Broach Sexual Health Issues

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continued to complete yearly assessment questionnaires that were used for comparisons.

Interestingly, three times as many 13-year-olds wanted to sign up compared with older teens, Dr. White observed. They were more likely to stay in the program, and did better on all the follow-up assessments than did those who were older on entry into the AERC program and those who chose not to participate.

In addition to employment and Social Security status, the measures included the Ansell-Casey Life Skills Assessment, Career Maturity Index, Pediatric Quality of Life Scale, and Schalock Quality of Life Questionnaire.

After 1 year in the program, the youngest participants were more engaged and similar to youngsters their age without disabilities compared with the older teens. "The gap between norms and participants increased with age of participants," Dr. White observed.

The youngsters who stuck with the program for 3 years had more education and more paid work experience. They were also more likely to leave the Social Security system. Three had already done so, and three more were going through a Social Security Administration planning process to leave within the year.

She calculated the return on investment, as one youth leaving Social Security paying for 1year of the program. Roughly half a million dollars saved over a lifetime of Social Security benefits would cover 1 year of the program for 300 children, she said.

Although the program focused on work issues, Dr. White said that compared with the youths not in the program, the long-term participants were more likely to feel their health had improved and more likely to have made the transition to an adult primary care physician.

Fifty percent had made the transition to an adult physician, but none of the adolescents who were not in the program had done so.

"This is the first large-scale study that has looked at a generic transition program," Dr. White said. And the conclusion is that kids don't want their hands held. "They want to get a job and become independent. If you help them do that, the medical transition will follow."

A common theme among young people with chronic illnesses is that they don't want to be treated like children. They want to be recognized as individuals. The program participants "were not interested in discussing medical issues. They wanted independence," said Dr. White, who urged pediatric rheumatologists to treat adolescent patients accordingly.

Dr. McDonagh of the Institute of Child Health, London, and Birmingham (England) Children's Hospital, also emphasized the importance of work readiness in transition programs. In a survey of 175 occupational therapists, she and her colleagues reported that 91% saw "a need to address vocational issues in the health setting."

Dr. McDonagh also emphasized the need for physicians to overcome their discomfort and initiate discussions about sexual health with their chronically ill adolescent patients. Young children with disease may be just as active as their healthy peers, and yet their sexual knowledge may be less because the adults in their lives haven't broached the topic.

The conversation should be wide ranging and include issues of primary importance to boys. "Sexual health is not just about pregnancy avoidance," Dr. McDonagh said, adding that in one study of young adults with juvenile idiopathic arthritis 58.3% had disease-related sexual problems.

"If you have limited hand function, how would you get to use a condom? That is rarely discussed," she said.

Dr. McDonagh presented a list of circumstances that provide windows of opportunity to discuss sexual health issues. Among the situations that provide such an opportunity were pubertal assessment, last menstrual period for pelvic x-rays, adduction deformities of the hip, and limited hand function as it relates to condom use and to masturbation.

Physicians should be sure to address contraception issues, egg/sperm storage in patients on cyclophosphamide, drug side effects upon the menstrual cycle, risk of infections such as human papilloma virus and candida while taking immunosuppressants, and increased risk of cervical dysplasia with lupus as well as heredity and fertility concerns.

Dr. McDonagh suggested asking whether the teenager's friends are sexually active.

"The best friend of an adolescent is the best predictor of what they are getting up to," she said, adding that often several visits will go by before a teenager asks questions about sexual health. Physicians need to take the first step by initiating the conversation.

Put Teens at the Helm of Their Care

In addition to creating a transition plan for each adolescent patient, Dr. White suggested the following tips for rheumatologists who see teenagers in their practices:

- ► Decorate the waiting room with posters that will appeal specifically to adolescents or show disabilities in a cool way.
- ► Have parents leave the examining room, so the adolescent can speak in confidence with his or her health care provider.
- ► Suggest that parents give teenagers the responsibility of calling to schedule their own appointments.
- ► Provide ample time in the schedule for adolescents to have appointments after school hours.
- ► Encourage adolescents to become responsible for their own health by having them compose a list of questions to ask at their next appointment.
- ► Foster self-reliance by stressing the importance of the disabled teenager taking responsibility for household chores.

