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The Effect of Family Routines on Care for Inner City Children with Asthma

Kathleen Peterson-Sweeney, PhD, RN, PNP-BC [Associate Professor],
The College at Brockport, State University of New York

Jill S. Halterman, MD, MPH [Associate Professor],
Department of Pediatrics, University of Rochester School of Medicine and Dentistry

Kelly Conn, MPH [Senior Project Coordinator], and
Department of Pediatrics, University of Rochester School of Medicine and Dentistry

H. Lorrie Yoos, PhD, RN, CPNP [Professor]
University of Rochester School of Nursing and Department of Pediatrics, University of Rochester School of Medicine and Dentistry

Asthma is the most common chronic illness in children; affecting approximately nine million children less than 18 years of age in the United States (Vital and Health Statistics [VHS], 2005). Children aged zero to four years of age have the largest prevalence and greatest health care utilization related to asthma (National Center for Health Statistics [NCHS], 2005). In addition, deaths from asthma still exist in children, with adolescents having the highest mortality rate. Children of minority racial and ethnic backgrounds experience greater prevalence and hospitalization rates related to asthma compared to non-minority children (Gendo & Lodewick, 2004; Redd, 2002). The disparity of asthma is also seen in children of poor families, who are more likely to be diagnosed with asthma than children in families that are not poor (VHS, 2005).

Over the past several years, the treatment of asthma has improved because of a greater understanding of the pathophysiology, new medication regimens to keep asthma in control, and national guidelines that have been established by the National Asthma Education and Prevention Program (NAEPP) of the National Health Lung and Blood Institute (NHLBI). These guidelines recommend the use of preventive asthma medications for all children with persistent symptoms, and avoidance of triggers that exacerbate symptoms. However, undertreatment with preventive medications is common, and many children continue to be exposed to triggers likely contributing to preventable morbidity (Halterman, Aligne, Auinger, McBride, & Szilagyi, 2000; Halterman, J. et al., 2002).

Corresponding author: Kathleen Peterson-Sweeney, PhD, RN, PNP-BC, The College at Brockport, State University of New York, Department of Nursing, 350 New Campus Drive, Brockport, NY 14468, (585)395-5319, kpeterso@brockport.edu.

Adherence has also been extensively studied in relation to medication use. A report published by the World Health Organization suggests that 50% of patients with chronic disease in developed countries do not use their medications for these chronic diseases as prescribed and instructed (World Health Organization [WHO], 2003). The lack of adherence to asthma medication regimens is very concerning. In fact, it has been demonstrated that low rates of adherence to asthma medications are associated with higher rates of hospitalization and death (Horne, 2006). There is little evidence pointing to the relationship of asthma medication adherence to morbidity measures such as quality of life and burden of illness. Improving medication adherence may lead to improved morbidity and mortality related to asthma.

Having a chronic illness such as asthma, often adds burden to the individual with the chronic illness and their family. Increased burden has been correlated with decreased quality of life for parents of children with asthma (Peterson-Sweeney, 2006). Further examination of how routines are associated to illness burden may provide insight as to how to improve disease management and to improve morbidity measures such as quality of life.

Asthma outcomes may be improved if families have access to effective health care interventions. It has been hypothesized that routines within a household may protect its members from illness and adverse outcomes by providing structure to family members' lives, as well as assisting in organizing health related tasks within household activities (Denham, 2002, 2003a, 2003b; Fiese, et al., 2002). The overall purpose of this study is to examine the effect of family routines on the asthma care measures of medication adherence and trigger control as well as well-being in parents of children with asthma as measured by parental quality of life. If having a certain level of routines promotes optimal health, then an important health care intervention for a family with asthma is to assist in formulating appropriate routines in the household.

Theoretical Framework

The Family Health Model suggests that all families have certain routines and practices relevant to health which provide a way to discuss, describe, intervene, and evaluate outcomes pertinent to individual and family health (Denham, 2003a). Family routines may be describes as behavior patterns that are related to events, occasions, or situations that are often repeated regularly and consistently by members within a family (Denham, 2003a). Denham states that routines are:

Key structural aspects of family health that can be assessed by nurses, provide a focus for family interventions, and have potential for measuring health outcomes. Routines supply information about behaviors and their predictability, member interactions, family identity and specific ways families use values (2003a, p. 145). There are many factors that affect the health routines of families, such as member participation, tasks to be completed, motivation of family members, goals to be accomplished, effectiveness of the care functional processes, and constraints or resources available (Denham, 2003a). Routines are bound by time, have predominance and often preempt or interrupt other activities, are connected to family heritage, and are transmitted across generations (Denham, 2003a). Family routines are

generally viewed by family members as constant in their lives, and can be recalled, discussed and taught. Those health routines that are created in accord with family members' values and beliefs tend to have greater stability (Denham, 2003a). The Family Health Model suggests that nursing incorporate these factors into care when assisting families to design or change health routines, in order to have routines that will persist and be accepted and adapted into the family.

