. In this chapter, parents and participants are used interchangeably.

School-Aged Child

A school-aged child in this study is a person from the age range of 7 to 17.

Sample Size and Power Calculation

The study design consisted of parents of children with mild intermittent to severe persistent asthma. Participants were recruited from the Children's Lung Specialists, a pediatric pulmonology outpatient clinic located in Las Vegas, Nevada and managed by Dr. Craig Nakamura and Dr. Munawar Saeed. The data collection period took place from August 2008 to February 2009. Based on Cohen's (1988) estimation of medium effect size ($f=0.25$), power=80%, and $\alpha=0.05$, for correlational studies, the sample size should be set at $N=83$. The target sample size for this study was 100.

Sample Selection

Consisting of a convenience sample, the study participants were parents of children ages 7-17 with asthma, who had scheduled an appointment at this pulmonology office. Parents of children from ages 7-17 were chosen because the PACQLQ has been validated for use in children from ages 7-17 by the authors of the questionnaire (Juniper, 1996a) and few studies exist that use the PACQLQ below age 7 (Osman et al., 2001). This population was chosen for several reasons: Since this is a large pediatric pulmonology clinic in Las Vegas, most pediatric patients who need medical care from a pulmonologist are referred to this clinic by their pediatrician or other primary health care provider. The clinic sees a variety of patients in terms of asthma severity (i.e. mild, moderate, severe) and sociodemographic factors (i.e. health insurance coverage, parental age and race, and other variables). In addition, all pediatric patients who see Dr. Nakamura or Dr. Saeed

are required to go to the appointment with a parent or caregiver. This population was chosen since it would be representative of asthmatic children in Las Vegas.

Potential participants were approached as they came into the pediatric pulmonology clinic for their scheduled appointments. While the patients and their parents were in the waiting room, the researcher reviewed the patient's chart to verify the diagnosis of asthma and age of the child. The parents of the patients were then approached by the researcher and asked if they would like to participate in the study. If they agree to participate, they will be asked (1) Has your child been diagnosed with asthma? (2) How old is your child? (3) How are you related to the child? In order to qualify for the study, the parents must have responded to the questions: (1) Yes, (2) Between the ages of 7 to 17 years old, and (3) Biological parent, adoptive parent, stepparent, legal guardian, foster parent, or adult who lives with the child. All participants were informed of the purpose and procedures of the study and were given both verbal and written informed consent information which emphasized voluntary participation and confidentiality. The participants were given a copy of the study purpose and informed consent (Appendix A).

Inclusion and Exclusion Criteria

Inclusion criteria included: (1) the patients were between ages of 7 through 17, (2) the patients are medically diagnosed with asthma, (3) the parent or caregiver is the biological parent, adoptive parent, stepparent, legal guardian, foster parent, or adult who lives with the child, (4) the patients (assent) and parents (consent) are willing to participate in the study, and (5) the parents speak English. Exclusion criteria included the patient having a diagnosis of other chronic conditions such as cardiovascular, renal, gastrointestinal, neurological, metabolic, and other diseases. Specific examples include depression,

cerebral palsy, diabetes, hypothyroidism, and cancer. Since most children with asthma concurrently suffer from atopic conditions such as eczema, allergies, and rhinoconjunctivitis, for the purpose of this study, these were not labeled as a chronic condition (Lack, 2001; Su, Kemp, Varigos, & Nolan, 1997; Reichenberg & Broberg, 2001).

Instrumentation

The research instrument used in this study is the Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) which was used to measure the physical and emotional limitations experienced by the caregiver in caring for the child with asthma (Juniper et al., 1996a). Two other questionnaires presented to participants included asthma severity of the child and sociodemographic factors.

Paediatric Asthma Caregiver Quality of Life Questionnaire (PACQLQ)

Permission was granted by Professor Elizabeth Juniper to use the PACQLQ for this study (see Appendix B). Developed by Juniper and colleagues (1996a), the Paediatric Caregiver's Quality of Life Questionnaire (PACQLQ) is a 13-item questionnaire measuring activity limitation and emotion that has been regularly utilized to measure the burden parents experience in caring for a child (ages 7 to 17) with asthma. The questionnaire contains four items that address activity limitations and nine items addressing emotional function. An example of an activity limitation question is "During the past week, how often did your child's asthma interfere with your job or work around the house?" An example of an emotional function question is "During the past week, how often were you bothered because your child's asthma interfered with family relationships?" Parents respond to this questionnaire using a 7-point scale where 1

represents severe impairment while 7 represents no impairment. Each of the 13 items are weighed equally and results are expressed as a mean score for each domain (activity limitation and emotional function) and for overall quality of life. The PACQLQ scores will be categorized into mean activity limitation scores (i.e. questions 2, 4, 6, and 8), mean emotional scores (i.e., questions 1, 3, 5, 7, 9, 10, 11, 12, and 13), and mean scores of the total questionnaire (Juniper et al., 1996a). The parents of asthmatic children completed the questionnaire in the waiting room of the pulmonology clinic.

The questionnaire has been studied to be both reliable and responsive with moderate validity. To test for responsiveness, the PACQLQ was used to measure longitudinal change in the parents and longitudinal construct validity. To test for reliability, the PACQLQ was used to measure the ratio of differences between subjects to difference within subjects and also tested for cross-sectional construct validity. Results showed that the PACQLQ was able to detect quality of life changes in caregivers over time ($p < 0.001$) and detect stability in those who did not change ($p < 0.0001$). The PACQLQ is reproducible in stable subjects (intraclass correlation coefficient = 0.84) (Juniper et al., 1996a).

Asthma Severity Questionnaire

Several studies in the literature review have cited asthma severity impacting caregiver quality of life (Juniper et al, 1996a; Halterman et al., 2004; Osman et al., 2001; Williams et al., 2000; Reichenberg and Broberg, 2000). This questionnaire asked questions in order to categorize the child's asthma severity according to the National Asthma Education and Prevention Program's classification guidelines (see Appendix C). Categories set by NAEPP (2007) include intermittent asthma, mild persistent asthma,

moderate persistent asthma, and severe persistent asthma. This categorization was labeled “researcher rating” of asthma severity. Questions such as the amount of days missed from school, the amount of days spent in the emergency room or hospitalized, as well as parental perception of asthma severity and control were asked. The questionnaire does not ask about lung function measures. However, spirometry readings, including FEV1 and FEV1/FVC, will be obtained from the child’s medical records in order to further categorize the child’s asthma severity based on the NAEPP guidelines. Additionally, participants will be asked about medication use within the past week to verify asthma severity based on NAEPP guidelines for severity-specific treatment.

Sociodemographic Factors Questionnaire

Several studies in the literature review indicate several demographic variables including being a minority, being from a low-income family, and living in the inner-city as being associated with morbidity and mortality in the asthmatic child (Akinbami & Schoendorf, 2002; Crain et al., 1994; Lang & Polansky, 1994; Litonjua et al., 1999; Aligne et al., 2000). This questionnaire asked questions regarding age, race, income, education level, place of residence, employment, health insurance coverage, social support, and other variables (see Appendix D).

Procedures

Data collection was conducted at the time participants agree to take part in the study. This process continued until 101 participants were obtained.

Human Subjects Review Consideration

The study, Asthma Severity in School-Children and the Quality of Life of Their Parents, will be approved by the University of Nevada, Las Vegas’ Institutional Review

Board (IRB). Participants who agreed to enter the study were given verbal and written informed consent information (ICD) about the study purpose and procedures by the researcher. They were given a copy of the study purpose and informed consent. To keep confidentiality of the participants, participants were assigned numbers and participant names or any other identifying information such as address, telephone number, or birth date were not recorded. The parents returned the questionnaires to the researcher in an unmarked manila envelope to ensure confidentiality. The compilation of data in this manner makes it impossible to identify individual participants after data collection is completed. All data will be stored in a locked file cabinet in the researcher's office and will be destroyed after a period of 3 years.

