

PEDIATRICS

Association of caregiver health beliefs and parenting stress with medication adherence in preschoolers with asthmaMegan L. Armstrong, PhD¹, Christina L. Duncan, PhD², Jocelyn O. Stokes, MS², and Deidre Pereira, PhD³¹Department of Physiology, Louisiana State University Health Sciences Center, New Orleans, LA, USA, ²Department of Psychology, West Virginia University, Morgantown, WV, USA, and ³Department of Clinical & Health Psychology, University of Florida, Gainesville, FL, USA**Abstract**

Objective: This study examined the associations of parenting stress and caregiver negative health beliefs with medication adherence in a sample of preschool-aged children with asthma. **Methods:** Participants included 43 caregivers and their child with asthma, aged 2–5 years, who were prescribed a preventative or controller medication. Assessment included parent report of parenting stress associated with parental characteristics and difficult child behavior, health-related beliefs, and adherence to inhaled corticosteroids (ICS). Pharmacy refill records were reviewed to measure medication adherence objectively. Statistical analyses included paired samples *t*-test and Pearson's correlation coefficients.

Results: Parent-report and objective measures of adherence to ICS were significantly different, with parents reporting significantly higher rates of medication adherence ($p < 0.001$). Also, increased caregiver negative health beliefs, but not parenting stress, were significantly and negatively associated with an objective measure of ICS adherence ($p < 0.01$).

Conclusions: Because the findings for parenting stress are not consistent with that of the literature on school-aged children with asthma, our results may suggest that preschool children are a unique developmental group. A review of endorsed health beliefs also highlights strengths and concerns for caregivers of these very young children. Overall, our study findings underscore the importance of caregivers' health-related beliefs in promoting adherence to ICS in young children with asthma.

Keywords

Adherence, asthma, corticosteroid, children, management

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Introduction

Asthma is the most common chronic illness in children [1], affecting as many as 6.5 million children in the United States [2], with prevalence rates rising in children age 4 years or younger [3]. If asthma is not managed effectively by following a treatment regimen consistently, it can lead to poor outcomes, including school absences, missed work for parents, and even death of the child [4]. Asthma-related hospitalization rates are highest in preschool-aged children [5] and reduction of pediatric asthma-related deaths, hospitalizations, and emergency department visits is a top priority [6]. Non-adherence to long-term daily asthma controller medications in youth has been found to correlate with asthma morbidity, such as hospitalization rates [7] and emergency room visits and school absences [8]. Therefore, factors associated with adherence to treatment regimens are important to understand to promote optimal adherence and, ultimately, prevent the potential negative effects of asthma.

Non-adherence rates for ICS in pediatric asthma range from 17% to 90% [9]; rates vary greatly, which likely is due to different methods of adherence measurement, with more objective methods yielding lower rates of adherence. When measured objectively by electronic monitors, McQuaid and colleagues [10] found that adherence to ICS in children with asthma aged 8–16 years was 48%, while DeMore and colleagues [11] found that adherence to ICS in children aged 8–12 years was 67%. Preschool children require parental administration of medication, yet adherence also is poor [12]. For example, 28% of young children (aged 2–9 years) with persistent asthma did not refill prescription controller medications within a 6-month study period [13].

Because asthma can affect the child's whole family [14], it is necessary to consider family factors when understanding adherence and disease management. This is particularly pertinent with young children who cannot administer their asthma medications without parental prompting, guidance, or direct assistance. Thus, responsibility falls on the caregivers to be cognizant of the benefits attributable to following prescription guidelines [15] and to maintaining treatment regimens. Direct parental involvement in and responsibility for administering medications with preschoolers on a daily

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basis is unique to this age group and may pose a significant burden for families.

Young children often take their preventative asthma medications via nebulizers or metered dose inhalers with a spacer to ensure children inhale a sufficient dose of medication into the lungs. The complex equipment involved in these delivery methods and the requirement for children to remain stationary and be compliant with parental requests for a number of minutes may potentially provide a barrier to treatment success in preschool children, especially if children exhibit difficult behaviors (e.g. high activity levels, opposition). Anti-inflammatory medications must be taken regularly (i.e. daily) in order to be effective, and non-adherence resulting from difficult child behavior may potentially interfere with experiencing full benefits of these medications.