Asthma is a major concern in the health of children today. Following the Family Health Model, health care professionals may be able to assist families to provide optimal preventive care by suggesting the use of new routines and modifications for existing routines surrounding asthma care. Routines are often challenged by persons, information, support or available resources, and are often modified through life. Denham (2003a) suggests the creation and modification of family routines as an excellent intervention for current nursing practice and research.

Review of the Literature

The Benefits of Routines

Routines within families have been shown to have a protective function on the health and well-being of individuals within a family as well as the family as a whole. Early studies on routines suggest that routines within a family buffer the impact of stressful experiences on the family and protect its members against illness (Jensen, Sherman, Boyce, & Hartnett, 1983). Other early studies on routines found that episodes of upper respiratory infections were shorter in poor African American families when these families had more patterned household routines (Boyce, Jenson, James, and Peacock, 1983). More recently family routines were found to maintain family determination and provide hope for families living in an urban homeless shelter (Schultz-Krohn, 2004). Effective mealtime routines have been associated with the adequacy of feeding infants and children (Yoos, Kitzman, and Cole. 1999). The lack of routines surrounding family meal times has been associated with a decrease in healthy eating habits (Gillman, et al., 2000). The lack of consistent daily mealtimes and bedtimes for children has been associated with poorer nutrition and academic performance, and more injuries (Flores, Tomany-Korman, and Olson, 2005). Studies have also shown that adherence to routines support the management of children with chronic diseases; those children with Type 1 Diabetes Mellitus had poorer glycemic control during summer vacations when there was a lack of routines, as compared to when school was in session (Boland, Grey, Mezger, and Tamborlane, 1999).

Barbara Fiese has associated household routines with many positive health outcomes. Fiese and associates (1993) found that the presence of more meaningful routines was associated with greater marital satisfaction. In a separate study, it was found that families with more routines had children with asthma who had lower levels of anxiety (Markson and Fiese, 2000). In a third study, families were noted to describe discord and stress when household routines were disrupted (Fiese et al., 2002). Most recently, Fiese and associates (2007) demonstrated that disruptions in bedtime routines within a 24-hour period were associated with the likelihood that children would awaken in the middle of the night.

Fiese and associates have examined medication adherence in relation to asthma management. Fiese and Wamboldt (2003) found that families with the fewest routines had the lowest adherence to asthma management strategies. In addition, using The Asthma Routines Questionnaire with 133 families, Fiese and associates (2005) found that routines connected to medication use were positively related to medical adherence, and that the burden associated with management routines was negatively related to quality of life. These authors also found that parents who were able to organize their lives to include routine monitoring of medications found it easier to incorporate medication use into their daily patterns. In addition, this research demonstrated that there was less emotional investment in asthma care routines and more of an emotional drain when parents and children reported poorer quality of life. In total, this work suggests that predictable routines in families' lives can potentially facilitate the families' ability to follow doctor's orders, reduce anxiety-related symptoms, and improve overall quality of life (2005).

Adherence

As stated earlier, the lack of adherence to asthma medication regimens is very concerning. A few barriers that children and their parents have identified to asthma medication adherence have been fear of addiction, difficulty with administration, and dividing responsibility for asthma treatment between the child with asthma and their parent (Elliot, 2006). To treat asthma effectively, it is important to examine barriers to asthma medication adherence and to promote such adherence. Horne (2006) suggests a three phase approach to facilitating optimum adherence to asthma preventive medications. First, he suggests that patients have a clear understanding of why asthma medications are needed. Second, health care providers should address patients' concerns about the potential side effects of asthma medications. Third, practical barriers to adherence should be addressed with patients, which may include making the regimen as convenient as possible for the family by tailoring the medication regimen to family routines and life style. Fiese and Everhart (2006) performed several recent correlation studies that examined the links between family management strategies, family climate, and medical adherence. These studies demonstrated that family daily management practices facilitated adherence to medical protocols. These authors suggest that remediation of daily routines may be one way to improve adherence.