In France, the national health program for rare diseases is opening adolescent centers to help patients make the transition from pediatric to adult care, added Loïc Guillevin, M.D., of Hôpital Cochin in Paris. He described the centers as focusing on "all the aspects of adolescent medicine." ■

'Just Growing Pains' Denounced as Unresponsive Diagnosis

BY JANE SALODOF MACNEIL
Southwest Bureau

VERSAILLES, FRANCE — Physicians should stop dismissing nighttime lower limb pain in children as just growing pains, Raju P. Khubchandani, M.D., told attendees at the annual scientific meeting of the 12th European Pediatric Rheumatology Congress.

Such nighttime lower limb pain is a syndrome with multiple causes, the most common of which is likely hypermobility, according to Dr. Khubchandani of Jaslok Hospital and Research Centre in Mumbai, India.

Dr. Khubchandani, a pediatrician and consultant in pediatric rheumatology, urged that the label growing pains be changed to a more medical term with a catchy acronym, so that clinicians will take the children's complaints seriously.

"Even parents have stopped perceiving that 'growth' is responsible," he said, characterizing growing pains as "a big but neglected issue" around the globe.

Presenting the findings from an investigation of 448 middle-income children in a Mumbai elementary school, Dr. Khubchandani reported that 28.1% suffered from lower limb pain at night. Prevalence rates in studies from other countries have ranged from 4.2% to 38%, he said, attributing the variation in part to different diagnostic criteria.

Dr. Khubchandani and his co-investigator Vijay Viswanathan, M.D., also of Jaslok Hospital, included intermittent pain and pain that lasted at least 3 months in the past in their criteria. Only bilateral, nonarticular, lower limb pain was considered. It had to occur in late evening or overnight with the child well by morning.

The criteria also required a normal physical exam with normal laboratory work and x-rays when available. Children with neuromusculoskeletal disorders were excluded.

'Any kid who comes with this syndrome, we automatically make a preconceived diagnosis. We tell them it is growing pains. It will go away. We should evaluate further.'

Prevalence of growing pains ranged from 22% of children at age 6 years to 35% at age 9 in the Mumbai study, which assessed children aged 4-10 years. About a quarter of the boys (57/226) and nearly a third of the girls (69/222) presented with the condition.

The most common site was the calf (51%) followed by the anterior thigh (25%) and behind the knee (24%). In addition, 38% of children with growing pains complained of abdominal pain, 21% of headache, and 21% of sleep disturbances.

Hypermobility was so common among children presenting with growing pains that the investigators recommended in a poster that children presenting with growing pains be screened for that condition as well.

The school population included 98 children with hypermobility and growing pains. Another 139 had hypermobility without growing pains; only 28 had growing pains without hypermobility. The remaining 183 children had neither.

Other possible causes include restless legs, hyperactivity, emotional factors, fatigue, and anatomic defects, according to Dr. Khubchandani.

About a quarter of the children had a family member with a rheumatologic condition, leading him to speculate that some might have been using the adult as a behavioral model.

"This is not one entity. There are several things that can cause this syndrome," he said in an interview after his talk.

"Any kid who comes with this syndrome, we automatically make a preconceived diagnosis," he said. "We tell them it is growing pains. It will go away. We should evaluate further."

Parents do take the condition seriously, according to Dr. Khubchandani. About 86% of the parents in the Mumbai investigation stayed up at night to massage their children's legs, while 10% gave a "warm fomentation" and the rest did both. "There was no parent who thought they should do nothing about it," Dr. Khubchandani noted.

From the parents' points of view, the leading explanations were nutrition (34%), overexertion (29%), and calcium deficiency (26%).

Six percent thought their children had rheumatism. Only 3% attributed the pains to growth and even fewer, 2%, to attention seeking.

Dr. Khubchandani said that one of his concerns is that children are given unnecessary nutrients and calcium supplements in the absence of medical attention. "Mere reassurance does not prevent parents from acting," he warned.

"Our 'no action' advice is considered as inaction." ■