Carson and Schauer [16] found that parents of school-aged children with asthma reported significantly higher levels of parent stress related to both parental characteristics (i.e. depression, role restriction, social isolation) and child characteristics (i.e. child adaptability, child demandingness, how much the child reinforces the parent) than parents of children without asthma in a normative sample. Indeed, in addition to forgetting to take medication, child oppositional behavior is another common parent-reported barrier to adherence in asthma treatment [17]. Difficult child behavior may adversely affect parental adjustment and increase parental demands related to following an asthma treatment plan. Parenting stress related to both parental characteristics and difficult child behavior has been significantly and inversely related to adherence to asthma medication in school-aged children [11]. Additionally, increased asthma-related hospitalizations have been associated with high caregiver life stress [18]. Thus, stress and fatigue associated with caring for a child with asthma, especially if combined with difficult child behavior, may present a barrier to treatment adherence in families with preschool-aged children who require more medication assistance from caregivers.

To our knowledge, the examination of parenting stress and difficult child behavior in pediatric asthma populations has been limited to school-aged children. It is likely that school-aged children are able to take some degree of personal responsibility for the management of their asthma, whereas very young children require full parental monitoring and involvement. The demands involved in providing care to young children likely increase parental burden of treatment, especially if the child displays stressful, difficult behaviors.

Caregivers' beliefs about health and medication may also impact the preschool child's adherence to their ICS. Adults with asthma who have more skeptical beliefs about the necessity and efficacy of their prescribed asthma medications (i.e. belief that they do not have to use their preventative medication when symptoms are not present) refilled their asthma medications significantly fewer times than those who did not hold these beliefs [19]. Pediatric research has revealed similar relations with regard to caregivers who provide care to children with asthma [20] and adolescents with chronic illnesses [21]. However, these results were based on subjective-reports of adherence rather than objective measurements.

Using a sample of preschoolers with asthma, the purpose of this study was to (1) assess the difference between caregiver-reported and objectively measured adherence, and (2) examine the association of parenting distress related to caregiver characteristics, parenting stress related to difficult child behavior, parental health-related beliefs, and medication adherence. First, it was hypothesized that a significant difference would be found between subjectively and objectively measured adherence to ICS. Second, it was hypothesized that parenting stress related to difficult child behaviors and caregiver health-related beliefs would have significant associations with the adherence to ICS among preschool-aged children with asthma. Specifically, it was anticipated that higher levels of parenting stress related to both parental characteristics and difficult child behavior and more negative health-related beliefs would be significantly associated with poorer adherence to asthma medication.

Methods

Participants

Participating families were recruited from a pediatric pulmonary clinic in a medium-sized city surrounded by a rural area in the southeastern United States. Eligibility criteria for participation included having a child who was (a) diagnosed with persistent asthma by a physician; (b) between the ages of 2 and 5 years; and (c) prescribed a daily controller or preventative medication for asthma. Caregivers were excluded if (a) they were non-English speaking, (b) they had significant cognitive impairments that rendered them unable to consent and/or complete study-related measures, or (c) child was prescribed only an "as needed" asthma medication.

Measures

Parenting Stress Index – short form

The PSI-SF is a 36-item, self-report measure, utilizing a 5-point Likert-type scale, intended for parents of children aged 1–12 years [22]. It yields three subscale scores: parental distress (PD), parent–child dysfunctional interaction (P-CDI), and difficult child (DC). Scores at or above the 90th percentile indicate clinically significant parenting stress. These subscales have good reliability [22] and validity [23,24]. The PSI-SF also includes a defensive responding score on which scores at or below 10 indicate that the parent is trying to present himself/herself in a very favorable light or the parent actually is a highly competent parent [22]. In the current study, the parenting distress subscale (e.g. "I feel trapped by my responsibilities as a parent") was used as an index of parenting stress related to personal parental characteristics (i.e. depression, social isolation, role restriction), and the difficult child subscale (e.g. "My child gets upset easily over the smallest thing") was used as the index of parenting stress related to difficult child behavior.

