

## Relationships among Functional Health Literacy, Asthma Knowledge and the Ability to Care for Asthmatic Children in Rural Dwelling Parents

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### Abstract

**Purpose:** This Orem-based study examined the relationships among functional health literacy, asthma knowledge, the ability to care for asthmatic children and sociodemographic factors among rural parent/guardians.

**Method:** A descriptive correlation design was used. The convenience sample of 57 parents and one guardian who cared for asthmatic children was recruited from three rural health districts in the eastern United States (Virginia, North Carolina, and upstate New York). Subjects completed the Test of Functional Health Literacy in Adults (TOFHLA) and the Asthma Questionnaire-Parent Survey (AQ-P) and provided additional demographic and health status information.

**Findings:** The results show that TOFHLA scores were directly related to asthma knowledge (AQ-P scores),  $p=.04$ . Subjects who had not completed high school had significantly lower TOFHLA scores than those who had completed high school, and their children were hospitalized more often ( $p=.05$ ). Those with higher income also had higher health literacy (TOFHLA scores) ( $p=.008$ ) and regression analysis revealed that smoking status was also directly associated with functional health literacy ( $p=.004$ ).

**Conclusions:** The findings confirm that rural health care providers need to be diligent in assuring that health education materials and verbal instructions are presented in the most simple and easy to read format in order to maximize understanding.

**Keywords:** Health Literacy, Asthma Knowledge, Orem's Theory of Dependent Care Agency

## **Relationships among Functional Health Literacy, Asthma Knowledge and the Ability to Care for Asthmatic Children in Rural Dwelling Parents**

Despite advances in asthma management, childhood asthma remains one of the highest ranked causes of pediatric hospitalizations and school absences in the US (Cox & Taylor, 2005). The 2002 National Health Interview Survey (NHIS) estimated that there were 9 million US children under the age of 18 years diagnosed with asthma, and that 7.7% were between 0-4 years of age (Center for Disease Control & Prevention [CDC], 2002). Because asthma management is centered in the home, it is crucial that parents/caregivers have the information that they need to provide effective care for their children.

A number of studies have shown that caregivers with low health literacy capacity have difficulty comprehending written materials, that they may not understand the importance of asthma prophylactic therapy, and that they may not be able to demonstrate the proper use of the asthma metered-dose inhaler (Apter et al., 2006; DeWalt, Dilling, Rosenthal, & Pignone, 2007; Williams et al., 1995). Addressing these issues, this study examined the relationship between rural parent/guardian's level of formal education and their functional health literacy score, in relation to their capacity to effectively manage their child's asthma.

### **The Impact of Health Literacy on Health Outcomes**

It is generally assumed within our current health care system that adequate literacy is the norm and that the individuals we see are capable of providing self-care or dependent care. Therefore, printed instruction booklets, brochures, and single sheet instructions are often issued without consideration of reading and comprehension ability. While most education materials are written at the eighth to twelfth grade reading levels, approximately half of the population struggles with basic third to fifth grade reading skills (Davis et al., 1994).

Three of the ten objectives of *Healthy People 2010* regarding asthma focus on (a) reducing the rate of hospitalization for children under age five; (b) reducing emergency department visits related to asthma; and (c) increasing the proportion of individuals with asthma who receive formal asthma education. Another objective affirms the commitment to improve the health literacy of persons with inadequate or marginal literacy skills (*Healthy People 2010*, 2008). It is therefore essential that nurses and other health care professionals determine when a knowledge deficit exists, and that information be provided in a format that the patient can understand. However, this determination is difficult at times, because patients and caregivers may be embarrassed to tell their health care provider that they cannot read or understand medical terminology (Parikh, Parker, Nurss, Baker & Williams, 1996).

### **Theoretical Perspective: Orem's Theory of Dependent Care Agency**

Orem's theory of Dependent Care Agency (DCA), a parallel extension of her original Self-Care Deficit Nursing Theory (S-CDNT), provides the theoretical underpinnings for this study (Orem, 2001). As a dependent-care agent, the mature or maturing person meets the therapeutic self-care demands of another person, in this case a child diagnosed with asthma. The specific actions of the dependent care agent to provide health care are determined by changes in the health of the dependent person, and may include the management of complex technology associated with care (Orem, 2001; Taylor, Renpenning, Geden, Neuman & Hart, 2001). The general action themes that the caretaker engages in are 1) detects, interprets, and monitors meaningful symptoms; 2) regulates and administers medications; 3) identifies and avoids environmental triggers; and 4) seeks appropriate medical advice in a timely manner.

Thus the care of children with asthma constitutes an exemplar of Orem's dependent care agency.

