NON-ADHERENCE WITH ASTHMA THERAPY: MORE THAN JUST FORGETTING

The ubiquity of non-adherence with medication regimens is well-known to clinicians and has been extensively documented in the literature. Research that has quantified the frequency of pediatric non-adherence across a range of chronic illnesses such as diabetes, rheumatoid arthritis, and cystic fibrosis has found that adherence levels ≤50% of prescribed dosage are common.1,2 Studies of children’s adherence with asthma therapy have reported similarly poor average rates of adherence.3-5

Non-adherence with treatment regimens has been repeatedly implicated as a contributor to sub-optimal clinical control in chronic pediatric illnesses.6 Although the consequences of periodic non-adherence with therapy among children with mild asthma may be insignificant, for some children drug holidays or chronic under-use of controller medications can result in persistent asthma symptoms, increased missed days of school, unnecessary urgent healthcare visits, and increased risk of fatal or near fatal asthma attacks.5,7,8 Understanding those factors that contribute to non-adherence with asthma therapy has the potential to help families more effectively manage their child’s asthma and reduce asthma morbidity.

As reported in this issue of The Journal, Fiese, Wamboldt, and Anbar sought to develop a reliable measure of asthma management routines and to evaluate its association with adherence with therapy, as well as parent and child quality-of-life and healthcare utilization.9 The investigators based the development of this instrument on their previous work, which suggested that family routines might be instrumental in assisting families manage asthma and adhere with therapy.10 Factor analysis of the eight-item Asthma Routine Questionnaire resulted in the identification of two factors; the first factor was labeled “Medication Routines” because these four questions dealt primarily with medication-taking activities, and the second factor was labeled “Routine Burden” because these three questions primarily measured whether asthma care was considered a burden. The “holy grail” of adherence research has long been to develop measures that can identify specific and modifiable determinants of patient non-adherence. A brief, valid, and reliable measure that could predict families at risk of non-adherence would not only be a useful clinical tool it also would contribute to our understanding of the potentially modifiable determinants of adherence. The measure developed by Fiese et al shows promise in this regard. As the authors note, however, the measure is limited by relatively modest internal consistency; thus additional studies with a larger sample will be needed to establish the validity and reliability of the measure. In addition, it also is worth recognizing that the creation of behavioral questionnaires is as much an art as it is a science. Labeling scales or measures derived from factor analysis can at times have a Rorschach-like quality—the label used to describe the “truth” of the underlying construct is necessarily defined by the theoretical perspective of the investigators. In this instance the investigative team has a long interest in examining the role that family routine plays in successful disease management. The subset of items labeled Medication Routine (i.e., medications refilled on a regular basis, whole family reminds child to take medications, routine around when to take medications, appointments scheduled in advance) was described by the investigators as centering around planning, regularity, and predictability of medication use. Based on this conceptualization the authors conclude that “parents who reported better medication

See related article, p 171.

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routines had children with better medication adherence.9 It is important to recognize, however, that the observed correlation between the Medication Routine subscale and adherence behavior is inherently limited by the tautology of using predictor variables that are overlapping or redundant with the outcome variable. Thus, as the investigators note, the correlational study design does not allow a determination of causal association between family reports of established medication routines and children’s adherence with therapy.

Yet even without clear evidence of a causal association the potential benefit of established family routines to effective asthma management practices is intuitively obvious. A recent study of adherence with antiretroviral therapy further supports this premise. Wagner et al found that the extent to which a patient’s daily activities (eg, eating breakfast, watching favorite television programs) were routinized was the single best predictor of adherence with therapy.11 And Irvine et al has reported that parents of children with well-controlled asthma and good refill adherence were more likely to report organized morning and evening routines related to inhaler administration, compared with parents of poorly controlled children and low refill adherence.12 It makes sense that families that function in an orderly, structured, and predictable fashion can provide the every day “bones” on which regular medication routines can be hung. Family routines can not only facilitate regular adherence, they also can model and reinforce the skills and values necessary for children to develop effective disease self-management when they transition to adolescence. However, the reality for many families today is that day-to-day life is anything but predictable or routine. Between day care, soccer practice, weekends at Dad’s house, and car pooling, household schedules can change on a daily basis. And for low-income families or families struggling with other stressors such as marital discord, substance abuse, or other health problems, the challenges of daily life may overwhelm family routines. In fact, chaotic family life has not only been associated with poor adherence but also with increased asthma morbidity.8,12

