Ask the Expert

Education Is Key to Treatment Adherence

Therapy for juvenile ideopathic-arthritis includes treatment with medications that have to be taken consistently for long periods of time and continued exercise. Often, the therapy is associated with unwanted, short-term side effects such as stomach upset or pain, and the benefits of the treatment are not always immediately recognized. These factors—as well as the reality that getting children and adolescents to "take their medicine" can be challenging under the best of circumstances—contribute to dismal treatment adherence rates, which in turn can have a negative impact on treatment efficacy and, potentially, long-term outcome, according to Dr. Michael A. Rapoff, professor of pediatrics at the University of Kansas Medical Center in Kansas City.

MICHAEL A. RAPOFF, M.D.

In this month's column, Dr. Rapoff, who is also chief of the medical center's division of behavioral pediatrics, discusses the obstacles to ensuring treatment adherence in juvenile ideopathic arthritis (JIA), the consequences of poor adherence, and interventions to improve patient and parent compliance with the sometimes complex therapeutic regimens.

Rheumatology News: How common is treatment nonadherence in JIA?

Dr. Rapoff: In the literature, when parents and kids themselves are asked about medication adherence, the rates look pretty high, from 83% to 95%, but using more objective measures, such as drug assays or electronic monitoring that records the time of day the medication bottle is open, the rates range from 45% to 70%, which is pretty consistent with the literature regarding treatment adherence in pediatric chronic illness. In some studies, adherence is measured by how much medication is needed to get a good effect, with 80% or more being the typical cutoff point. Based on this measure, about 48% of patients are nonadherent—or take their medication less than 80% of the time—which, again, is pretty consistent with the general literature regarding chronic illness in kids. With respect to exercise adherence, the numbers are difficult to assess. This is an area that hasn't been well studied, but in general, parents and kids report that it's much more of a hassle to exercise. It obviously requires effort and often it can be painful for these kids.

RN: What are some of the factors that contribute to a high rate of nonadherence?

Dr. Rapoff: Adherence tends to be symptom driven, and the symptoms in JIA are episodic. At the beginning of treatment, adherence is typically high. As the symptoms subside, the perceived need for treatment wanes and parents and children become less vigilant. Adherence also tends to correlate with disease severity. Side effects can be an issue as well. Drugs such as nonsteroidal anti-inflammatories can produce gastrointestinal irritation, which may compromise adherence. Finally, when disease-modifying antirheumatic drugs such as methotrexate are prescribed, the efficacy is not immediately noticeable, which can affect adherence.

RN: What are some of the short- and long-term consequences of treatment nonadherence?

Dr. Rapoff: Over the long run, nonadherence might compromise the benefits of therapy. It can definitely compromise therapeutic efficacy, which in turn results in higher health care costs, to both the family and to society in general, as disease severity and necessary interventions increase. Uncontrolled disease in children and adolescents leads to substantial reductions in quality of life. These kids are more likely to have interference in their social, school, and family interactions. The symptoms may keep them from engaging in normal, age-appropriate activities that promote physical and mental health. Such consequences, as well as struggling with the disease symptoms and the idea of being different from their peers, can lead to anxiety and depression.

There are some technical considerations as well. Treatment nonadherence can negatively affect research. If you have a clinical trial comparing one drug to the other, nonadherence can alter the findings. Also, physician judgment can be affected. If the physician prescribes a certain treatment, such as an NSAID, and the patient appears not to be getting better, the physician may decide to ramp up therapy, either increasing the dose or moving to stronger medication with a higher side effect profile.

RN: In clinical practice, how can rheumatologists assess adherence?

Dr. Rapoff: In general, such assessment is not done outside of the research arena. It might become more practical if HMOs and large providers would adopt electronic monitors or some other assessment vehicle. Right now, rheumatologists ask questions to identify potential problems with following prescribed therapies. It's important, at every visit, for the rheumatologist to ask, in a nonjudgmental way, about adherence, such as, 'Everyone has trouble remembering their medication now and then. Have you had any difficulty? Is there anything specific getting in your way?" This will encourage dialogue and will let the patient know that it's okay to be honest about whether he or she is taking the medication. When talking about starting therapy, it's also important to get agreement from the family about what is required and whether they anticipate any problems with adherence. At each visit, the issue should be addressed at the outset. If there are concerns about whether a particular patient is complying with treatment, check pharmacy records to determine if prescriptions have been filled at regular intervals and determine if that coincides with adherence self-reports.