Method of Data Collection

While the patients and their parents were in the waiting room, the researcher reviewed patient's chart to verify the diagnosis of asthma and age of the child. The parents of the patients were then be approached by the researcher and asked if they would like to participate in the study. If they agreed to participate, they were asked (1) Has your child been diagnosed with asthma? (2) How old is your child?, (3) How are you related to the child? In order to qualify for the study, the parents must respond to the questions: (1) Yes, (2) Between the ages of 7 to 17 years old, and (3) Biological parent, adoptive parent, stepparent, legal guardian, foster parent, or adult who lives with the child. All participants were informed of the purpose and procedures of the study and were given both verbal and written informed consent information which emphasized voluntary participation and confidentiality. A copy of the study purpose and informed consent were given to the participants. The researcher gave the parent three questionnaires: (1) the

PACQLQ, (2) the asthma severity questionnaire, (3) and the sociodemographic factors questionnaire.

Participants received explicit instructions on how to answer each item of the questionnaire. They were also told to respond to each item honestly and that there is no right or wrong answer. If participants had questions after they started responding to the questionnaire, they were told to choose the answer that they most strongly agree with and they did not have to respond to questions they feel they are not comfortable answering. To keep confidentiality of the participants, participants were assigned numbers and participant names or any other identifying information such as address, telephone number, or birth date are not recorded. Each of the three questionnaires were marked with correlating numbers to match the questionnaires to each other. For example, participant #27 was given three questionnaires all marked #27 to allow for comparison of data during the data analysis portion of the study. The parents were instructed to return the questionnaires to the researcher in an unmarked manila envelope to ensure confidentiality.

Response Rates

A total of 114 parents who met the study criteria were invited to participate in the study. Ten parents were not interested in participating in the study, two parents did not meet inclusion criteria, and one parent did not return the survey back to the researcher. Out of the original 114 parents invited, a total of 101 parents (88.59%) participated in the study.

Data Analysis

Data entry and analysis were performed utilizing the Statistical Package for the Social Sciences (SPSS), Version 17.0, a software program for all statistical analysis. To assess the relationship between asthma severity and caregiver quality of life, Spearman's correlation (ρ), analysis of variance (ANOVA), and linear and multivariate regression were performed to analyze the data. To determine the relationship between sociodemographic factors and caregiver quality of life, Spearman's correlation (ρ), Chi-square, and independent t-tests were performed. To assess the relationship between medically-diagnosed asthma severity and parental perception of asthma severity, descriptive statistics, Kendall tau rank correlation coefficient, and Chi-square were performed with the data.

Descriptive analysis using frequency distributions, percentages, and measures of central tendencies were performed for the following variables: age, sex, marital status, ethnicity, zip code, hours worked per week, annual income, days missed from work in the past year due to the child's asthma, number of people living in the household, number of children the parent has, number of children with asthma, age of child, sex of child, length of time child has been diagnosed with asthma, asthma symptoms (day and night) during the past month, rescue inhaler use during the past month, number of times the child has been brought to the ER, number of times the child has been hospitalized, number of days of school missed due to the child's asthma, and parental rating of their asthmatic child. It was expected that demographic factors, which showed predictive utility in previous studies, would also show significant findings in this study.

Based on previous studies, it was hypothesized that (1) asthma severity based on symptoms rather than spirometry readings would affect parental quality of life (Juniper et al., 1996a, Osman et al., 2001; Reichenberg and Broberg, 2001; Williams et al., 2000; Juniper et al., 1995; Rutten-van Molken et al., 1995; Rowe & Oxman, 1993; Leidy & Coughlin, 1998), (2) demographic variables expected to be associated with lower PACQLQ scores included parents who are minority, living in inner-city areas, and have low educational attainment and annual income (Mansour et al., 2000; Osman, 2001; Halterman, 2004; Erickson et al., 2002; Chen & Escarce, 2008), and (3) parental perception of asthma severity would not coincide with medically-diagnosed asthma severity (Dozier et al., 2006; Moonie et al., 2005).

CHAPTER 5

RESULTS

Demographic Characteristics

A total of 114 parents who met the study criteria were invited to participate in the study. Ten parents were not interested in participating in the study, two parents did not speak English, and one parent did not return the survey back to the researcher. Out of the original 114 parents invited, a total of 101 parents (88.59%) participated in the study. All participants scored all items on the questionnaires and there were no uncertainties with wording or interpretation of the questions. See Table 1 and 2 for demographic characteristics of both the asthmatic child and caregiver.

The mean age of the asthmatic children was 10.26 (n=101). About 55.4% were male and 44.6% were female. The mean length of diagnosis with asthma was 6.49 years. The mean number of emergency department visits within the past 12 months was 1.01 times, the mean number of hospitalizations within the past 12 months was .25 times, and number of school days missed within the past 12 months was 5.85 days. Using the NAEP guidelines on the questionnaire to categorize the children by asthma severity (i.e., daytime symptoms, nighttime symptoms, exercise symptoms, and use of rescue inhaler), the researcher grouped the children: Of the 101 children, 36.6% (n=37) had mild intermittent asthma, 18.8% (n=19) had mild persistent asthma, 29.7% (n=30) had moderate persistent asthma, and 14.9% (n=15) had severe persistent asthma. Parents

rated their children's asthma as follows: 48.5% (n=49) had mild asthma, 33.7% (n=34) had moderate asthma, and 16.8% (n=17) had severe asthma. See Table 9 for details. Most parents (74.3%, n=75) felt their child's asthma was under control. About 95% of parents drove their own automobile to the clinic.

About 89.1% of parents stated English was their primary language while 4% stated Spanish, 5.9% stated both English and Spanish, and 1% stated other. About 38.6% of the caregivers in the study were medically diagnosed with asthma and 73.3% had a family history of asthma. Of the caregivers in the study, 20.8% were male and 79.2% were female. The mean age of the caregivers was 39.34 with 11.9% being ≤ 30 and 87.1% being >30 . About 9.9% of parents smoked. About 12.9% state they were single, 64.4% state they were married, 18.8% state they were separated/divorced, and 4% stated they were living with a significant other. About 58.4% stated they were White or Caucasian, 20.8% stated they were Hispanic or Latino, 15.8% stated they were Black or African, and 5% stated they were other. About 75.2% of the caregivers identified themselves as the mother, 18.8% as the father, 3% as grandparents, and 3% as guardians. About 32.7% had some high school education, 58.4% had some college education, and 8.9% have completed graduate school and beyond. About 69.3% of the parents were employed. For those who were employed, about 24.5% worked <40 hours a week while 42.1% worked ≥ 40 hours a week. For those who were employed, 15.8% make less than \$30,000 a year, 18.8% make \$30,000 to \$45,000 a year, 10.9% make \$45,000 to \$60,000 a year, 9.9% make \$60,000 to \$75,000 a year, and 12% make greater than \$75,000 a year. The mean number of days missed from work in the past 12 months due to their child's asthma was 4.46 days. About 5% had no insurance, 16.8% had Medicaid, and 78.2% had private

insurance. About 86.1% of parents stated they are able to pay for their child's asthma-related health care expenses. About 68.3% own their home and 29.7% rent their home. The mean number of people living in the home was 3.67 and the mean number of children the caregivers had was 2.63. About 88.1% of caregivers felt they had family or friends to turn to when they needed support.

Asthma Severity and Caregiver Quality of Life

To assess the relationship between asthma severity and caregiver quality of life, Spearman's correlation (ρ), analysis of variance (ANOVA), and linear and multivariate regression were performed. Using the PACQLQ in this current study, the Cronbach alpha coefficient reported .89 of the total score which suggests good internal consistency.