Asthma Care: Preventive Medications and Trigger Control

The National Heart Lung and Blood Institute (NHLBI) guidelines clearly address the need for medication depending on children's symptoms of asthma such as cough, shortness of breath, and night time wakening (NAEPP, 2007). Preventive medication often is prescribed with twice a day dosing, with rescue medications taken as needed for acute symptoms. It is likely that household routines can help families remember to take medications as prescribed. For example, suggesting children take their preventive inhaled anti-inflammatory medication when they brush their teeth, or after their morning and evening meals may enhance the likelihood of medication administration. Encouraging families to have an organized and readily accessible place to keep medications may also help to ensure children are getting medications as prescribed.

NHLBI criteria also suggest that many triggers create worsening of asthma symptoms in children and make recommendations to decrease the likelihood of triggers causing exacerbations of asthma symptoms (NAEPP, 2007). Eliminating household triggers takes time, energy, and commitment on the part of the family and many families may find the task of elimination of triggers daunting. These tasks may seem less daunting if they are presented in the context of family and household routines that allow for relatively simple changes to reduce triggers.

Burden of Asthma

It is difficult to establish a single estimate for the "burden of asthma". Standard symptom assessments for asthma capture daytime and night time symptoms and medication use, but fail to capture the full impact of the disease on the child and family. According to Fischer, Camargos, and Mocelin (2005), the burden of asthma includes direct and indirect costs, with direct costs including hospitalizations, emergency visits, office visits, medication, diagnostic tests, and procedures; and indirect costs referring to loss of work days and school absences. Other parameters have been used to quantify the burden of asthma, such as the burden of treatment regimens, morbidity such as quality of life, and limitations in normal life (Sennhauser, Braun-Fahrlander, & Wildhaber, 2005). Evidence demonstrates that the burden associated with asthma management routines is negatively related to quality of life for the parent of the child with asthma (Fiese et al, 2005, Peterson-Sweeney, 2006). Improving routines may be associated with less disease burden and greater quality of life for the individual and their family.

Research Study

This manuscript reports on a study that utilized data from the first year of the School-Based Asthma Therapy Trial, an ongoing three year full-scale randomized research study (Halterman, Borrelli, Fisher, Szilagyi, & Yoos, 2008). The randomized trial includes two different components, the administration of preventive asthma medications in school (adjusted according to NHLBI guidelines), and for smoke-exposed children, an environmental tobacco smoke reduction program in the home. For this research report, baseline data collected upon entry into year one was used from this ongoing intervention to answer the following research questions: 1) Is the asthma routines questionnaire reliable for use among poor, minority families? 2) What is the association between family routines and the asthma care measures of medication adherence and trigger exposure? 3) What is the association between family routines and the outcomes of well-being in parents of children with asthma, as measured by quality of life? We hypothesized that more routines surrounding asthma care would be associated with improved medication adherence and lower environmental triggers, as well as improved parental well-being as measured by quality of life. Routines have been shown to be beneficial in studies with middle class families; this research used primarily high risk, poor families. If our hypotheses were founded, it would lend support for nurses to encourage the use of routines to aid in asthma management in high risk families.

Sample

This current research used year one data from the School-Based Asthma Therapy Trial. Two hundred and twenty-six three- to ten-year-old children were enrolled in year one, with two further years of data collection to continue. All children were attending schools within the public school system in a major city in upstate New York at the time of enrollment. Seventy-two percent of families who qualified for the study participated in the baseline data collection. Through a partnership with the city school district, the study team identified children with asthma by reviewing school health forms. To determine study eligibility, research assistants completed a telephone survey with primary caregivers who indicated that their child had asthma on the school health forms. At this time, parents gave verbal consent to contact their child's health care provider. All eligible children had a diagnosis of asthma made by their physician, and had persistent asthma symptoms as defined by the NHLBI guidelines for asthma (NAEPP, 2002). Participating families subsequently completed a one-hour long baseline assessment at their homes between August 2006 and November 2006. After baseline assessment data was completed, participating families were randomized into appropriate groups for the intervention. The University of Rochester's Institutional Review Board approved the study protocol.

Measures

All measures for this research report were administered to the families in their homes by research assistants during an hour long baseline home visit. Measures were completed with the parent of the child with asthma.