### **The Research Problem**

While parents are expected to be the dependent-care agents for their child diagnosed with asthma, the high number of hospitalizations and emergency room visits for their children (Akinbami & Schoendorf, 2002; National Center for Health Statistics [NCHS], 2001) would indicate that many parents are unable to effectively manage the complex care issues associated with childhood asthma. Critical learning activities include recognizing asthma triggers and performing the necessary dependent-care actions for children who have asthma (Cox & Taylor, 2005; National Asthma Education & Prevention Program [NAEPP], 2007). However, parents who are unable to read and understand the complex written instructions given to them during their brief visits with their healthcare providers may not be able to perform these actions effectively. Thus, the purpose of this study was to examine the relationship among rural parents'/guardians' capacity to read (as measured by their level of education, their scores on the Test of Functional Health Literacy in Adults (TOFHLA), their score on the Asthma Questionnaire-Parent Survey [AQ-P]), other sociodemographic characteristics and their ability to care for their children with asthma, as measured by the number of visits to the emergency department and hospitalizations of their child.

### **Methods**

#### **Study Design and Subjects**

A descriptive correlation design was used to determine the relationships among the parent/guardian's level of functional health literacy, their knowledge of asthma their asthma care and other sociodemographic characteristics relevant to their ability to manage their child's asthma symptoms. Permission to conduct the study was obtained from the Institutional Review Board at Binghamton University in upstate New York, and a signed informed consent was obtained from each participant before the interviews were conducted. Potential subjects were recruited from three health departments and three physician offices in rural health districts in three eastern states (a) Virginia, (b) North Carolina, and (c) upstate New York). The Census Bureau's classification was used to define rural for this study (Census 2000 Urban and Rural Classification, 2001).

The convenience sample (N = 58) consisted of 57 English-speaking parents and one guardian who were the primary caregivers for a child less than 9 years of age who had been diagnosed with asthma. The average age of the participants was 31.5 years, with a range of 20-55 years. All but one of the caregivers was female and the lone male participant was the father of the child. All of the female participants were the mothers, with the exception of one woman who was the child's guardian. The ages of the children that they acted as the dependent care agent for ranged from 4 months to 9 years, with a mean age of 5 years. Most (82.7%) of the sample was European-American (white, non-Hispanic), 10.3% was African-American, and 6.9% was Hispanic, non-white. Thus 17.2% of the parents were from minority segments of the population.

More than half (55.2%) of the sample had either completed high school or passed the GED equivalency exam (N = 15). Seven (12.1%) of the participants did not graduate from high school; 11 (19.0%) had completed two years of college; 5 (8.6%) had completed four years of college; and 3 (5.2%) reported more than four years of college education. Sixteen

(27.7%) of the participants reported a combined annual family income of less than \$10,000; eight (13.8%) reported an income of \$11-20,000 per year; nine (15.5%) reported their annual income to be \$21-30,000; four (6.9%) reported an annual income of \$31-40,000 per year; and 17 (29.3%) reported an annual income of \$41,000 or more. Three respondents (5.2%) declined to answer the question related to income, and one (1.7%) said that they did not know the amount of their annual household income.

## **Procedures**

As previously noted, subjects were recruited from health departments and physician offices in rural health districts in three eastern states (a) Virginia, (b) North Carolina, and (c) upstate New York. Subjects were contacted at the facilities and signed consents. They then completed the Test of Functional Health Literacy in Adults (TOFHLA) and the Asthma Questionnaire-Parent Survey (AQ-P), and provided additional demographic and health status information. All data were collected by the first author.

## **Assessment Tools**

**Test of Functional Health Literacy in Adults (TOFHLA).** The TOFHLA, developed by Nurss and colleagues, was used to measure literacy capacity in this sample (Nurss, Parker, & Baker, 2001). The TOFHLA measures reading comprehension and numeracy skills using real and relevant hospital materials and labeled prescription vials. It consists of two sections, including a 50-item reading comprehension assessment and a 17-item numerical assessment, and takes about 20 minutes to administer. The reading comprehension section uses a modified Cloze method, where every fifth to seventh word is omitted and a list of choices are provided for a fill-in-the-blank answer. To assess numeracy skills, the participant is given cue cards or labeled bottles and asked to respond to oral questions regarding the information written on the cue cards or bottles.

The TOFHLA has been tested for both its reliability and validity in measuring health literacy. Its internal reliability is excellent, with a Cronbach's alpha of .98 (Parker, Baker, Williams, & Nurss, 1995). It was also cross validated with the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) and the Wide Range Achievement Test-Revised (WRAT-R) (Jastak, Wilinon, & Jasteak, 1984), showing strong correlation with each (.84-REALM and .74-WRAT-R) (Parker et al., 1995).