Before performing any correlation analysis on the data, scatterplots were generated and checked for violation of assumptions of normality, linearity, and homoscedasticity. Spearman's correlation (ρ) was used to determine if a correlation exists between asthma severity and caregiver quality of life. A significant negative correlation was found between overall asthma severity, based on the NAEPP guidelines, and mean activity limitation scores ($\rho = -.400, p < .001$), mean emotional function scores ($\rho = -.258, p < .001$), and mean total of PACQLQ scores ($\rho = -.342, p < .001$). A significant moderate, negative correlation was found between PACQLQ scores (mean total, mean activity limitation, and mean emotional function) and asthma day symptoms, asthma night symptoms, and asthma exercise symptoms. A significant moderate, negative correlation was found between asthma rescue inhaler use and activity limitation ($\rho = -.309, p < .001$). This means the higher the asthma severity rating of the patient, the lower the PACQLQ scores are (i.e., 1 means "all the time" or "very, very worried/concerned"

while 7 means “none of the time” and “not worried/concerned”) indicating the parents experience decreased quality of life. Increased asthma day symptoms, increased asthma exercise symptoms, increased asthma night symptoms, and increased asthma inhaler use were associated with lower PACQLQ scores (i.e., mean total, activity limitation, emotion) indicating the parents experience decreased quality of life. No significant relationship was found between pulmonary function testing (PFT) scores and PACQLQ scores. No significant relationship was found between current medication use, based on the NAEPP’s severity-specific treatment, and PACQLQ scores. See Table 3 for details.

A significant moderate, negative correlation was found between PACQLQ scores (mean total, mean activity limitation, and mean emotional function) and emergency room visits in the past year, number of hospitalizations in the past year, parental perception of asthma severity, number of days of school missed in the past year, and work days missed in the past year. This means increased emergency room visits, increased hospitalizations, parental perception of increased or worse asthma severity, increased number of school days missed, and increased number of workdays missed were associated with lower PACQLQ scores (i.e., mean total, activity limitation, emotion) indicating the parents experience decreased quality of life. See Table 3 for details.

Using analysis of variance (ANOVA), a comparison of the mean PACQLQ scores of each asthma severity group was made. Subjects were divided based on asthma severity rating (i.e., mild intermittent, mild persistent, moderate persistent, and severe persistent) according to the NAEPP guidelines. The assumption of homogeneity of variance was not violated in performing the ANOVA for statistical analysis. Using ANOVA to compare overall PACQLQ scores, there was a statistical significance in overall PACQLQ scores

for the four asthma severity groups: $F(2, 101) = 4.942, p = .003$. Despite statistical significance, the actual difference in mean scores between the groups was quite small. The effect size, calculated using eta squared, was .132. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for the mild intermittent group ($M=5.25, SD=1.18$) was significantly different from the moderate persistent group ($M=4.31, SD=1.21$). The mild intermittent group ($M=5.25, SD=1.18$) was significantly different from the severe persistent group ($M=4.11, SD=1.49$). The mild persistent group did not differ significantly from the mild intermittent, moderate persistent, and severe persistent groups.

Using ANOVA to compare activity limitation scores, there was a statistical significance in overall PACQLQ scores for the four asthma severity groups: $F(3, 101) = 7.56, p = .0005$. Despite statistical significance, the actual difference in mean scores between the groups was quite small. The effect size, calculated using eta squared, was .189. Post-hoc comparisons using the Tukey HSD test indicated the mean score for the mild intermittent group ($M=5.37, SD=1.31$) was significantly different from the moderate persistent group ($M=4.02, SD=1.75$). The mild intermittent group ($M=5.37, SD=1.31$) was significantly different from the severe persistent group ($M=3.55, SD=1.91$). The mild persistent group ($M=5.13, SD=1.25$) was significantly different from the severe persistent group ($M=3.55, SD=1.91$).

Using ANOVA to compare emotional function scores, there was a statistical significance in overall PACQLQ scores for the four asthma severity groups: $F(3, 101) = 2.855, p = .041$. Despite statistical significance, the actual difference in mean scores between the groups was quite small. The effect size, calculated using eta squared, was

.08. Post-hoc comparisons using the Tukey HSD test indicated no significant differences between any of the four groups of asthma severity.

Parents of children with mild intermittent asthma had a mean total PACQLQ score of 5.25, those with mild persistent scored 4.82, those with moderate persistent scored 4.31, and those with severe persistent scored 4.11. Parents of children with mild intermittent asthma had a mean activity limitation PACQLQ score of 5.37, those with mild persistent scored 5.13, those with moderate persistent scored 4.02, and those with severe persistent had a score of 3.55. Parents of children with mild intermittent asthma had a mean emotion PACQLQ score of 5.20, those with mild persistent scored 4.68, those with moderate persistent scored 4.43, and those with severe persistent scored 4.36. See Table 4 for details. It is shown here parents of children with mild intermittent asthma had higher mean PACQLQ scores (i.e., mean total, mean activity limitation, and mean emotion), followed by those with mild persistent asthma, followed by those with moderate persistent asthma, and lastly, those with severe persistent asthma who had the lowest PACQLQ scores (i.e., mean total, mean activity limitation, and mean emotion).

Univariate linear regression was used to determine what asthma severity factors and sociodemographic factors predict caregiver quality of life scores. Prior to performing linear regression, the data set was assessed for multicollinearity, singularity, outliers, normality, linearity, homoscedasticity, and independence of residuals. Predictors of better quality of life included increased income. Predictors of worse overall quality of life included increased hospitalization days, increased ER visits, increased school days missed, and increased work days missed. The following variables were not significant in predicting PACQLQ scores (i.e., mean total PACQLQ score, mean activity limitation

score, and mean emotion score): patient age, patient's length of asthma diagnosis, parent age, parent level of education, and employment hours. See Table 5 for details. Using multiple linear regression, the significant variables found in the univariate linear regression (i.e., income, ER visits, hospitalization days, school days missed, and work days missed) were further tested. Significance was found between ER visits and mean total PACQLQ scores, mean activity limitation scores, and mean emotional function scores. Significance was also found between mean activity limitation scores and work days missed (Beta = -.069, $p < .043$, $r^2 = .317$). The other variables (income, ER visits, hospitalization days, school days missed, and work days missed) did not show any significance. See Table 6 for details. More advanced statistical analysis on demographic information was possible to specifically test race, income, and location of home. However, it was not feasible at this time.

Sociodemographic Factors and Caregiver Quality of Life

To determine the relationship between sociodemographic factors and caregiver quality of life, Spearman's correlation (ρ), Chi-square, and independent t-tests were performed. According to Information Specialist for the Health Resources and Services Administration Lore McClain (personal communication, February 10, 2009), Medically Underserved Areas (MUAs) or Medically Underserved Populations (MUPs) are geographically divided by Census Bureau-defined areas, not U.S. Postal Service's zip codes. Because Census Bureau geography does not correlate with zip codes according to McClain, the zip codes obtained through the questionnaires were unable to be analyzed to determine if the patient and parent live in a MUA/MUP and if they live in an urban or rural area.

Spearman's correlation (ρ) was used to determine if a correlation exists between sociodemographic factors and caregiver quality of life. Before performing any correlation analysis on the data, scatterplots were generated and checked for violation of assumptions of normality, linearity, and homoscedasticity. A significant positive correlation was found between employment income and mean activity limitation scores (moderate correlation, $\rho = .363$, $p < .001$), mean emotional function scores (small correlation, $\rho = .291$, $p < .05$), and mean total of PACQLQ scores (moderate correlation, $\rho = .346$, $p < .001$). This means increased income is associated with higher PACQLQ scores (i.e., 1 means "all the time" or "very, very worried/concerned" while 7 means "none of the time" and "not worried/concerned") indicating the parents experience increased quality of life. No significant relationships were found between PACQLQ scores (i.e. mean total scores, mean emotion scores, and mean activity limitation scores) and the following factors: patient age, number of years patient had been diagnosed, parent age, employment hours, and number of people or children living in the household who do or do not have asthma. See Table 3 for details.