Baseline Assessment—The baseline assessment included child and parent demographic information (age, gender, race, ethnicity, employment, Medicaid status), asthma symptom measures and symptom severity according to NHLBI definitions, health care utilization (primary care and emergency room visits, number of hospitalizations), and asthma preventive and rescue medication use. The baseline assessment also included several structured survey tools, as follows.

The Asthma Routines Questionnaire—Fiese and associates (2005) developed a measurement tool, the Asthma Routines Questionnaire, to examine family based asthma management routines and their relation to medication adherence, health care utilization, and quality of life. The Asthma Routines Questionnaire is an eight-item, forced choice format questionnaire. The eight items pertain to role assignment, burden, house cleaning, medication administration, medical visits, filling prescriptions, and personal family growth as a result of the disease. The original work conducted by Fiese and associates identified two unique factors from the questionnaire. The first factor was labeled "*medications routines*" which centered around regularity, predictability, and planning medication use. The second factor was labeled *"routine burden"* and reflected the degree to which asthma management was perceived as a chore and hassle. The higher the medication routines score, the greater the number of routines; the higher the routine burden score, the greater the burden associated with asthma care. Permission was secured to use the Asthma Routines Questionnaire (Fiese, et. al, 2005). This questionnaire has been validated in prior research studies (Fiese, et. al, 2005; Fiese, Winter, Anbar, Howell, and Poltrock, 2008).

Adherence Score—The adherence scale was developed by Robert Horne (Horne, Weinman, and Hankins, 1999). This scale includes 4 items on a 5 point Likert scale, with questions such as “I sometimes forget to give my child his/her medicines” and “I sometimes alter the dose of my child’s medication to suit his/her needs”. This scale has validity and reliability determined in its prior use with adults (Horne and Weinman, 1999) and with children (Conn, et al., 2005). Higher adherence scores are associated with better adherence to the proper administration of medications. Adherence data in this sample is limited to the 156 children (70 %) of the total of 226 children who were using daily preventive asthma medications during the data collection.

Environment Score—A 14-item environmental survey was administered to evaluate asthma and allergy triggers within the home. The triggers included in this home environment survey have been identified by the NHLBI as prime allergy and asthma triggers (National Environmental Education & Training Foundation (NEETF), 2005). Examples of questions included are: “Is there wall-to-wall carpeting in your child’s bedroom?”, “Do you see or smell mold/mildew in your home?”, “Is there evidence of water damage in your home?”, and “Do you use unvented appliances such as a gas stove for heating your home?” The presence of a trigger was answered by parents as *yes/no*. Additionally, children with a smoker in the home were scored positively for smoke exposure and all 15 items were totaled and this became the environment score. A higher environment score represents a greater number of asthma triggers present in the home.

Quality of Life—The Pediatric Asthma Caregiver’s Quality of Life Questionnaire (PACQLQ) was developed to determine the impact of a child’s asthma on the parent who is the child’s primary care provider (Juniper, Guyatt, Feeney, Ferrie, Griffith, & Townsend, 1996). The PACQLQ is an interviewer or self-administered 13-item instrument, with four items relating to activity limitations and nine items concerning emotional function. Responses to the PACQLQ are given on a seven-point Likert scale from 1 (*all of the time*) to 7 (*none of the time*). Individual items are weighted equally and the results are expressed as a mean score per item in each of the domains as well as for overall quality of life. The questionnaire asks caregivers to recall impairments experienced during the previous week, and takes three to five minutes to complete (Juniper at al, 1996). Possible scores range from one to seven. Higher scores on this scale are associated with a higher quality of life.

Results

The Statistical Program for the Social Sciences (SPSS) version 16.0 was used for data analysis. A 2-sided alpha level of less than .05 was considered statistically significant.

The first research question was answered by completing a factor analysis of the Asthma Routines Questionnaire in this sample. The studies completed by Fiese using the Asthma Routines Questionnaire have been primarily with middle class families. The sample for the main study includes children from an inner city area in upstate New York, and therefore is different from other samples where this questionnaire has been used. The factor analysis is presented in Table 1. Principal components analysis was conducted on the variables, using a varimax rotation. The same two factors that had emerged in previous factor analysis (Fiese,

et. al, 2005) emerged in this analysis, providing reliability for this scale in this population. We found that two items that were reverse-scored in Dr. Fiese's original work had positive loadings in our sample, however in testing the scale on additional populations of patients, Dr. Fiese has reported the same directionality of findings as identified in this current sample (personal communication, March 11, 2008). Thus we included these items without reverse scoring. The two factors were referenced with the same labels as the original work, Medication Routines, with a Cronbach's alpha of .421, and Routine Burden, with a Cronbach's alpha of .422.

