JIA Patients Are Lost in Transfer to Adult Care

VITALS

Major Finding: More than half of patients with JIA who were transferred to an adult rheumatologist received inadequate follow-up at 2 years.

Data Source: Chart review of 100 patients with JIA.

Disclosures: The researchers disclosed having no relevant financial conflicts.

BY DOUG BRUNK

More than half of patients with juvenile idiopathic arthritis who transferred to an adult rheumatologist had inadequate follow-up for their disease 2 years after being transferred, judging from results of a Canadian study.

"Every effort should be made to ensure that young adults with JIA have timely access to a rheumatologist in the event of a disease flare, in order to minimize their disease burden," researchers led by Dr. Elizabeth M. Hazel, an adult rheumatologist at McGill University Health Centre in Montreal, wrote in a study published online in Pediatric Rheumatology.

In the first published analysis of its kind, the researchers conducted a systematic chart review of 100 patients with JIA who attended their final JIA clinic appointment at Montreal Children's Hospital between 1992 and 2005 when they were aged 17 years or older. More than two-thirds of the patients (68%) were female, and the mean age of disease onset was 9.84 years (Pediatr. Rheumatol. 2010 Jan. 11 [doi:10.1186/1546-0096-8-2]).

"Once the name of the adult rheumatologist was identified in the transfer letter, or the last clinic note, his/her office was contacted for permission for a chart review to be conducted," the researchers explained. The chart was then reviewed for 2 years after transfer.

A patient was deemed to have had an unsuccessful transfer if he or she "never made contact with the identified adult rheumatologist or was lost to follow-up at 2 years following transfer."

Of 100 patients, 52 met the criteria for unsuccessful transfer from pediatric to adult care. 'I was very surprised that more than half of the patients were lost to follow-up.'

Dr. Hazel and her associates also compared a number of factors among patients who did and did not have successful transfers, including sex, category of JIA, age at diagnosis, use of disease-modifying antirheumatic agents, active joint count, and level of educational attainment.

Of the 100 patients, 52 (52%) met the criteria for unsuccessful transfer from pediatric to adult care. Of these, 17 (33%) did not make initial contact with the appointed adult rheumatologist and 35 (67%) were lost to follow-up at 2 years.

"I was very surprised that more than half of the patients were lost to follow-up," Dr. Hazel commented in an interview.

Of the patient factors tested, only one was significantly associated with unsuccessful patient transfer: an active joint count of zero at the last visit (odds ratio, 2.67). "This group of young adults with relatively inactive disease should be educated about the importance of ongoing follow-up in the adult milieu given the high possibility of active disease into adulthood," the researchers advised.

Male sex trended toward a higher risk for unsuccessful transfer (OR, 2.15).

In her interview, Dr. Hazel acknowledged certain limitations of the study, including its retrospective cohort design. "This was a chart review, so we were limited by the information recorded in the charts," she said.

"We could not track patients who sought out other rheumatologists on their own if they did not request a transfer letter from the pediatric group. While this may have improved the rate of transfer, these cases would still represent a suboptimal situation, with the adult rheumatologist not having information about the pediatric course of illness." ■