Individuals scoring 0-59 on the TOFLA are considered to have Inadequate Functional Health Literacy; those scoring 60-74 are considered to have Marginal Functional Health Literacy, and those scoring 75-100 are considered to have Adequate Functional Health Literacy (Nurss, et al, 2001; Parker, et al. 1995). Interestingly, all 58 participants scored at an adequate level of functional health literacy (75-100); in fact, 27 (almost half) of the participants scored in the highest 94-100 range.

**Asthma Questionnaire-Parent survey (AQ-P).** The Asthma Questionnaire-Parent Survey (AQ-P) by Adams et al. (2001) was designed to obtain information about general asthma-related knowledge, basic facts about asthma, and problem solving capacity in the management of pediatric asthma. The survey consists of 23 general asthma knowledge questions, plus an additional three sections that assess competency if the parent uses a nebulizer (4 questions), inhaler (3 questions) and/or peak flow meter (3 questions) to manage their child's asthma. Participants are instructed to skip any of the last three sections

(nebulizers, inhaler, or peak flow meter) that are not a part of their child's asthma management regimen.

The AQ-P has a fourth grade readability level using the Flesch-Kincaid Grade Level Quotient (Adams, et al., 2001). All of the questions presented are in a multiple-choice format with the exception of the medication section. Each of the multiple-choice items has three incorrect response options, one correct option, and one choice of "I do not know the answer."

The range of correct responses on the basic knowledge asthma questions was 7 to 23 out of a possible 23 correct. Sections B, C, and D of the test were only answered by those for whom it applied: i.e., the nebulizer questions of section B were answered by 47 participants; the inhaler questions of section C were answered by 42 participants; and the peak flow meter questions of section D were answered by 19 of the participants.

**Demographic and health status information.** The demographic information questionnaire was designed by the investigators and contained a 13-item personal response format using items extrapolated from demographic questionnaires found in the literature regarding pediatric asthma (Bennett, Robbins, Al-Shamali, & Haecker, 2003; Dewalt, et al, 2007; Scherer & Bruce, 2001), and included assessment of variables such as gender, age, ethnicity, level of formal education, and income. Health status information for the child included whether or not the parent/guardian smoked, and if during the past year their child had been 1) taken to the emergency department, 2) hospitalized for asthma, or 3) taken for one or more unscheduled office visits for asthma-related symptoms. Participants were also asked to tell how many times during the past year that each of the above situations had occurred. The remaining check-off responses requested information related to race/ethnicity, relationship to child, and whether or not the parent or guardian had previously attended an asthma education program. The socioeconomic information consisted of the highest-grade level of school completed by the parent/guardian, and the combined household income. Finally, health status outcomes were measured by the answers to five questions: 1) Do you smoke? 2) Have you ever completed an asthma education program? 3) Have you taken your child to the Emergency Department (ED) during the past year? 4) Has your child been hospitalized for asthma during the past year? and 5) How many unscheduled office visits for asthma during the past year? Twenty-one (36.2%) of the dependent care agents reported that they smoked. Eighteen (31.0%) reported that they had taken their child to the ED during the past year for asthma related symptoms, while 40 (69.0%) had not. Most of the parents who said they had taken their child to the ED said they had gone between 1 and 3 times during the last year. However, one parent took their child to the ED 5 times, and another had taken their child to the ED 8 times within the past year. The mean number of visits for the parents who had reported taking their child to the ED was 2.3. Seven (12.1%) of the caregivers stated that their child had been hospitalized for asthma related symptoms during the past year. Collectively, these seven parents/caregivers reported a total of 12 hospitalizations. The range of child hospitalizations was 1 to 2 during the past year, with a mean of 1.6 visits per child. During the past year, 42 (72.4%) of the parents/guardian reported taking their child for unscheduled office visits. Of those who had made unscheduled office visits, the number of visits ranged from 1 to 20 visits during the year, with a mean of 4.2 visits per child.

Finally, fifty-three of the participants (91.4%) said they had never attended an asthma education program. The length of the educational programs attended by the five individuals ranged from one 45 minute session to several sessions over a five month period. Instruction in these sessions was received from a respiratory therapist from a home health company or

by participation in *Open Airways*, an ongoing national program offered by the American Lung Association.

### **Data Analysis**

It was hypothesized that the parents/guardians who scored lower on the TOFHLA would also score lower on the AQ-P (asthma knowledge), and report more frequent use of the ED, more hospitalizations, and more frequent non-scheduled office visits for asthma than those who scored within the adequate range on the TOFHLA. It was also postulated that parent/guardians who scored at the inadequate or marginal level of the TOFHLA would be more likely to smoke, to never have attended an asthma education program, to report a lower level of education completed, and to have a lower family income.