Negative health beliefs

Health beliefs were measured by a series of 19 questions developed for asthma research by Riekert and colleagues [25]. Caregivers rate items (e.g. "My child will become addicted to asthma medicines if he/ she takes them every day") using

a 5-point Likert-type scale in which 0 indicates “Strongly Disagree” and 4 indicates “Strongly Agree.” Internal consistency of the items in the current sample was 0.85 as measured with Cronbach’s alpha.

Medical record review

Patient medical record reviews were conducted to verify asthma diagnosis as well as to confirm prescribed daily controller medication name, dosage, and frequency. Information regarding length of prescription and prior medication trials was not obtained for the purposes of this study and this is further addressed in our limitations.

Medication adherence

Subjective adherence: On a medical and demographic information questionnaire designed for the purpose of this study, parents reported how many doses of medication their child missed in the 7 days prior to participation in the study. Based on prescription information, subjectively measured adherence was calculated from the number of doses of medication reported received divided by the total number of doses prescribed to be taken in 7 days, and then multiplied by 100 to yield a percentage of adherence based on caregiver-report.

Objective adherence: As an indirect but objective measure of medication adherence, pharmacy refill data were obtained for the child’s preventative or controller asthma medication (e.g. ICS). Due to the timing of refills, refill history was obtained for the 9 months prior to the study visit in order to gather and accurately calculate adherence for a full 6 months of data. For each medication, the number of doses refilled was divided by the number of doses prescribed, and then multiplied by 100 to yield a percentage of maximum possible adherence. Examination of pharmacy refill data has been found to be 92% accurate when compared to Medicaid reimbursement records, and pharmacy refill data better identified poor adherence (e.g. less than 50%) than physician assessments [26].

Procedure

Research staff approached caregivers meeting eligibility criteria during regularly scheduled clinic visits. Once informed consent was obtained, the primary caregiver completed the study measures. Caregivers were assured that their responses would not be shared with the pulmonary staff in order to decrease the risk of socially desirable responding. Upon completion, participants were compensated with a \$5 gift card.

For each pharmacy location that the caregiver reported using to obtain the child’s asthma medication, a release form was signed by the caregiver prior to contacting the pharmacies to obtain refill data. It is noteworthy that this procedure is common practice in the standard care of asthma patients in this clinic. Our university’s Institutional Review Board approved the aforementioned methods.

Statistical analysis

Data first were visually inspected in terms of minimum and maximum values, measures of central tendency, missing

values, and identification of outliers. Three participants were missing one item each from the negative health beliefs questions; for these cases, the mean of each participant’s items in this series of questions was imputed, and the total was calculated. Using mean imputation is a conservative approach for dealing with missing data because it does not change the mean distribution of that variable, as a whole. It also decreases the variance for the variable, which might reduce, but not inflate, a correlation with other variables [27]. A paired-samples *t*-test was conducted to measure consistency between objective and subjective reports of medication adherence. To investigate possible confounding variables with medication adherence, Pearson correlations were calculated.

Results

Participant demographics

Forty-six caregivers of children with asthma were enrolled in this study; however, three participants were excluded from analyses because pharmacy refill histories were not available. Thus, the sample consisted of 43 preschool-aged children (*M*/*SD* age = 3.3/1.2 years); their caregivers ranged in age from 21 to 58 years (*M*/*SD* = 33/8.2 years). The majority of caregivers were birth mothers (84%), with the remainder of the sample being composed of adoptive mothers (7%), fathers (5%), and grandmothers (5%). Most caregivers (65%) were non-Hispanic/Caucasian, 26% were Black or African American, and 9% were of Hispanic ethnicity. Approximately 58% of the caregivers were married, and the majority (58%) were employed outside of the home at the time of participation. Six months before the study, caregivers reported taking an average of 34.2 hours (*SD* = 80.7) off of work to care for or to obtain treatment for their child’s asthma. Participant demographics are shown in Table 1.