Chi-square for independence was used to explore the relationship between sociodemographic factors and caregiver quality of life. Prior to performing Chi-square on the data, at least 80% of cells had expected frequencies of 5 or more. Significant relationships were found between mean PACQLQ scores and family history of asthma ($\chi^2 = 7.684$, $p = .021$), marital status ($\chi^2 = 6.959$, $p = .031$) and caregiver perception of asthma control ($\chi^2 = 9.384$, $p = .009$). No significant differences were found in mean PACQLQ scores and the following variables: patient sex, caregiver rating of asthma severity, language, owning a car, parent diagnosis of asthma, parent sex, parent smoking

in the home, Hispanic or Latino ethnicity, Black or African ethnicity, how parent is related to child, presence of employment, education level, other people contributing to household expenses, childcare, health insurance, owning a home, and social support. Most caregivers who did not have a family history of asthma (70.4%), were married or living with a significant other (62.3%), and perceived their child's asthma as under control (57.3%) had mean PACQLQ total scores from 4 to 5. (Again, reviewing PACQLQ total scores, 1 means "all the time" or "very, very worried/concerned" while 7 means "none of the time" and "not worried/concerned"). Most caregivers who were single, divorced, or widowed (40.6%) and did not perceive their child's asthma as under control (50%) had mean PACQLQ total scores from 1 to 3. Most caregivers who had a family history of asthma (40.3%) had mean PACQLQ total scores from 4 to 5. See Table 7 for details. This means a large percentage of caregivers who are single, divorced, or widowed; did not perceive their child's asthma as under control; and had a family history of asthma had lower mean total PACQLQ scores which indicate poorer caregiver quality of life.

Independent t-tests were performed to compare the mean PACQLQ scores between two different groups of subjects (i.e. male versus female, owning a home versus renting, and other groups). Prior to performing the data analysis, the sample was checked for normal distribution, homogeneity of variance, independence of observations, and level of measurement. A significant difference in scores was found for Black or African ethnicity, owning a car, ability to pay for health costs, owning a home, and caregivers perceiving their child's asthma as under control. See Table 8 for details. Caregivers of patients who were not Black or African in ethnicity, owned a car, were able to pay health

costs, owned a home, and perceived their child's asthma as under control had higher mean PACQLQ total scores, mean activity limitation scores, and mean emotional function scores. No significant differences in scores were found for the following variables: presence of employment, family history of asthma, Hispanic or Latino ethnicity, others contributing to household expenses, presence of insurance coverage, Spanish being the primary language, others besides family living in the household, parent diagnosis of asthma, parent sex, parent smoking in the home, parent education, parent marital status, and presence of a support system.

Medically-Diagnosed Asthma Severity and Parental Rating of Severity

To assess the relationship between medically-diagnosed asthma severity and parental perception of asthma severity, descriptive statistics, Kendall tau rank correlation coefficient, and Chi-square were performed with the data. Due to the pulmonologists at this clinic not charting asthma severity with every patient examined, only 53 out of the 101 had a medically-diagnosed asthma severity rating. Because of the low number of diagnoses given regarding asthma severity, the relationship between physician diagnosis of asthma severity versus parental perception of asthma severity was chosen by the researcher to be analyzed by descriptive analysis. See Table 9 for details. Of the 53 diagnosed by the physician, 24.52% (n=13) had mild intermittent asthma, 33.96% (n=18) had mild persistent asthma, 28.30% had moderate persistent asthma (n=15), and 13.21% (n=7) had severe persistent asthma. Comparing the physician diagnosis of asthma severity with the parent's rating of asthma severity, it was found that 52.83% (n=28) both agreed on the asthma severity diagnosis. About 7.55% (n=4) of parents rated their child's asthma severity greater than the physician. About 39.62% (n=21) of physicians

diagnosed the child's asthma severity greater than the parents' ratings. Caution is needed in interpreting these particular variables since the sample size is small.

Using Kendall tau rank correlation coefficient, a significant positive correlation was found between researcher rating of asthma severity and caregiver rating of asthma severity ($\rho = .492, p < .01$). This means increased researcher rating also shows an increase in caregiver rating. No significant correlation was found between caregiver rating and PFT rating as well as researcher rating and PFT rating. See Table 10 for details.

Using Chi-square, no significant relationship was found between researcher rating and caregiver rating of asthma severity. (Again, researcher rating is defined as caregiver reports of asthma symptoms categorized into appropriate asthma severity based on NAEPP guidelines by the researcher). No significant relationship between researcher rating and caregiver perception of asthma control. Additionally, no significant relationship was found between caregiver rating and caregiver perception of asthma control.

CHAPTER 6

DISCUSSION

Several studies examined the influence of asthma severity and sociodemographic factors on caregiver quality of life and parental perception of asthma severity (Juniper et al., 1996a, Osman et al., 2001; Reichenberg and Broberg, 2001; Halterman et al., 2004; Dalheim-Englund et al., 2004, Osman et al., 2001; Chen and Escarce, 2008; Claudio et al., 2005). This study has contributed additional information to this current knowledge base. However, it is not without some limitations. In this chapter, a discussion of overall findings and application of Roy's Adaptation Model as well as strengths and limitations will be presented.

Discussion of Overall Findings

This study examined the effects of the child's asthma severity and parental sociodemographic factors on parental quality of life and parental perception of asthma severity. It also explored the level of agreement between medically-diagnosed asthma severity and caregiver rating of asthma severity. Based on previous studies, it was anticipated that asthma severity based on symptoms rather than spirometry readings would affect parental quality of life (Juniper et al., 1996a, Osman et al., 2001; Reichenberg and Broberg, 2001; Williams et al., 2000; Juniper et al., 1995; Rutten-van Molken et al., 1995; Rowe & Oxman, 1993; Leidy & Coughlin, 1998), demographic variables expected to be associated with lower PACQLQ scores included parents who are

minority, living in inner-city areas, and have low educational attainment and annual income (Mansour et al., 2000; Osman, 2001; Halterman, 2004; Erickson et al., 2002; Chen & Escarce, 2008), and parental perception of asthma severity would not coincide with medically-diagnosed asthma severity (Dozier et al., 2006; Moonie et al., 2005).

This study did support the idea of asthma severity rather than spirometry readings affecting caregiver quality of life. A significant negative correlation was found between overall asthma severity, based on the NAEPP guidelines, and mean activity limitation scores ($\rho = -.400, p < .001$), mean emotional function scores ($\rho = -.258, p < .001$), and mean total of PACQLQ scores ($\rho = -.342, p < .001$). Moderate, statistically significant correlations were found between quality of life as shown through the PACQLQ and asthma day symptoms, asthma night symptoms, asthma exercise symptoms, and rescue inhaler use. It also found moderate, statistically significant correlations between quality of life as shown through the PACQLQ and factors such as number of ER visits, days hospitalized, days missed from school, and days missed from work. As asthma severity and other asthma factors increased, PACQLQ scores decreased indicating poorer quality of life. Williams and colleagues (2000) found a negative correlation between PACQLQ scores for caregivers and their children's asthma severity scores using 7-item questionnaire on wheezing frequency, day and night symptoms, and other measures in the past four months ($r = -.39, P < .001$). Additionally, PACQLQ scores correlated negatively with the number of days missed from school in this study ($r = -.24, p < .001$). In caring for their child with asthma, caregiver's quality of life is affected through concerns for the disease process, availability of social support, treatments and access to medical

care, and the impression of the disease on daily activities in the home (Williams et al., 2000).

