Volitional Nonadherence in Pediatric Asthma: Parental Report of Motivating Factors

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Volitional nonadherence is thought to be common among patients with chronic health conditions, including pediatric asthma. To date, no data have been published on the extent to which, and reasons why, families purposefully adjust their child’s asthma regimen. This study provides descriptive data for parental report of volitional nonadherence in a sample of 101 children (ages 1–17 years) with asthma. Families tended to decrease rather than increase use of controller medication, but were more likely to increase rather than decrease preventive medication. Motivating factors for increasing medications centered around achieving better symptom control, whereas reasons for decreasing medications involved a perception of less need (ie, asthma was better) and desire to reduce treatment burden. Our results suggest it is important to better understand volitional nonadherence so that behavioral interventions aimed at promoting adherence and health outcome can be more effective.

Introduction

Adherence, or compliance, can be defined as the extent to which a patient follows a treatment plan as prescribed by the health care provider. The word “adherence” is preferred by many health care providers, because “compliance” suggests that the patient is passively following orders in a treatment plan that is not based on a partnership between the patient and health care provider [1]. Ideally, health care providers and patients develop a working alliance [2], leading to concordance between the prescribed regimen and the treatment that is actually carried out [3]. Yet, evidence from the medical literature has documented that concordance rarely is achieved [4]. In fact, a systematic review of asthma adherence literature found that across studies, patients only took the prescribed number of inhaled corticosteroid (ICS) doses on 20% to 74% of days measured [5]. Additionally, one evaluation of adherence in families with at least one child with asthma found that children only took an average of 48% of their prescribed ICS doses across 1 month [6].

The significance of this relatively low level of adherence is particularly salient when considering the evidence of morbidity associated with nonadherence (eg, increased rates of emergency department visits, hospitalization, and school absences) [7]. Increasing evidence also suggests that nonadherence to ICS can lead to permanent airway restructuring or lung scarring [8]. Thus, it is important to understand the factors underlying medication nonadherence, so that health care professionals can work more effectively with families to create better health outcomes.

When attempting to understand nonadherence, it can be helpful to consider that two types have been posited: inadvertent and volitional [9]. Inadvertent nonadherence occurs when families desire to be fully adherent but fail to do so because of forgetfulness, misunderstanding the doctor’s instructions, or poor medication-taking techniques. On the other hand, volitional nonadherence involves patients making a reasoned or purposeful decision to change the regimen by increasing, decreasing, or even stopping prescribed medications [10]. These decisions may be based on a good understanding of their disease [11] (eg, recognizing that asthma flares during certain allergy seasons); however, some patients may base decisions on misinformation (eg, fear of long-term side effects) [12]. Thus, the outcomes of volitional nonadherence could vary widely. For example, patients may feel that their quality of life is improved when they change the medical regimen to better fit their treatment goals (eg, reducing medication schedule decreases treatment burden).

On the other hand, volitional nonadherence may increase the negative short-term and long-term consequences from poorly controlled symptoms and lead to higher health care costs. In a study of adults, patients...
with moderate-to-severe asthma who chose to take less medication than prescribed had worse outcomes (ie, unscheduled health care service use, decreased quality of life) than adherent patients with comparable disease severity; by comparison, patients with mild asthma who reported purposefully taking their medication less than directed had health outcomes similar to those with mild asthma who reported good adherence [13]. These results suggest the impact of volitional nonadherence may vary as a function of disease severity; further research is necessary to confirm such findings and to examine whether they apply to pediatric patients.

The waxing and waning nature of asthma symptoms may tempt patients to be volitionally nonadherent. For example, patients may choose to increase or decrease their medication use based on symptom levels [10••,13••]. On the other hand, different aspects of the treatment plan itself may result in decisions to reduce the amount of medication or frequency of taking it. In fact, high costs of medications [14], desire to reduce the complexity or inconvenience of the regimen [15,16], and dislike for the route of delivery (ie, preference for pills over inhaled medications) [12,17] are regimen-related factors that already have been associated with nonadherence. The quality of the relationship between the health care provider and patient can also influence volitional adherence [18•,19•]. For example, if the provider does not adequately explain the need for a medication or the patient does not trust the provider’s judgment or diagnosis, the patient may choose not to follow the prescribed regimen. Finally, perceptions of treatment efficacy and the seriousness of the illness may affect the extent to which a patient follows a prescribed regimen [20,21].

In summary, families make decisions about their child’s asthma care based on a complex set of beliefs, information, lifestyle decisions, and priorities. Although behavioral treatment research has focused primarily on the risk factors and outcomes of inadvertent nonadherence, some nonadherence may reflect careful and deliberate decision making (ie, volitional nonadherence). Thus, it is important to examine these types of nonadherence separately when evaluating risk factors and outcomes and when designing interventions to improve adherence. To date, there have been no published data about the extent to which, and the reasons why, families of children with asthma engage in this purposeful decision making. This study reports data, from the parents’ perspective, with regard to volitional nonadherence in pediatric asthma.

Method

Participants
Our sample consisted of 101 primary caregivers of children (ages 1–17 years; mean = 8.0; SD = 4.1) with an established diagnosis of asthma (average time since diagnosis 5.2 years; SD = 3.6). Participants were recruited from two specialty asthma and/or allergy clinics within university-affiliated hospitals, one in the midwestern and the other in the southern United States. This sample of asthma patients was 65% male, with 52.5% self-identified as white, 34.3% African American, 6.1% Hispanic American, 2.0% Asian American, and 5.1% other or mixed ethnicity. Most children had mild or moderate persistent asthma (37% and 38%, respectively), with 19.6% diagnosed with mild intermittent and 5.4% with severe persistent asthma.

Of participating caregivers, nearly 87% were mothers, 10.1% were fathers, and 3.0% were other family members (eg, grandparent). Half of the sample came from intact families (ie, both biologic parents in home), with 15.3%, 26.5%, and 8.2% coming from blended, single-parent, and other (eg, living with relatives) family structures. Median education level for mothers and fathers was at least some college or specialized training. Families reported, on average, an annual income level of $30,000 to $39,999. These data suggest that most families were within the lower to middle socioeconomic range.

Procedure

Primary caregivers of eligible children (ie, with existing diagnosis of asthma and within age range of 1–17 years) were approached by a researcher during a scheduled visit to the allergy and/or asthma clinic. After providing informed consent, caregivers completed a demographic and medical information form. Following this, instructions for completing the study questionnaire (Asthma Care Behaviors) were reviewed in detail, caregivers’ questions were addressed, and if necessary, reading assistance was provided.

The Asthma Care Behaviors measure was designed for this study to assess volitional nonadherence to asthma medications over the past 3 months. Its content and format were revised through a series of standard stages in questionnaire development (eg, item development, expert review of content, piloting with families). The measure provides instructions clarifying the difference between inadvertent and volitional nonadherence, with reminders throughout the questionnaire to be certain that caregiver responses were capturing volitional nonadherence only. The questionnaire is divided into three sections: 1) extent to which families engage in volitional nonadherence for each specific class of asthma and allergy medication (eg, asthma controller inhaler/discus); 2) motivating factors for purposefully increasing (eg, anxiety about symptom control) and/or decreasing (eg, financial concerns) medications in general; and 3) overall approach to volitional nonadherence (eg, communication with provider, monitoring effects).

In the first section, each potential class of medication included in an asthma patient’s treatment plan was listed and caregivers were asked to report whether the medication was prescribed for their child, and if so...