Statistical analysis was performed using SAS/STAT<sup>®</sup> Software (SAS Institute, 2008). Correlational analysis was used to examine associations among the number of correct responses for the general asthma knowledge questions (N = 23) (AQ-P (23), the TOFHLA score, the number of correct nebulizer questions (N = 3), the metered dose inhaler questions (N = 4), education level, income and the child's age. Correlations were considered statistically significant at  $p < 0.05$ . T-tests were conducted to determine if TOFHLA scores were significantly different between: 1) smokers and nonsmokers, 2) adults who had completed an asthma education program and those who had not, 3) ED use and no ED use, 4) adults whose child had been hospitalized for asthma during the last year and adults whose child had not been hospitalized, and finally, 5) adults whose child had been taken for an unscheduled office visit for asthma in the last year and adults who had not taken their child for an unscheduled office visit for asthma. TOFHLA scores were also compared by education level (less than 9<sup>th</sup> grade and some high school and income vs. high school graduate or GED to four year college graduate) and income (below \$30,000 vs. \$30,000 or above). Lastly, stepwise regression was used to develop the most parsimonious model of the predictors of TOFHLA scores. The F to enter criterion for the model was set at  $p < 0.05$ .

### **Findings**

Table 1 shows the results of the correlational analysis. As indicated, there was a direct association between health literacy as reflected in the TOFHLA scores and asthma knowledge (AQ-P (23) scores ( $p = .04$ ), such that the higher the health literacy, the higher the asthma knowledge. There was also a direct association between asthma knowledge (AQ-P (23) scores) and education level such that as education level increased asthma knowledge increased ( $p = .0003$ ). AQ-P (23) scores were also directly associated with income level such that as income increased, asthma knowledge also increased ( $p = .004$ ).

The results of the t-test analysis revealed no statistically significant differences in TOFHLA scores between smokers and non-smokers, adults who had completed an asthma education program and those who had not, those who had taken their child to the ED use and those who had not, those whose child had been hospitalized and those whose children had not been hospitalized, and finally, those whose child had been taken for an unscheduled office visit and those whose child had not. However, the comparison between the low education group (less than 9<sup>th</sup> grade and some high school, (N = 7; Mean = 86.3) and the higher education group (high school graduate or GED to four year college graduate (N = 51; Mean = 92.6)) showed that those with higher education had higher TOHFLA scores ( $p = .008$ ). The comparison between the low and high income groups (below \$30,000 (N = 33) and \$30,000

or above (N = 21)) showed a difference of 3.3 in TOFHLA score, with the high income group having the higher score ( $p = 0.04$ ).

Table 1

*Correlations among TOFHLA Scores, AQ-P Knowledge Scores and Selected Demographic Variables*

	Number of Subjects	Estimated Correlation	p-value
TOFHLA and AQ-P (23)	58	0.27	0.04
TOFHLA and number of correct nebulizer questions (3)	47	0.37	0.01
AQ-P (23) and Child's Age	58	0.3	0.02
AQ-P (23) and Education Level	58	0.46	0.0003
AQ-P (23) and Income	58	0.37	0.004
AQ-P (23) & correct Metered Dose Inhaler questions (4)	42	0.66	0.0001

The results of the stepwise regression analysis are shown in Table 2. As indicated, level of education ( $\beta = -6.48$ ,  $p = 0.01$ ), number of nebulizer questions answered correctly ( $\beta = 3.6$ ,  $p = 0.002$ ), being a non-smoker ( $\beta = 3.6$ ,  $p = 0.004$ ) and child hospitalizations ( $\beta = -4.42$ ,  $p = 0.05$ ) were independent predictors of TOFHLA scores. These results support previous findings and provide additional information regarding the competence level of rural parents whose children have asthma.

Table 2

*Stepwise Regression Results of Factors Predicting TOFHLA Scores.*

Parameter	Estimated Beta Coefficient	p-value
Intercept	83.22	0.0001
Education Indicator	-6.48	0.01
Smoking Status	3.6	0.004
Hospital Admission Indicator	-4.42	0.05
Number of Correct Nebulizer Questions	3.6	0.002

## Discussion

Despite the fact that all participants in this study scored at an adequate level of FHL, the findings show that functional health literacy (as reflected in the TOFHLA score) was directly related to asthma knowledge (as reflected in the AQ-P(23) score) among dependent care agents who provide care for children with asthma. Consistent with the findings of previous studies that used TOFHLA to determine the level of health literacy (Gazmarain, Williams, Peel, & Baker, 2003; Montalto & Spiegler, 2001; Yin, Dreyer, Fotlin, van Schaick, & Mendelsohn, 2007), the participants in this study who had completed a higher level of education and reported a higher income also had higher health literacy scores. The fact that no participants scored below an adequate level on the TOFHLA test precluded a more definitive examination of the relationship between functional health literacy and the other demographic variables of interest. In addition, asthma knowledge as reflected in the AQ-P(23) was related to education and income, such as those who were better educated and who had higher income had greater asthma knowledge.