In this study, no significant relationship was found between pulmonary function testing (PFT) scores and PACQLQ scores. Reichenberg and Broberg (2001) found a negative correlation between asthmatic symptoms as recorded by a parental diary and PACQLQ scores (overall $\rho = -.637$, $p < .001$) but found no correlation between PACQLQ scores and peak expiratory flow rate (PEFR). Several other studies show weak to moderate correlation between PFTs and patient quality of life (Juniper et al., 1995; Rutten-van Molken et al., 1995; Rowe & Oxman, 1993; Leidy & Coughlin, 1998). This suggests that clinical measures may be useful in providing information regarding airway status but do not explain the functional and emotional status of the patient in their daily routine (Juniper, 1998).

Being grouped into asthma severity based on NAEPP guidelines, it was found each group showed statistically significant differences in PACQLQ scores. As asthma severity increased, mean PACQLQ scores of parents decreased indicating poorer quality of life ($df = 3$, $F = 7.56$, $p = .0005$, $\eta^2 = .189$). For example, parents of children with mild intermittent asthma reported higher PACQLQ scores (or better quality of life) than the other categories of asthma severity. This suggests that caregivers of children with a higher asthma severity require an increased level of care and thus, places activity restrictions and emotional responsibility on the caregiver.

This study did support the idea that sociodemographic factors do influence caregiver quality of life. Using univariate linear regression, it was significantly shown that predictors of better quality of life included increased income while predictors of worse

overall quality of life included increased hospitalization days, increased ER visits, increased school days missed, and increased work days missed. From the multiregression model, only increased ER visits significantly predicted worse overall quality of life. Halterman and colleagues (2004) showed in examining PACQLQ mean summary scores, predictors of better quality of life in their study included increased symptom-free days and the parent's perception that the child's asthma was under control. Their predictors of worse quality of life included Hispanic ethnicity, use of daily maintenance medication, and secondhand smoke exposure in the home. Erickson and colleagues (2002) found household income and caregiver's perceived severity of their child's asthma was a significant predictor in asthma-related quality of life based on PACQLQ scores. Annett and colleagues (2003) suggest parent scores of quality of life are more of a response to social, economic, and emotional burdens associated with the child's asthma than a response to asthma symptoms alone. These findings suggest sociodemographic factors in addition to asthma severity have potential to impact caregiver quality of life and support this current research study (Halterman, 2004).

Several studies have suggested prevalence and severity of asthma are associated with the Black and Hispanic population as well as poverty-related factors such as young maternal age, maternal cigarette smoking, low birth weight, and living in crowded conditions in the inner-city (Schwartz et al., 1990; Weitzman et al., 1990; Coultas et al., 1994). This study did support the idea that sociodemographic factors including minority status influence PACQLQ scores. Significant relationships were found between mean PACQLQ scores and family history of asthma, marital status, and caregiver perception of asthma control. Those with a family history of asthma; were single, divorced, or

widowed; and did not perceive their child's asthma as under control had lower PACQLQ scores. Using independent t-tests, a significant difference in scores was found for Black or African ethnicity, owning a car, ability to pay for health costs, owning a home, and caregivers perceiving their child's asthma as under control. Reviewing mean PACQLQ scores, caregivers of patients who were not Black or African in ethnicity [M=4.83, SD=1.58, $t(101) = -2.49, p < .01$ (two-tailed)], owned a car [M=4.73, SD=1.65, $t(101) = 4.73, p < .04$ (two-tailed)], were able to pay health costs [M=4.89, SD=1.58, $t(101)=3.77, p < .006$ (two-tailed)], owned a home [M=5.06, SD=1.48, $t(101)=3.67, p < .0005$ (two-tailed)], and perceived their child's asthma as under control [M=4.99, SD=1.18, $t(101)=3.86, p < .0005$ (two-tailed)] had higher PACQLQ scores indicating better quality of life. Osman and colleagues (2001) found that younger mothers, those from less affluent families, and those with increased socioeconomic deprivation scores (based on Carstairs deprivation scoring) had lower, or worse, PACQLQ scores. Dalheim-Englund and colleagues (2002) found place of residence, age of the child, and severity of the child's asthma had an impact on PACQLQ scores. These findings suggest that many factors in addition to asthma severity can influence caregiver quality of life.

Non-adherence to national guidelines for asthma care has been linked to poor patient outcomes (Piecoro, Potoski, Talbert, & Doherty, 2001). Due to the low number of medical diagnoses of asthma severity given to the children of parents surveyed in this study, the topic of comparing medical diagnosis of asthma severity to parental rating of asthma severity could not be adequately analyzed. Reviewing the findings of Cabana and colleagues (1999, 2000), the low number of diagnoses and severity-specific care plans may be explained by physician's "lack of familiarity, awareness, agreement, self-

efficacy, outcome expectancy, lack of training, and ability to overcome inertia of previous practice” (Moonie et al., 2005, p.281). Physician estimates of asthma severity often determine subsequent asthma care and if patients are inappropriately diagnosed in terms of severity, this can lead to inadequate symptom control including the underuse of long-term controller medications and self-management measures such as home peak flow use and seeking education (Wolfenden et al., 2003). Despite the low number of physician-based asthma diagnoses of asthma severity, the researcher was still able to compare researcher rating (caregiver reports of asthma symptoms categorized into appropriate asthma severity based on NAEPP guidelines) and caregiver rating of asthma severity. A significant moderate correlation was found between the two ($\rho = .492, p < .01$) which indicates an increase in asthma severity based on researcher rating also shows an increase in asthma severity based on caregiver rating. This suggests as more severe symptoms of asthma appear (i.e., increased day symptoms, night symptoms, exercise symptoms, or rescue inhaler use), parents are more likely to observe its interference on activities and emotions (quality of life) and thus, rate their child’s asthma as more severe.

Utilizing Roy’s Adaptation Model as a guide, this study has displayed that environmental stimuli (e.g., asthma severity and sociodemographic characteristics) do influence biopsychosocial responses (e.g., caregiver quality of life and caregiver perception of asthma severity as shown through PACQLQ scores). Additionally, it has shown that the four adaptive modes (physiologic-physical, self-concept-group identity, role function, and interdependence modes) are interrelated. With the parent and asthmatic child portrayed as holistic, changing systems, they must interact with their environment to achieve a state of adaptation. This study showed each parent and child

are faced with various environmental stimuli everyday. However, particular stimuli such as asthma day symptoms and income, for example, exist which have potential to produce a greater influence on their biopsychosocial responses (or PACQLQ scores) than other variables (Roy & Andrews, 1999).

Strengths

Type of Study and Data Collection

One of the strengths of this study is the close timing of actual events and the reporting of them in the questionnaires. The PACQLQ and asthma severity questionnaire asks questions within the past week and past month, respectively. Since parents would better remember important events related to their child's asthma within these time frames, this reduced the risk of recall error and improved accuracy of reporting the data (Reichenberg and Broberg, 2001). Additionally, the asthma severity questionnaire and sociodemographic questionnaire were formatted in a way to allow parents to quickly understand and complete the questionnaire. The parents were allowed to complete the questionnaires in the waiting room which allowed sufficient time prior to seeing the pulmonologist. Additionally, by excluding children with chronic disorders, this eliminated the chance of type I error.

Standardized Measurement Tool

The PACQLQ has been studied to be both reliable and responsive with moderate validity (Juniper et al., 1996a) which strengthened the results obtained. Many studies have used the PACQLQ showing reliability and validity (Osman et al., 2001; Reichenberg and Broberg, 2001; Halterman et al., 2004; Dalheim-Englund et al., 2004). Please see Chapter 2 for more details. Additionally, the PACQLQ as a measurement tool

is easy to use and quick to complete which is practical in a busy outpatient clinic (Reichenberg and Broberg, 2001).

