



Symptoms, Feelings, Activities and Medication Use in Adolescents With Uncontrolled Asthma: Lessons Learned From Asthma Diaries

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Key words:

Uncontrolled asthma;
Adolescents;
Symptoms;
Emotional response;
Activity;
Medication adherence

This study was to describe symptoms, feelings, activities and medication use reported by adolescents with uncontrolled asthma on their 24-hour asthma diaries. Adolescents with uncontrolled asthma (13–17 years, $N = 29$) completed asthma diaries and audio-recorded symptom sounds for 24 hours. A variety of symptoms were reported, and the most frequently reported symptoms were coughing followed by wheezing. Most self-reported coughing and wheezing were verified by audio-recordings. Participants reported predominantly negative feelings and low levels of activities. High discordance between self-reports and medical records in medications was noted, raising a concern of poor treatment adherence in this vulnerable group.

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ASTHMA IS THE most common chronic health condition in children and adolescents. According to 2009 National Health Interview Survey (Center for Disease Control & Prevention, 2011), over 7 million children (9.6%) 17 years and younger had current asthma in the U.S. Of those, 39% (2.8 millions) were adolescents (12–17 years). Uncontrolled asthma takes a large toll on not only children with the disease but also the society. Over 14 million missed school days annually in the U.S. are attributable to uncontrolled asthma (American Lung Association, 2010) that is also responsible for 7.5 million outpatient office visits, over 640,000 ED visits and 157,000 hospitalizations in 2007 (Akinbami, Moorman, & Liu, 2011). Nonetheless, little is known about symptoms that adolescents commonly experience during the acute phase of uncontrolled asthma, and how they emotion-

ally respond to the symptoms. Further, prior reports do not address the levels of activities that adolescents engage in and types of medications used by adolescents during the acute phase.

The 2007 National Asthma Education and Prevention Program (NAEPP) Asthma Guidelines (National Heart, Lung, & Blood Institute, & Blood Institute, 2007) classify asthma control into three categories—“well-controlled,” “not well-controlled (NWC)” and “very poorly controlled (VPC)”—based on the levels of impairments including daytime symptoms, night-time symptoms, interference with normal activity and use of short-acting beta agonists (SABA, “quick relief medication”). It is important to assess the levels of asthma control as it becomes the basis of determining optimum asthma management plans. For individuals 12 years or older, uncontrolled asthma, which includes NWC and VPC, is indicated when daytime symptoms are more than 2 days per week, night-time symptoms are one to three times per week, “some to extreme” (NHLBI) activity

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limitations or use of SABA more than 2 days per week. Uncontrolled asthma has been a target of extensive research efforts that focus on effective treatments and managements. However, little is known about symptom and emotional experiences or the levels of activities in adolescents suffering from uncontrolled asthma.

Because the levels of asthma control are primarily determined by patients' symptom reports, the NAEPP guidelines emphasize the importance of individual patients' asthma monitoring for optimum asthma management (National Heart, Lung, & Blood Institute, & Blood Institute, 2007). An asthma diary, as recommended by the National guidelines, is one asthma self-assessment method. Clinically, asthma diaries can be used for gathering clinical information for better care of patients, guiding asthma self-management through symptom monitoring and medication adherence, and improving assessment and strengthening patient-provider communication (Cruz-Correia et al., 2007). In particular, symptom diaries are useful to those whose asthma is not under control or persistent in nature, as it can aid in the identification of asthma of higher severity (National Heart, Lung, & Blood Institute, & Blood Institute, 2007; Reznik, Sharif, & Ozuah, 2005). Asthma diaries completed on a day-to-day basis, thus eliminating recollection errors (Hensley et al., 2003), are a better means for identifying patients with persistent asthma compared to retrospective reports, as in a periodic self-assessment form completed at the time of an office visit (e.g., Asthma Control Test). Use of asthma diaries has been limited to clinical settings on an individual basis, and no attempt has been made to achieve collective understanding or descriptions of asthma experiences based on data provided by asthma diaries. Unlike a standardized questionnaire, an asthma diary is not stringent in its format or collected information, and can be modified to obtain a wide range of experiences (e.g., symptoms, activity, emotions or medication use) pertaining to the disease. Therefore, asthma diaries seem to be an appropriate tool with which to gauge experiences of adolescents with uncontrolled asthma. The range of experiences captured in this study reflects key concepts of the self-regulation theory (Johnson, 1999). The theory assumes that people use their perceptions of health events (e.g., symptoms) to regulate their functional (e.g., activity or medication adherence) and emotional responses (e.g., feelings) (Johnson).

The purpose of this descriptive study was to examine self-regulation in adolescents with uncontrolled asthma through the descriptions and in-depth analysis of information provided in the asthma diaries, including symptoms, feelings, activities, and medications, all major components of the self-regulation theory. Specific research questions of the study included the following: (RQ1) What are the common asthma symptoms experienced by adolescents with uncontrolled asthma? (RQ2) What are the adolescents' emotional responses to uncontrolled asthma? (RQ3) What are the levels

of activities in which the adolescents engage? and (RQ4) What are the types of medication used by the adolescents to control their symptoms, and what is the extent to which the adolescents' self-reported medications concur with the providers' prescriptions?

Method

This was a cross sectional, descriptive study analyzing written descriptions in 24-hour asthma diaries provided by adolescents with asthma ($N = 29$). The asthma diaries were collected as part of a larger research study. The diary data reported in the current study capture one aspect of the self-regulation theory, perception of their experience (i.e., symptoms) to regulate their emotions (i.e., feelings) and subsequent behavior including activity and medication use.

Sample and Setting

Eligibility criteria included ages between 13 and 17 years, having an asthma diagnosis, meeting criteria for uncontrolled asthma by the NAEPP guidelines and currently experiencing asthma symptoms (acute asthma) as verified by healthcare providers. Only those who could speak and write English were included in the study. A total of 173 adolescents with asthma diagnosis who visited outpatient clinics or pediatric emergency department (ED) in a major academic medical center were screened. Of those, 39 were found to be eligible, with 29 enrolling and 10 declining participation. The majority were recruited from the pediatric ED ($n = 19$; 66%) followed by pediatric primary practice ($n = 8$; 27%), pediatric pulmonary outpatient clinic ($n = 2$; 7%).

Data Collection Procedure

The study team devised a 24-hour asthma diary format that allowed participants to record symptoms, feelings, activities, and medication use in the morning, afternoon, evening and nighttime (Figure 1). Participants recorded this health information in the open-ended format of the diary. Simultaneously, participants continuously audio-recorded their breathing sounds to capture audible asthma symptoms (e.g., wheezing or coughing) using a commercially available compact digital recorder during the 24 hours. Electronic medical records of the participants were also reviewed to obtain information about their current asthma medications.

At enrollment, participants completed a simple socio-demographic form and were given detailed verbal and written instructions about operating the digital recorder and completing the 24-hour asthma diary. The recorder was turned on during the enrollment meeting and the attached

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