The stepwise regression results revealed that there were several independent predictors of health literacy (TOFHLA scores). The regression model suggests that education and smoking status as well as one aspect of asthma knowledge and one measure of asthma care (number of hospitalizations) each have independent contributions to the variation in parental health literacy, even though all the study participants had relatively high health literacy. These findings suggest that even small changes in functional health literacy of rural parents is related to their background and health habits and variation in their child's asthma care.

The findings of this study also raise awareness of the important link between the parent/caregiver's level of education and their ability to gain the knowledge that they need to be successful in caring for their children with asthma. Likewise, the findings confirm that the TOFHLA score predicts asthma knowledge, and that a higher level of education and income are also associated with higher asthma knowledge. While none of the participants scored within the inadequate level of health literacy, the TOFHLA scores of those parents who had not completed high school were significantly lower than those who had completed high school, and their children were hospitalized more often than the children of those who had completed high school.

A limitation of the study was a failure to recruit any participants who scored in the inadequate range of the TOFHLA. This limitation is likely to pose a similar challenge to future researchers on this topic, and indicates the need to develop more effective recruitment strategies for future studies that focus on level of literacy. It is possible that parents with low literacy skills may not have been able to read and interpret the information on the recruitment flyers, or that they may have been self-conscious or fearful that their participation in the study might lead to the discovery that they did not know how to read. That the recruitment activities yielded no participants with a low literacy score is a poignant reminder that illiteracy is silent and unrecognizable, and raises awareness of the need to devise ways to reach and enroll individuals with low literacy into health related studies such as this one. This finding also reminds clinicians of the need to take the level of health literacy into account in their day-to-day assessments of the health care recipients that they see.

Conversely, a notable strength of the recruitment strategy for this study is that 17.2% of the sample represented minority populations, including African American (10.4%) and Hispanic non-white (6.9%). While it would have been desirable for the minority representation to have been even higher, this feature does represent a positive characteristic of the sample.

### **Implications for Nursing Practice**

Perhaps the most important observation in terms of the immediate clinical application for nurses is that 91.4% of the literate and relatively well educated participants in this study reported that they had never attended an asthma education program. This finding reveals a serious and generally unrecognized gap in the availability/attendance of asthma education programs, and holds immediate implications for community health nurses who interface with caregivers of children with asthma. It provides evidence that a stronger system of community based education for individuals who care for children with asthma is needed in order to decrease the health care costs associated with asthma management for children and improve the health related quality of life for the children and parents involved. Asthma education to properly manage asthma is listed as an objective in *Healthy People 2010 (2008)*, and is also a recommendation of the Asthma Education and Prevention Program (NAEPP) Expert Panel-3

(2007). Unfortunately the findings of this study provide overwhelming evidence that these objectives are far from being met.

Likewise, the surprising frequency of emergency department visits and the high number of hospitalizations and unscheduled office visits identified in this study have additional important implications for clinical practice. Almost one third of the parents in this study had taken their child to the ED at least once during the past year, and one parent had taken their child to the ED eight times during the year. In addition, 8 parents (13.8%) reported that their child had been hospitalized for asthma related symptoms, and 42 (72%) had taken their child for unscheduled office visits. This possibly preventable use of health care services increases costs within the larger health care system, and may impose additional stress on the parents and their child. Formal and informal processes of education need to be developed within the healthcare environment to address this issue. These findings also confirm that health care providers need to be more diligent in assuring that health education materials as well as verbal instructions can be read and understood by the health care recipients that they serve.

### Conclusion

This study builds on and extends the work of Cox and Taylor (2005), who postulated pediatric asthma to be an exemplar of Orem's theory. The tenets of Orem's theory of dependent care were shown to be consistent with and supported by the findings of this study, in terms of factors that enhance the capacity of parents or guardians to care for their child with asthma. The findings also provide support for the dependent care capacity of parents who care for their children with asthma, and point to the need for additional research to test and extend Orem's conceptualization of dependent care in children. It is also important that research-based models be developed to increase the capacity of parents and guardians to care for their children with asthma.

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