Limitations

Objective Measure of Asthma Severity

Results of pulmonary function testing were available in the children's medical records and provided one objective measure of asthma severity. However, in this study, there was no objective validation of parent-reported information of asthma severity as well as other information on the questionnaires since the researcher was only allowed limited access to the children's medical records. (The researcher only had access to spirometry readings, reason for visit, and patient age). However, several studies have shown parent questionnaires are adequate assessment tools for children's asthma. Sharek and colleagues (2002) performed a 52-week study of asthma outcomes in low-income children with moderate-to-severe asthma and found caregiver reports of symptoms had higher correlations with health care utilization and functional health status than diaries and PFTs. Hensley and colleagues (2003) found a parent-completed retrospective questionnaire of respiratory symptoms was consistent with past symptoms recorded by children and parents in a daily diary. The PACQLQ, asthma severity questionnaire, and sociodemographics questionnaire also do not take into account other life situations that the child or family may be experiencing that may influence answers to these questionnaires.

Study Design

The PACQLQ and asthma severity questionnaire only measured asthma symptoms from a fixed period of time, the preceding week for the PACQLQ and the preceding

month for the asthma severity questionnaire. Utilizing a cross-sectional study design provides a snapshot of the lives of children with asthma and their parents at a specific moment in time and thus, answers to the questionnaires could possibly have been different if a longer time period or a different time period (seasonal influence of certain types of asthma) were used (Dalheim-Englund et al., 2004; Reichenberg and Broberg, 2001). Patients and parents who saw the pulmonologist could have made an appointment for various reasons ranging from a routine asthma check-up to an asthma exacerbation which due to the cross-sectional design of the study, influence the answers to the questionnaires.

Generalizability

The relative sample size was small which decreased the power of the study and participants were enrolled from one pulmonology clinic in Las Vegas, Nevada. Additionally, 78.2% of parents had private insurance and 95% owned their own vehicle to drive the clinic which could influence results. Selection bias is a factor since some parents were more willing to participate in the study due to the manifestation of their child's asthma severity. Some pediatricians' offices may attempt to treat their asthmatic patients before referring them to a specialist such as a pulmonologist and the patients used in this study may have more severe asthma than the general pediatric asthma population. However, this particular pulmonology clinic was chosen for the study since it is a large pediatric pulmonology clinic, most pediatric patients who need medical care from a pulmonologist are referred to this clinic by their pediatrician or other primary health care provider, and the clinic saw a variety of patients in terms of asthma severity (i.e. mild, moderate, severe) and sociodemographic factors (i.e. health insurance

coverage, parental age and race, and other variables). Though the study results cannot be generalized to parents and children with asthma in other locations, it may extend to observations of asthmatic children in Las Vegas (Erickson et al., 2002).

CHAPTER 7

CONCLUSION AND RECOMMENDATION

Quality of life embodies physical, mental, and emotional aspects of a person's health and through this study, offers a holistic focus when reviewing the well-being of a caregiver and their asthmatic child (WHO, 2006). The evidence presented in this study supports the idea that numerous factors such as asthma severity and sociodemographic factors are capable of influencing caregiver quality of life. Not only is it the disease process of the child's asthma and its associated care which affects parents quality of life but also the parent's socioeconomic background and living environment. Developed by Juniper and colleagues, the PACQLQ is a valuable tool used to measure the quality of life of parents caring for children with asthma (Juniper et al., 1996).

Implications of Research to Nursing

Measuring parental quality of life allows nurse researchers to measure the burden parents experience in caring for their child in order to develop more effective asthma programs that emphasize adherence to medical treatment. This study is important to nursing study in that it provides a more holistic focus in reviewing the parent's quality of life, both in functional limitation and emotional dimensions. Taking the Roy Adaptation Model (RAM) into consideration, the effect of environmental stimuli such as the child's asthma severity and sociodemographic factors on biophysiological responses such as

parental quality of life and caregiver perception of asthma severity can be measured. This allows for further understanding in adaptation modes represented by separate questionnaires on quality of life and sociodemographics. Measuring parental quality of life will allow nurse researchers to assess the emotional as well as physical expenses parents experience in caring for their child and can help to develop more effective asthma programs that take these experiences into consideration (Haltermann et al., 2004). Quality of life is shown to be an important outcome measure and being aware of its effect on the individual is important for the successful medical care (Mahajan et al., 1998; Bender et al., 1998).

Directions for Future Research

This research study was conducted using a small sample size (n=101) and one pulmonology clinic in Las Vegas. However, it provides a sufficient contribution to the current knowledge base on the subject and offers a good stepping stone for future research studies on the topic. One area for future research could be to use a similar research design to test a larger number of participants and in multiple settings. In this particular study, it was shown a higher asthma severity rating was associated with poorer quality of life among parents and annual income was a significant predictor in quality of life scores. Examining a larger number of participants in different settings will allow assessment for study consistency.

Though the PACQLQ proves to be an effective tool in measuring the quality of life of parents caring for children with asthma, it allows researchers to measure only two characteristics of quality of life (i.e., activity limitation and emotional function) when in fact several other measures such as parent's own physical disabilities, coping abilities,

psychological health, family context, and other unknown factors may exist. Recent studies have suggested psychological factors and mental health of the parents influence PACQLQ scores and health care utilization for their asthmatic children (Vila et al., 2004; Goldbeck et al., 2007). Thus, another area of future research should be to examine other factors besides asthma severity and sociodemographic factors that may influence quality of life and also to determine if other measurement tools in addition to the PACQLQ provide a more comprehensive measure of quality of life.

Another area of future research is to take interventions into consideration when assessing parents for quality of life. For example, performing the PACQLQ questionnaires on parents before and after education regarding asthma or local resources such as government assistance may or may not show a difference in scores. Caregivers are responsible for many aspects of the child's care including symptom observation, medication administration, transportation to health care services, and medical decision-making. Measuring the burden parents experience in caring for their child can help to develop asthma programs that take these experiences into consideration which can be more effective in providing appropriate education, support, and resources to parents (Halterman et al., 2004).

Finally, another area for future research involves further assessment of physician and parent familiarity with the NAEPP guidelines. Specifically, research should focus on the relationship between appropriate diagnosis or rating by the physician and parent and the subsequent measure of quality of life of the parent. The low number of diagnoses and severity-specific care plans may be explained by physician's lack of experience, knowledge, understanding, motivation, and other characteristics (Moonie et al., 2005;

Cabana et al., 1999; Cabana et al., 2000). The care asthmatic patients receive is often determined by the accurate physician diagnosis of asthma severity. If patients are not diagnosed appropriately, this can lead to undertreatment of symptoms and underutilization of medications and assistance from the physician (Wolfenden et al., 2003).

APPENDIX A: UNLV INFORMED CONSENT



INFORMED CONSENT

Department of Nursing

TITLE OF STUDY: Asthma Severity in School-Children and the Quality of Life of their Parents

INVESTIGATOR(S): Dr. Patricia Alpert, DrPH, and Noelle Cerdan, RN, BSN

CONTACT PHONE NUMBER: 702-895-3810 (Dr. Patricia Alpert)

Purpose of the Study

You are invited to participate in a research study. The purpose of this study is to examine the effect of the child's asthma and sociodemographic factors (income, education, age, etc.) on the parent's quality of life through the use of questionnaires.

Participants

You are being asked to participate in the study because you are the parent of a child ages 7-17 with mild or moderate asthma. You are qualified for the study if: (1) your child is between the ages of 7 through 17, (2) your child is medically diagnosed with mild or moderate asthma, (3) you are the biological parent, adoptive parent, stepparent, legal guardian, foster parent, or adult who lives with the child, (4) you are willing to participate in the study, and (5) you speak English. You are not qualified for the study if: (1) your child is medically diagnosed with severe asthma and (2) your child has a diagnosis of other chronic conditions such as cardiovascular, renal, gastrointestinal, neurological, metabolic, and other diseases. Specific examples include depression, cerebral palsy, hypothyroidism, diabetes, and cancer.