Descriptive statistics

Table 2 displays descriptive statistics for all study measures, while Table 3 summarizes correlations among study

Table 1. Participant demographics.

Children (<i>n</i> = 43)	Mean (SD)/percentage
Age	3.3 (1.2) years
Sex	
Male	67.4%
Female	32.6%
Caregivers (<i>n</i> = 43)	Mean (SD)/percentage
Age	33 (8.2) years
Race/ethnicity	
Non-Hispanic Caucasian	65%
Non-Hispanic African American	26%
Hispanic	9%
Role	
Birth mother	84%
Adoptive mother	7%
Father	5%
Grandmother	5%
Marital status	
Married	58%
Unmarried	42%
Hours taken off of work to care for child	34.2 (80.7) hours

variables. Results revealed that none of the demographic variables were significantly related to objectively measured adherence. Thirty-five percent of parents had scores at or above the 90th percentile (i.e. clinically significant) on the Difficult Child subscale. Also, 37% of caregivers had a score of 10 or lower for Defensive Responding indicating that they may have been trying to present themselves in a favorable light.

Table 4 lists positive health belief items where at least 80% of caregivers endorsed "agreed" or "strongly agreed," as well as negative or inaccurate health beliefs where at least 20% of caregivers responded with these same ratings. These data highlight some strengths in parents' beliefs regarding their ability to deliver their child's medication (e.g. "Even when there are things my child would rather be doing, I am sure I can get him/her to take his/her asthma medicine exactly the way the doctor said to") and the effectiveness of the medication as well as some concerns regarding misconceptions about asthma and effective disease management (e.g. "Even if my child takes asthma medicines, he/she will still have asthma symptoms").

Table 2. Descriptive statistics.

Variable	Range	Mean	SD
PSI – parenting distress ^a	12–46	23.33	9.47
PSI – difficult child behavior ^a	11–47	26.81	9.61
Negative health beliefs	8–52	23.51	11.96
Parent-reported adherence (%)	0–100	92.36	17.60
Objective adherence (%)	0–100	56.70	31.44

Data reported are for raw scores.

^aPSI, Parenting Stress Index – short form.

Table 3. Correlations.

Variable	1	2	3	4
1. Parenting distress	–			
2. Difficult child behavior	0.62**	–		
3. Negative health beliefs	0.25	0.60**	–	
4. Objective adherence	–0.18	–0.16	–0.33*	–

* $p < 0.05$; ** $p < 0.01$.

Relation between subjectively and objectively measured medication adherence

Parents reported a mean adherence rate of 92.36% ($SD = 17.60$) for ICS over the 7 days prior to participation. The mean percentage for adherence based on pharmacy refill data was 56.70% adherent ($SD = 31.44$). Subjective, parent-reported adherence was significantly higher than objectively measured adherence, $t(42) = -8.02$, $p < 0.001$ [95% CI: -44.64 to -26.69], indicating that parents over-estimated their level of adherence.

Correlations between parenting stress, negative health beliefs, and adherence

Negative health beliefs were moderately and significantly correlated with objectively measured medication adherence, $r = -0.33$, $p = 0.03$. Thus, as negative health beliefs increased, medication adherence decreased. Neither parenting distress ($r = -0.18$, $p = 0.25$) nor difficult child behavior ($r = -0.16$, $p = 0.30$) was significantly correlated with our objective measure of adherence. Negative health beliefs were correlated significantly with difficult child behavior ($r = 0.60$, $p < 0.001$), suggesting that negative health beliefs are positively associated with higher levels of difficult child behavior.

Discussion

Consistent with asthma-related adherence research [9,10,11,13], objectively measured medication adherence was poor in this sample and was subjectively over-reported by caregivers [28,29]. Contrary to our hypothesis, our findings do not suggest that parenting stress as a function of personal parental characteristics or difficult child behavior was significantly associated with medication adherence in preschool-aged children. Thus, the current study fails to extend to preschool children the findings of DeMore and colleagues [11], which demonstrated that these types of parenting stress significantly predicted ICS adherence as measured by a dose monitor in children aged 8–12 years. Perhaps because school-aged children have more responsibility in taking their ICS, children who exhibit more difficult behavior may also be more rebellious regarding taking their medication. In contrast, in a preschool sample, parents are responsible for administering the ICS and may be able to

Table 4. Percent of caregivers for each response to health beliefs that were highly endorsed by the overall sample.

