

Pediatric onset multiple sclerosis study examines baffling, often-overlooked disease

March 7 2019, by Sharita Forrest



Parents of a child with pediatric onset multiple sclerosis may need long-term supports from mental health professionals and advocacy organizations to cope with the emotional and financial impact the disease has on their family, according to a new study co-written by Theodore P. Cross, a senior research specialist in social work at the University of Illinois. Credit: L. Brian Stauffer

Seemingly overnight, healthy children develop mysterious, potentially disabling symptoms. When children finally receive a diagnosis, often after weeks of tests and office and hospital visits, the parents may be shocked to learn that they have multiple sclerosis—a potentially disabling autoimmune disease once believed to affect only adults.

"For many years, the tagline for MS was that it was the 'leadingcrippler of young adults,'" said Theodore P. Cross, a senior research specialist in social work at the University of Illinois. Cross is also a co-author of a recent study on families of children with pediatric onset MS, published in the *Journal of Child and Adolescent Trauma*.

"Many of these kids went through a diagnostic odyssey where they would go from pediatricians to emergency rooms to other pediatricians, and it could take weeks to even get the diagnosis that they had MS," Cross said. "Meanwhile, their bodily function is off. They're suffering from fatigue. Their vision and mental processes may be affected. They have no idea why and no diagnosis to explain it."

The parents in the study were recruited from the pediatric MS centers at Boston Children's Hospital, where co-author Lisa V. Duffy practices, and Massachusetts General Hospital, where co-authors psychologist David J. Rintell and Alane K. Shanks practiced with Partners Pediatric MS Center.

According to Rintell, "The pediatric form of MS wasn't even diagnosed until perhaps a little more than a decade ago. It wasn't recognized."

Rintell, who has conducted extensive research on families in which a parent has MS, said little is known about families' experiences when a child develops the disease.

Currently, 400,000 people in the U.S. have some form of MS, a disease

in which [white blood cells](#) damage the myelin coatings of nerve cells in the spinal cord and brain, often causing neurological problems. But just 3-10 percent of those patients have pediatric onset MS, which occurs in youths younger than 18.

According to Duffy, a nurse practitioner certified in MS nursing, children often present with very different symptoms than adults, such as vision changes and memory and attention deficits, complicating diagnosis.

"Many times we would see patients where their primary symptom was that they were starting to fail classes or their grades were really dropping, and somebody picked up on it that way," Duffy said. "The underlying disease is different in youths. It's more inflammatory, and they have more MS lesions when they're diagnosed."

Several parents among the 21 couples interviewed for the study said they did not perceive their child's symptoms as indicative of a serious illness right away, often dismissing them as the result of sleeping in the wrong position or the child being mischievous or lazy because they were clumsy, tired or sleeping more.

To minimize the "long and demanding diagnostic odyssey" families often undergo, educational campaigns are needed for all types of [health care providers](#) to help them recognize the symptoms of pediatric onset MS, the researchers wrote.

Adapting to life with the child's illness and treatment was very demanding, stressful and disruptive for the families, Cross said.

"From meeting these children and adolescents and their families, it was very clear that the parents were suffering gravely," Rintell said. "They were very worried and concerned about their kids, as one would expect."

Many parents were distressed by administering or seeing their child receive painful intramuscular injections once or twice daily that left welts or bruises, and by watching their child struggle with medication side effects and the emotional, cognitive and physical challenges associated with the illness.

Some parents were overwhelmed by managing numerous diagnostic procedures, doctor and [hospital visits](#), and from working with multiple health care providers. They grappled with keeping track of voluminous amounts of information, paperwork and treatment costs, the researchers found.

Some of the families sought financial or [emotional support](#) from the National Multiple Sclerosis Society, which funded the report on which the study was based, and found helpful the [social support](#) from other [parents](#) of children with the disease. According to the researchers, patients' families may need long-term emotional support, including mental health services and resources from advocacy organizations.

The researchers recommended that health care providers carefully plan discussions about the child's diagnosis and insure that families' questions are answered so they feel equipped to make treatment decisions.

"Despite the stresses of the diagnosis and the demands of treatment, these families benefited from disease-modifying treatments, and most students had adapted successfully to the demands of school," Cross said. "Supported by their peers in the community of families with pediatric onset MS, and with the help of the National Multiple Sclerosis Society, these families demonstrated considerable resilience in dealing with the practical issues of living with the disease."

More information: Theodore P. Cross et al, Families' Experience of Pediatric Onset Multiple Sclerosis, *Journal of Child & Adolescent*

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