Procedures

If you volunteer to participate in this study, you will be asked to do the following: Using 10 minutes of your time, you will be asked to complete three questionnaires regarding your child's asthma severity, parental quality of life, and sociodemographic factors. After you have completed the questionnaires, you will place them in an unmarked manila envelop provided by the researcher and return the envelope to the researcher.

Benefits of Participation

There *may not* be direct benefits to you as a participant in this study. However, we hope to learn about the effects of asthma severity of the child and sociodemographic factors on parental quality of life. This research information may be used for future studies.

Risks of Participation

There are risks involved in all research studies. This study may include only minimal risks. The study is voluntary and you may refuse to participate in this study or in any part of this study. You may be asked to answer some sensitive questions. You may ask questions at any time during the study and do not have to respond to questions you feel uncomfortable answering. You may withdraw at any time

TITLE OF STUDY: Examining Students in School Classrooms and the Quality of Life of their Parents
INVESTIGATOR(S): Dr. Patricia Alpert, Ph.D., and Noelle Carter, Ph.D., BSN
CONTACT PHONE NUMBER: 702-895-3810 (Dr. Patricia Alpert)

without prejudice to your relations with the university. You are encouraged to ask questions about this study at the beginning or any time during the research study.

Cost /Compensation

There *will not* be financial cost to you to participate in this study. The study will take 10 *minutes* of your time. You *will not* be compensated for your time.

Contact Information

If you have any questions or concerns about the study, you may contact Dr. Patricia Alpert at 702-895-3810. For questions regarding the rights of research subjects, any complaints or comments regarding the manner in which the study is being conducted you may contact the **UNLV Office for the Protection of Research Subjects at 702-895-2794.**

Voluntary Participation

Your participation in this study is voluntary. You may refuse to participate in this study or in any part of this study. You may withdraw at any time without prejudice to your relations with the university. You are encouraged to ask questions about this study at the beginning or any time during the research study.

Confidentiality

All information gathered in this study will be kept completely confidential. No reference will be made in written or oral materials that could link you to this study. All records will be stored in a locked facility at UNLV for 3 years after completion of the study. After the storage time the information gathered will be destroyed.

Participant Consent:

I have read the above information and agree to participate in this study. I am at least 18 years of age. A copy of this form has been given to me.

Signature of Participant

Date

Participant Name (Please Print)

Participant Note: Please do not sign this document if the Approval Stamp is missing or is expired.

APPENDIX B: PERMISSION FROM PROFESSOR ELIZABETH JUNIPER

Delete | Reply | Reply to All | Forward | Redirect | Blacklist | Message Source | Save as | Print

Date: Mon, 2 Mar 2009 14:59:21 -0000

From: Elizabeth Juniper <juniper@gottech.co.uk>

To: cerdann@unlv.nevada.edu

Cc: Jill Styles <jill@gottech.co.uk>

Subject: PACQLQ

2 unnamed text/html 3.07 KB

Dear Noelle,

I am delighted that you used the PACQLQ in your study/thesis. You may certainly say in your thesis that I gave permission for you to use it in your study. However, I cannot allow you to include the full questionnaire as an appendix in your thesis. I would be very happy for you to include a couple of questions with the relevant response options so that readers can get a feel for what the questionnaire is like but I do not allow reprinting of the whole questionnaire.

With all good wishes
Liz Juniper

Professor Elizabeth Juniper MCSP MSc,
20 Marcuse Fields,
Bosham, West Sussex,
PO18 8NA, UK
Tel: +44 (0) 1243 572124
Fax: +44 (0) 1243 573680
E-Mail: juniper@gottech.co.uk

APPENDIX C: ASTHMA SEVERITY QUESTIONNAIRE

Asthma Severity Questionnaire

1. Age of child? _____ Years Old
2. Sex of child? Male Female
3. How long has your child been diagnosed with asthma? _____ Months or _____ Years
4. Does your child have other chronic conditions? (Examples include cerebral palsy, diabetes, cancer, scoliosis, etc).
 - a. If yes, what condition(s)? _____
5. In the past 7 days, what asthma medications did your child use? *Please list only the names below.*

6. In the past 30 days, how often has your child had asthma symptoms such as coughing, wheezing, and shortness of breath during the day?
 2 or less times per week 3-6 times per week daily more than once per day
7. In the past 30 days, how often has your child had asthma symptoms such as coughing, wheezing, and shortness of breath *while exercising, playing, or other activities?*
 2 or less times per week 3-6 times per week daily more than once per day
8. In the past 30 days, how often has your child *needed to use a rescue inhaler or nebulizer* (used for symptom control, not preventative)?
 2 or less times per week 3-6 times per week daily more than once per day
9. In the past 30 days, how often has your child *woken up during the night* due to asthma symptoms such as coughing, wheezing, and shortness of breath?
 2 or less times per month 3-4 times per month more than one time per week daily
10. In the past 12 months, how many times did you bring your child to the ER due to asthma? _____ Times
11. In the past 12 months, how many times has your child been hospitalized due to asthma? _____ Times
12. In the past 12 months, how many days of school has your child missed because of asthma? _____ Days N/A
13. How would you rate your child's asthma? Mild Moderate Severe
14. Do you feel your child's asthma is under control? Yes No
15. What is your primary language? English Spanish Other _____
16. How do you get to the clinic? Your own car Someone drops you off Bus Taxi Walking Other
17. Have you, *the parent*, been medically diagnosed with asthma? Yes No
18. Is there a family history of asthma? Yes No

APPENDIX D: SOCIODEMOGRAPHICS QUESTIONNAIRE

Parent Questionnaire

1. Your age? _____ Years
2. Sex? Male Female
3. Do you smoke? Yes No
4. Marital status? Single Married Separated/Divorced Living with Significant Other
5. Ethnicity? White/Caucasian Black/African Descent Latino/Hispanic Asian Native American
 Middle Eastern East Indian Pacific Islander Other _____
6. How are you related to your child? Mother Father Grandmother Grandfather Legal Guardian/Other
7. What is your highest level of educational attainment? Some high school High school graduate Some college
 College graduate Graduate school Post graduate
8. What is your zip code? _____
9. Are you currently employed? Yes No *If "No," skip to #10.*
 - a. If yes, how many hours a week do you work? 1-19 hours per week 20-39 hours per week
 40-59 hours per week 60 or more hours per week
 - b. Do other people in your household work and contribute to household expenses? Yes No
 - c. Who watches your child while you are at work? Daycare Family Friends Other
 - d. What is your yearly income? Less than \$30,000 \$30,000-\$45,000 \$45,000-\$60,000
 \$60,000-\$75,000 \$75,000-\$100,000 \$100,000-\$150,000
 \$150,000-\$250,000 \$250,000 and higher
 - e. How many days of work have you missed due to your child's asthma in the past year? _____ Days
10. Do you have health insurance coverage? No insurance Medicaid Private Insurance
11. Are you able to pay for the health services and costs related to your child's asthma? Yes No
12. Are other people (family or friends) besides your immediate family living with you? Yes No
13. How many people live with you? _____ People
14. How many of the people living with you have asthma? _____ People
15. How many children do you have? _____
16. How many of those children (including the child you bring to the clinic today) have asthma? _____
17. Do you have family or friends you can turn to when you are in need of support? Yes No
18. Do you own or rent your home? Own Rent Other

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Table 1: Demographic Characteristics by Mean

Demographic Characteristics by Mean	
	Mean
<i>Child Characteristics</i>	
Age in years	10.26
Length of diagnosis in years	6.49
ER visits in past year	1.01
Hospitalizations in past year	.25
School days missed in past year	5.85
<i>Parent Characteristics</i>	
Age	39.34
Work days missed in past year	4.46
# of people living in home	3.67
# of children living in home	2.63

Table 2: Demographic Characteristics by Percentages

Demographic Characteristics by Percentages	
	Percentage (n=101)
Child Characteristics	
Male	55.4
Female	44.6
Caregiver Characteristics	
Male	20.8
Female	79.2
Age	
≤30	11.9
>30	87.1
Marital status	
Single	12.9
Married	64.4
Separated/Divorced	18.8
Living with significant other	4
Ethnicity	
White/Caucasian	58.4
Hispanic	20.8
Black/African	15.8
Other	5
Caregiver type	
Mother	75.2
Father	18.8
Other	6
Parent perception of control	74.3
Owning a vehicle	95
Language	
English	89.1
Spanish	4
English and Spanish	5.9
Parent with medically diagnosed asthma	38.6
Family history of asthma	73.3
Smokers	9.9
Employed	69.3
Work hours per week*	
<40	24.5
≥40	42.1
Education	
High school	32.7
College	58.4
Graduate school	8.9

*n=72.