Item content	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
<i>More than 80% endorsed a positive belief</i>					
I am sure that I can help my child take his/her medicine exactly the way the doctor said to	53.5	41.9	0	2.3	2.3
Even when there are things my child would rather be doing, I am sure that I can get him/her to take his/her asthma medicine exactly the way the doctor said to	46.5	44.2	0	4.7	4.7
Taking asthma medicines keeps my child from having to go to the hospital.	32.6	51.2	7.0	7.0	0
<i>More than 20% endorsed a negative belief</i>					
Even if my child takes asthma medicines, he/she will still have asthma symptoms	4.7	48.8	9.3	18.6	16.3
Taking asthma medicines makes my child hyper	11.6	27.9	14.0	32.6	11.6
Even when they feel well, children with asthma should limit how much they play or exercise	11.6	27.9	4.7	16.3	37.2
Taking medicine makes me worry more about my child's asthma	4.7	23.3	9.3	34.9	25.6
It is hard to make my child take medicine when he/she feels fine	7.0	16.3	4.7	23.2	48.8

overcome difficult child behavior to promote child health. This explanation is corroborated by high parental endorsement of the health belief items regarding being able to give the asthma medication “even when my child would rather do other things.” The focus on preschoolers precluded an evaluation of the relation between parenting stress related to difficult child behavior and adherence across developmental phases. Because preventative asthma medications are typically part of a long-term treatment regimen, it would be interesting to examine the relation between these variables via longitudinal design in future research.

Current results are consistent with that of previous research that has found skeptical beliefs about effectiveness of medication treatment regimens to be related to adherence in adults [19], adolescents [21], and children [20]. By focusing specifically on parents of preschoolers with asthma, a patient group with potentially unique barriers to adherence, the current study extends the finding of a significant association between beliefs and medication adherence to the preschool-aged child and the caregivers who are responsible for their medication administration. Furthermore, past research about health beliefs and medication adherence have relied on self-reported adherence. Therefore, the findings from the current study further expand upon previous research by relating negative health beliefs to objectively measured adherence.

The fact that our results revealed that caregiver negative health beliefs regarding asthma medications are related significantly to medication adherence in preschool-aged children implies that these parental health-related beliefs are a potential treatment barrier and an important target of interventions to improve medication adherence in this young group of asthma patients. Consequently, medical professionals should be encouraged to routinely assess caregivers’ beliefs about asthma medication and attempt to rectify misperceptions and misinformation.

Examination of specific items regarding parental beliefs highlights both strengths in parents’ beliefs regarding their ability to deliver their child’s medication and the effectiveness of the medication, as well as concerns regarding misconceptions. For example, parents marked “strongly agree” or “agree” for the following statements: “I am sure that I can help my child take his/her medicine exactly the way the doctor said to” (95.4), and “Taking asthma medicines keeps my child from having to go to the hospital” (83.8%). Thus, many caregivers expressed confidence in their ability to follow the prescribed medication regimen and that the medications would decrease emergency hospital visits. In contrast, 20% or more of caregivers endorsed some inaccurate beliefs regarding asthma medication, such as “Even if my child takes asthma medicines, he/she will still have asthma symptoms.” If the parent believes that the child will experience symptoms of asthma even when taking medications, the parent may not raise concerns with the healthcare provider. This may prevent the healthcare provider from working with the family to identify barriers to adherence or to develop an alternative asthma action plan.