Table 2 shows the demographic results of the sample. The average age of children enrolled was 7 years, with 37 % of the children having mild asthma symptoms and 63 % of the children having symptoms of moderate or severe persistent asthma. Fifty-eight percent of the children were male, and 65 % of the children were black. Twenty-eight percent of the children received Medicaid as the health insurance carrier. In terms of parent demographics, 64% of the parents were employed, and 65% were black. Thirty-four percent of the parents were between 21 and 29 years of age and 66 % were over the age of 30. The mean quality of life score for parents were 5.3 (out of a total of 7). Independent *t* tests were used to measure the differences between group means for routine burden and medication routines. No significant differences were found for either routine burden or medication routines with age, gender, Medicaid status, race, parent age, or asthma severity.

The second research question considered the association between family routines and asthma care measures including medication adherence and trigger exposure, with the use of Spearman Correlations. Significant correlations were found between medication routines and the medication adherence score (Table 3). Those with more medication routines had a higher adherence score ($r = .36$, $p < .001$), representing better adherence in taking asthma medications. In addition, the relationship between medication routines with the environmental trigger score was also significant ($r = -.22$, $p = .001$); those with more medication routines had fewer environmental triggers in their home. These findings remained significant in a multivariate model controlling parent race, ethnicity, insurance, education, stress, and depression. The routine burden subscale did not correlate significantly with either the adherence or the environment score.

The third research question of this study was to determine the associations between asthma routines and well-being, as measured by quality of life of the parents of the children with asthma, as well as other asthma morbidity measures. There were many variables examined in this study, such as Pediatric Asthma Caregiver's Quality of Life, symptom burden, and health care utilization. Pearson correlation coefficients were calculated to determine relationships between study variables with medication routines and routine burden. No significant correlations existed for routine burden or medication routines to parent quality of life, or other morbidity measures such as child emergency room visits, number of hospitalizations for the asthmatic child, or any of the symptom measures (symptom-free days, daytime symptoms, nighttime symptoms, missed days of school or daycare due to asthma, and use of quick relief asthma medications).

Discussion

This research supports the use of the Asthma Routines Questionnaire in a poor, inner city population. Consistent with Dr. Fiese' prior work, we identified two factors from the questionnaire with reasonable internal consistency. Since urban children suffer the greatest morbidity from asthma, and also are the population at greatest risk for undertreatment, we feel a focus on this population is pertinent. Adopting the Asthma Routines Questionnaire in asthma research could give further information on the effects of routines in different ages of children and adolescents on asthma morbidity outcomes. Incorporating this questionnaire in an intervention study that assisted families in developing and modifying routines could show further support for incorporating this easy, cost effective intervention in nursing care.

The main findings of this study lend support for Denham's Family Health Model. We found that a greater number of routines surrounding asthma medications had a significant relationship with better adherence to asthma medication use. Assisting families to develop and modify routines that incorporate medication and asthma care into the everyday life of family members could enhance adherence to medication. For example, it could be useful to suggest the administration of steroid inhaler doses before brushing teeth, and storing the inhaler with the toothbrush to assist in medication adherence. Nurses also can suggest having families keep medication in a certain place to be taken with meals on a daily basis to help with medication adherence.

This research also demonstrates a significant relationship between medication routines and fewer environmental triggers in the home, which support the suggestions put forth by the NAEPP national guidelines. Discussions with family members on how to eliminate triggers in conjunction with current household routines may be very helpful in improving asthma care. For example, families could incorporate mattress and pillow encasings to their laundry routine. Routines could be developed to avoid exposures to harmful irritants, in particular secondhand smoke. Simple suggestions for the incorporation of environmental measures to decrease triggers in every day household routines could greatly improve the health of the child with asthma.

We did not find significant associations between asthma routines and asthma related morbidity of parent quality of life. This may be related to the enrollment criteria for the study which required all children to have persistent asthma, thus limiting the variability in symptoms for this sample. In previous research including children with all levels of asthma severity, we found that household routines, as measured by nurse ranking and parent self-assessment, correlated with asthma morbidity outcome measures (Peterson-Sweeney, 2006).