RN: Can interventions improve adherence?

Dr. Rapoff: First and foremost is education. Educate families and children about the disease, the diagnosis, the symptoms, and the available therapies and why we recommend them, then secure the cooperation of the family. Educational and peer support groups can be helpful in this domain. Clinically, make adherence part of taking the patient's history and try to identify potential barriers to adherence that might be easily addressed through simple measures such as using pillbox reminders or incentive strategies. Making the treatment regimen as simple as possible is another important consideration. Talk with the families about how it will fit in to their schedules and what can be done to make it easier.

Currently, our group is developing educational CD-ROMs and online resources for children with JIA and their families. These will serve as additional resources for education and support and will address the importance of adherence. This will be a great tool for kids in particular, who are so adept with technology. The ability to engage in Web chats and get information interactively will help provide support in a nonthreatening manner to these kids. ■

Dr. Rapoff is the Ralph L. Smith Professor of Pediatrics at the University of Kansas Medical Center, Kansas City. He is also chief of the division of behavioral pediatrics and vice chair of research scholarship and faculty development at the center.

By Diana Mahoney, New England Bureau

Pediatric SLE: Ethnicity and Age Affect Incidence, Course

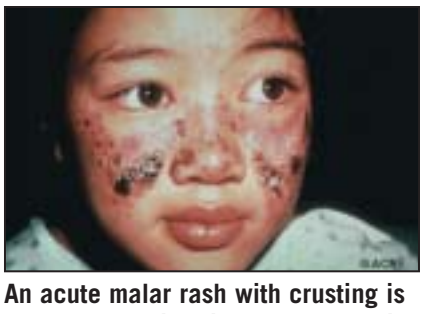
BY SHARON WORCESTER
Southeast Bureau

Destin, Fla. — Ethnicity appears to play an important role in the incidence and clinical manifestations of pediatric systemic lupus erythematosus, data from a recent study suggest.

Findings from the study of 87 white and 154 nonwhite children showed that whites accounted for more than 60% of age-matched controls without pediatric systemic lupus erythematosus (SLE) but fewer than 40% of the children with pediatric SLE. Specifically, Black, Asian, and South Asian patients are overrepresented in the pediatric SLE population, Dr. Earl Silverman reported at a rheumatology conference sponsored by Virginia Commonwealth University, Richmond.

Mucocutaneous manifestations—usually malar rash and photosensitivity—were more common in white children and organ involvement—usually renal—was more common in nonwhite children, reported Dr. Silverman, professor of pediatrics and immunology at the University of Toronto.

Although anti-DNA, anticardiolipin, lupus anticoagulant, and anti-La antibodies were similar in white and nonwhite children, anti-Sm, anti-RNP, and anti-Ro were expressed more in the nonwhite patients (34% vs. 56%; 30% vs. 42%; and 28% vs. 45%, respectively). The differences in course and incidence of SLE, based on ethnicity, are likely a result of interactions between genes and environment, he said.



An acute malar rash with crusting is demonstrated in this 13-year-old girl with systemic lupus erythematosus.

Painful palatal ulceration is seen in this 12-year-old girl with systemic lupus erythematosus.

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Rates of arthritis, serositis, renal disease, central nervous system disease, and hematologic complications have been shown by other researchers not to differ between groups, nor did median SLE disease activity index, he noted.

However, findings from one study show intensive care unit admissions and deaths occurred more often in those younger than age 11 years, compared with those 11 years and older (32% vs. 21% and 11% vs. 0% , respectively), which suggests that SLE may be more severe in younger patients, Dr. Silverman said. Neuropsychiatric manifestations also can occur in pediatric SLE. Studies suggest that, among patients with neurologic involvement (about 25% of SLE patients), headache occurs in 68%, psychosis occurs in 36%, cognitive dysfunction occurs in 27%, cardiovascular disease occurs in 24%, seizures occur in 18%, mood disorders occur in 15%, and chorea occurs in 11%, noted Dr. Silverman. ■