Although some portion of children’s poor adherence with asthma therapy may be attributable to irregular family medication routines, it also is important to recognize that not all non-adherence is the result of forgetting or disordered routines. Considerable research suggests that pediatric non-adherence is multidimensional and dynamic. Factors such as comprehension of the therapy and health beliefs each may influence parents’ ability and willingness to follow prescribed therapy. Parents may be inadvertently non-adherent with the prescribed asthma therapy if they fail to fully understand what medications their child should take or how to take them. In addition, if parents do not understand the importance of regular daily adherence with controller medications they may discontinue use when their child’s symptoms improve. Research suggests that parents’ knowledge of their child’s prescribed asthma regimen is often inaccurate, with parents frequently misunderstanding the role or value of controller therapies.13,14 Studies in adults suggest that patients forget or misunderstand close to half of the information provided by their doctor during an office visit, and for some patients low health literacy may be a particular barrier to understanding and adhering to therapy.15,16 Parents’ opinions about the value and role of asthma medications for their children do not necessarily match those of the treating physician. Parental concerns about giving an otherwise healthy child a daily medication may lead parents to use as little medication as possible. Reikert et al found that mothers who expressed greater concerns about the safety or value of asthma controller medications were more likely to be discordant with their child’s physician about whether the child was prescribed daily ICS therapy for asthma.17 Parent’s well-being also can influence their ability to adhere with their child’s prescribed therapy. For example, Bartlett et al found that mothers with more depressive symptoms reported greater non-adherence with their child’s asthma therapy.18 This is consistent with a growing body of research that suggests that depression may be one of the most important red flags for non-adherence in both adults and children.19

Finally, it’s worth remembering that non-adherence with therapy does not necessarily result in worsening asthma. Parents may find some variation of the prescribed therapy that they believe works better for their child than the doctor-prescribed regimen. Parents may be hesitant to candidly tell their child’s pediatrician that they have not followed “doctor’s order.” Regardless of the child’s level of adherence or asthma control, pediatricians will need to use sensitive interviewing and active listening in order for parents and children to feel comfortable discussing actual patterns of medication use.

Solutions to adherence problems in asthma management will be as varied and idiosyncratic as each family being treated. As Fiese et al suggest, most families will benefit from concrete behavioral advice on establishing regular medication routines such as schedules for refills, reminders, or linking medication use to existing daily routines.9 Some families also will require additional patient education and review to fully understand and endorse the value of daily prophylactic asthma therapy. And a few high-need families will require more extensive social or psychological services and support in order to create a stable home life compatible with effective asthma adherence and management. The one essential adherence intervention appropriate for all families will be open-ended, non-judgmental provider-patient communication about the families’ knowledge, concerns, barriers and motivation to adhere with the prescribed therapy.

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REFERENCES


TESTING DIAGNOSTIC TESTS: WHY SIZE MATTERS

For more than 50 years, quantitative determination of sweat chloride has been the gold standard in the diagnosis of cystic fibrosis (CF). Currently, the sweat chloride test is used to confirm or rule out the diagnosis of CF in two populations: neonates identified by newborn screening programs and patients presenting with clinical features suggestive of the disease. The sweat chloride test, when performed correctly, is accurate and reliable but labor intensive. In an effort to simplify the test, sweat conductivity methods have been developed. Conductivity represents the nonspecific measurement of the total anion activity in a solution and therefore has a higher concentration in sweat than chloride. Sweat collected in Macroduct coils and transferred to the Sweat-Chek conductivity analyzer (Wescor Inc., Logan, Utah) has been used in some settings as a screening test for CF. Individuals with a conductivity result above a prescribed cut-point are then referred for a confirmatory quantitative chloride measurement at a CF care center. Some have suggested that sweat conductivity performs as well as sweat chloride in diagnosing CF and could be used alone as a confirmatory test.

Recently, a new point of care conductivity analyzer, Nanoduct (referred to as the "new system"), has been developed for use especially in the neonatal population. As described in the accompanying article by Barben et al, the new system combines sweat collection and analysis into a single disposable conductivity sensor, using 3 μL of sample. The sensor and readout provide conductivity results within 30 minutes. The potential advantages over the traditional sweat chloride test are ease of use and availability of results within a short period of time. The important question remaining to be answered is whether the new system is as diagnostically accurate as the quantitative sweat chloride test in discriminating between CF and healthy individuals. The Barben article is the first published paper evaluating this new instrument.

In their study of 20 patients with classic CF, 73 patients referred for sweat testing, and 1 patient with nonclassic or borderline CF, Barben et al reported 100% sensitivity (95% CI, 83% to 100%) and 100% specificity (95% CI, 95% to 100%) for the new system compared with sweat chloride testing. We cannot know the true sensitivity or specificity of a diagnostic test. We can only observe the results from studies with relatively small numbers of individuals. From this imperfect information, we conclude that the chances...