A few other concerning beliefs that may impact adherence were apparent from our data. Forty percent of parents believed that asthma medication made their child “hyper.” Given that parenting stress related to difficult child behavior

was significantly and strongly associated with negative health beliefs, parents of children who are very active may mistakenly attribute their children’s hyperactivity to side effects of the ICS. Also, in an attempt to decrease their child’s activity level, parents may not give their child the ICS as prescribed. When asking parents about observed side effects of medication, healthcare providers should be ready to dispel any misconceptions about hyperactivity and ICS. If the caregiver reports hyperactivity, the healthcare provider should explore with the caregiver the frequency and severity of the problem and make a referral for a behavioral health evaluation and treatment, if warranted.

Additionally, 28% of caregivers agreed that “Taking medicine makes me worry more about my child’s asthma,” and 23% agreed that “It is hard to make my child take medicine when he/she feels fine.” Because negative health beliefs were significantly related to medication non-adherence, it is possible that some parents may avoid giving their child medication because this triggers feelings of anxiety about their child’s health. It may be important for healthcare providers to assess parents’ feelings surrounding giving medication when children appear healthy, especially because children will appear healthy when the asthma is well-controlled.

The results of the current study may be limited by socially desirable responding. For example, the PSI-SF Defensive Responding Scale indicated that 37% of respondents may have under-reported levels of parenting stress. Although results did not differ when these participants were excluded, it is possible that a significant relation between the hypothesized risk factors and medication adherence may have failed to emerge due to caregivers’ defensive or socially desirable responses. Indeed, the high level of parent-reported medication adherence, in contrast to the objective measure, further supports the presence of socially desirable responding in our sample.

Additionally, there are limitations inherent to the use of pharmacy refill data to objectively measure adherence. We do not have any data regarding the context in which the physician prescribed medication nor are we aware of the way in which families were provided education regarding medication use, all of which could potentially impact family perception of the importance of adherence. Adherence may also be overestimated for cases in which medications are refilled but not ingested; however, it may also be underestimated in families who share medication. Further, some children of caregivers who participated in this study were prescribed their daily asthma preventative medication only one to two months prior to caregiver participation; therefore, their rates of adherence were based on shorter intervals of time than desirable for study purposes (e.g. 6 months). Adherence data based on shorter intervals may be more variable and less representative of true adherence than those based on longer intervals. A shorter interval of medication usage may also indicate that the child was recently diagnosed and/or recently initiated treatment; however, this was not formally assessed in this study. Lastly, we acknowledge that our sample size of 43 participants is modest and serves as a limitation as it may ultimately decrease the generalizability of study results. Nevertheless, we believe that our findings demonstrate the

feasibility of measuring barriers to adherence in preschool-aged children with asthma and will serve as a basis for future studies in this population.

Taken together, our results highlight the necessity of further research that tests the utility of adherence-promoting interventions in young children aimed to rectify caregivers' misunderstandings about the importance of asthma medications. A recent study tested a mobile-based intervention that delivered individually tailored text-messages based on medication and illness beliefs in adults with persistent asthma [30]. Medication adherence in intervention participants significantly improved as compared to controls and was maintained at 9-month follow-up. Although these results are based on a sample of adult patients, it suggests that a physician-delivered, individualized psychoeducational intervention may increase medication adherence in parents of young children with asthma. Family-based interventions early in the child's life and quickly after diagnosis may establish good understanding of and habits related to medication adherence that will promote optimal health. Consequently, it is suggested that providers especially make time to work collaboratively with parents of young children with asthma, carefully explaining the purpose underlying each medication and the importance of adherence as well as asking non-confrontational questions to assess caregiver understanding and beliefs.

Conclusions

Caregivers of preschool-aged children with asthma are critical in medication adherence because they are responsible for medication administration. Thus, barriers to adherence in this population may differ from those of children at higher developmental levels because school-aged children and adolescents can take a more active role in their medication regimens. As caregivers model adherent practices early in their child's life, the child may be more likely to engage in similar health behaviors when he or she begins to take more responsibility for asthma treatment with advancing age. Conversely, parents with negative or inaccurate beliefs about medications may transmit these beliefs to their child resulting in less treatment adherence when the child takes on more responsibility for his or her own treatments. Thus, continued research is needed to identify barriers to and factors that promote adherence in young children to facilitate developing early and effective strategies toward a life-long pattern of regimen adherence.

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