Table 2: Demographic Characteristics by Percentages (Continued)

Demographic Characteristics by Percentages (Continued)	
	Percentage (n=101)
Annual income*	
Less than \$30,000	15.8
\$30,000 to \$45,000	18.8
\$45,000 to \$60,000	10.9
\$60,000 to \$75,000	9.9
Greater than \$75,000	12
Insurance	
No insurance	5
Medicaid	16.8
Private insurance	78.2
Ability to pay for health expenses	86.1
Residence type	
Own	68.3
Rent	29.7
Family or friend support	88.1

*n=72.

Table 3: Correlation between Asthma Severity Rating and PACQLQ Scores

Correlation between Asthma Severity Rating and PACQLQ Scores			
	Activity limitation subscale (rho)	Emotional function subscale (rho)	PACQLQ summary scores (rho)
Asthma severity	-.400**	-.258**	-.342**
Day symptoms	-.425**	-.285**	-.373**
Exercise symptoms	-.443**	-.304**	-.393**
Night symptoms	-.482**	-.325**	-.425**
Rescue inhaler use	-.309**	NS	NS
ER visits	-.445**	-.410**	-.461**
Hospitalization days	-.218*	-.199*	-.238*
Parental perception of asthma severity	-.578**	-.493**	-.576**
Parental perception of control	-.365**	-.283**	-.341**
School days missed	-.363**	-.239**	-.308**
Work days missed	-.490**	-.235*	-.365**
Annual income	.363**	.291*	.346**

rho = Spearman rho. NS= not significant. *p < .05. **p < .001

Table 4: PACQLQ Scores and Researcher Rating of Asthma Severity

PACQLQ Scores and Researcher Rating of Asthma Severity			
Asthma severity rating by caregiver	Activity limitation subscale mean (SD)*	Emotional function subscale mean (SD)**	PACQLQ summary scores mean (SD)***
Mild intermittent	5.37 (1.31)	5.20 (1.22)	5.25 (1.18)
Mild persistent	5.13 (1.25)	4.68 (1.14)	4.82 (.95)
Moderate persistent	4.02 (1.75)	4.43 (1.14)	4.31 (1.21)
Severe persistent	3.55 (1.91)	4.36 (1.51)	4.11 (1.49)

SD = standard deviation. *df = 3, F = 7.56, p = .0005, eta squared = .189. **df = 3, F = 2.855, p = .041, eta squared = .08. ***df = 2, F = 4.942, p = .003, eta squared = .132

Table 5: Univariate Regression Model Predicting Quality of Life

Univariate Regression Model Predicting Quality of Life						
	Activity limitation subscale (B)	p r ²	Emotional function subscale (B)	p r ²	PACQLQ summary scores (B)	p r ²
Annual income	.231	< .001 .078	NS	NS	.143	< .036 .048
Hospitalization days	-.572	< .006 .063	NS	NS	-.304	< .0005 .026
ER visits	-.333	< .0005 .145	-.199	< .002 .088	-.240	< .0005 .130
School days missed	-.078	< .0005 .177	-.031	< .025 .040	-.045	p < .001 .099
Work days missed	-.108	< .0005 .208	-.043	< .039 .047	-.063	< 0.02 .115

B = Unstandardized beta coefficient. NS= not significant. r²=adjusted r squared

Table 6: Multiple Regression Models Predicting Quality of Life

Multiple Regression Models Predicting Quality of Life						
	Activity limitation subscale (B)	p r ²	Emotional function subscale (B)	p r ²	PACQLQ summary scores (B)	p r ²
ER visits	-.246	< .01 .317	-.178	<.031 .079	-.199	< .011 .194
Work days missed	-.069	< .046 .317	NS	NS	NS	NS

B = Unstandardized beta coefficient. NS= not significant. r²=adjusted r squared.

Table 7: Relationship between Sociodemographic Factors and Quality of Life

Relationship between Sociodemographic Factors and Quality of Life

	PACQLQ Mean Score from 1-3	PACQLQ Mean Score from 4-5	PACQLQ Mean Score from 6-7
Family history of asthma*			
Yes	35.1%	47.3%	17.6%
No	7.4%	70.4%	22.2%
Marital status**			
Married/Living w/ Sig. Other	21.7%	62.3%	15.9%
Single/Divorced/Widowed	40.6%	34.4%	25%
Parental perception of control***			
Yes	20%	57.3%	22.7%
No	50%	42.3%	7.7%

n=101. * $\chi^2=7.684$, $p<.021$. ** $\chi^2=6.959$, $p<.031$. *** $\chi^2=9.384$, $p<.009$

Table 8: Comparison of Mean PACQLQ Scores between Groups

Comparison of Mean PACQLQ Scores between Groups						
	Activity limitation subscale (SD)	p (t)	Emotional function subscale (SD)	p (t)	PACQLQ summary scores (SD)	p (t)
Black/African						
Yes	3.72 (1.94)	<.014	3.81 (1.14)	<.001	3.78 (1.201)	<.001
No	4.83 (1.58)	(-2.49)	4.93 (1.21)	(-3.42)	4.9 (1.21)	(-3.39)
Own a car						
Yes	4.73 (1.65)	<.046	4.82 (1.26)	<.029	4.79 (1.26)	<.02
No	3.2 (1.8)	(2.02)	3.56 (.39)	(2.22)	3.44 (.72)	(2.36)
Ability to pay health costs						
Yes	4.89 (1.58)	<.006	4.89 (1.25)	<.0005	4.89 (1.24)	<.001
No	3.18 (1.59)	(3.77)	3.89 (.95)	(2.83)	3.68 (.96)	(3.5)
Own a home						
Yes	5.06 (1.48)	<.0005	5.03 (1.18)	<.002	5.04 (1.13)	<.0005
No	3.8 (1.82)	(3.67)	4.19 (1.26)	(3.24)	4.07 (1.33)	(3.76)
Parent perception of control						
Yes	4.99 (1.18)	<.0005	4.98 (1.21)	<.002	4.99 (1.18)	<.0005
No	3.94 (1.22)	(3.86)	4.1 (1.21)	(3.19)	3.95 (1.12)	(3.86)

SD=standard deviation.

Table 9: Asthma Severity Diagnosed by Physician, Caregiver, and Researcher

Asthma Severity Diagnosed by Physician, Caregiver, and Researcher						
	Researcher Percent	n=101	Physician Percent	n=53	Caregiver Percent	n=101
Mild intermittent	36.6	37	24.52	13	48.5 *	49*
Mild Persistent	18.8	19	33.96	18	48.5 *	49*
Moderate persistent	29.7	30	28.30	15	33.7	34
Severe persistent	14.9	15	52.83	58	16.8	17

Note. Mild intermittent and mild persistent asthma combined for caregiver rating.

Table 10: Correlation Between Researcher and Caregiver Rating of Severity

Correlation Between Researcher and Caregiver Rating of Severity	
	Caregiver Rating (τ)
Researcher Rating (τ)	.546*

τ = Kendall tau rank correlation coefficient. * $p < .01$.

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