Limitations

There are some potential limitations to this study. First, the data are taken from a cross-sectional sample, and therefore we were not able to examine the longitudinal impact of routines on adherence and outcomes. While we were able to replicate the core factor structure, factor analysis of the Asthma Routines Questionnaire did not produce strong Cronbach alphas. As mentioned the population studied is fairly homogeneous, with the majority being African American and poor, and all being families in a major city in upstate

New York, Thus the findings of this study can be generalized only to similar populations. Further research with similar populations may provide additional evidence for nurses to assist families to develop family routines to prevent morbidity and mortality related to asthma in inner city, high risk families.

Conclusion

This research uses the Asthma Routines Questionnaire (Fiese, et al., 2005) in an inner city population to determine the relationship between routines and asthma care. We found that medication routines significantly correlated with better adherence to the prescribed asthma medication regimen, and to fewer triggers in the home. Both of these factors are imperative to improve overall asthma care. Other research studies also have shown support for a positive relationship between routines and favorable health care outcomes, consistent with Denham's Family Health Model. While further study in this area is needed, it may be prudent for health care team members to assist families in developing and modifying routines within the home and surrounding the care of family members with chronic illness. In the future, studies are needed to test the effectiveness of interventions to support families in developing routines to provide enhanced preventive care to their children. This research did not demonstrate improved asthma morbidity outcome of parental quality of life with more routines. Further research in larger and more diverse samples is needed to further evaluate the effect of asthma routines on asthma morbidity outcomes.

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Table 1

Factor Analysis of Asthma Routines Questionnaire

Item	Factor 1 Medication Routines	Factor 2 Routine Burden
The whole family shares responsibility to remind child to take asthma medications	**.525**	.257
There is a set routine around when to take asthma medications	**−.510**	.372
Asthma appointments are scheduled in advance	**.597**	−.267
Asthma medications are filled on a regular basis before they run out	**.674**	.035
People have certain roles in managing asthma	−.211	**.531**
Asthma management is a chore	.268	**.659**
Cleaning happens whenever it can	−.069	**.438**
Having a child with asthma is no big deal	−.007	**.625**

Principal component analysis, varimax rotation

Table 2

Population Demographics

N = 226	Overall N (%)	Routine Burden Mean (SD)	Medication Routine Mean (SD)
Child Age in Years, mean (sd)	7.0	r = .007	r = .015
Child Gender			
Male	131 (58)	2.17 (.77)	3.13 (.63)
Female	95 (42)	2.22 (.68)	3.09 (.64)
Child Race			
White	24 (10.6)	2.62 (.78)	3.24 (.60)
Black	147 (65)	2.12 (.70)	3.06 (.67)
Other	55 (24)	2.19 (.72)	3.20 (.55)
Child Ethnicity			
Hispanic	63 (26.9)	2.14 (.709)	3.22 (.57)
Non-Hispanic	163 (72.1)	2.21 (.741)	2.08 (.66)
Parent Race			
White	31 (13.7)	2.68 (.75)	3.22 (.60)
Black	147 (65)	2.11 (.70)	3.07 (.68)
Other	48 (21.2)	2.10 (.64)	3.18 (.52)
Parent Ethnicity			
Hispanic	51 (22.6)	2.02 (.63)	3.16 (.54)
Non-Hispanic	175 (77.4)	2.24 (.75)	3.10 (.67)
Medicaid			
Yes	63 (27.9)	2.12 (.70)	3.16 (.64)
No	163 (72.1)	2.39 (.79)	2.99 (.62)
Parent Age			
21–29	76 (33.8)	2.28 (.72)	3.07 (.59)
30–64	148 (66.2)	2.13 (.73)	3.14 (.67)
Parent Employed			
Yes	144 (63.7)	2.14 (.71)	3.10 (.62)
No	70 (31.0)	2.28 (.75)	3.13 (.65)
Asthma Severity			
Mild	83 (36.7)	2.22 (.72)	3.11 (.61)
MPSP	143 (63.3)	2.17 (.74)	3.12 (.66)
QOL (mean, sd)	5.3 (1.3)	r = .034	r = .019

Table 3

Correlations of Asthma Routines Questionnaire to Medication Adherence and Environmental Score

Item	Routine Burden *r*	Medication Routines *r*
Medication Adherence (n = 156)	−.13	**.36**
Environmental Score (n = 226)	−.03	**−.22**