

# Pediatric multiple sclerosis

## Perspectives from adolescents and their families

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### ABSTRACT

Supporting young people with pediatric multiple sclerosis can be challenging for families and health care providers. Adolescents may be more resilient than adults in reaction to the diagnosis but can have more difficulty planning for their futures. Appropriate, sensitive, and focused health provision should include consideration of the perspective of both the patient and parents. Multidisciplinary management strategies are often effective, as are referrals to programs that enhance individual and family coping and strengthen a sense of community. *Neurology*® 2016;87 (Suppl 2):S4-S7

### GLOSSARY

**MS** = multiple sclerosis.

Multiple sclerosis (MS), similar to other chronic illnesses, can affect young people's growth and development, appearance, identity, cognition, emotional well-being, engagement with education, and employment, as well as their relationships with peers and family. This review considers the patient's and family's perspective with respect to pediatric MS. Drawing from ongoing work at Massachusetts General Hospital<sup>1</sup> as well as individual and group discussions with patients and families conducted at Stony Brook Children's Hospital, and culling from the available literature, we describe how families initially respond to the diagnosis and share what patients and parents have told us with respect to learning to live with the disease. We summarize what most patients and families expect from us and outline steps that might enhance health care provider and family interactions. Incorporating both patients' and parents' viewpoints is critical as health care providers partner with families to achieve optimal health outcomes.

**RENDERING THE DIAGNOSIS** Understanding the psychosocial impact of being given a diagnosis of pediatric MS and recognizing the variety of reactions among family members is critical for establishing effective communication.<sup>2,3</sup> An added challenge is that in some cases the road to the diagnosis can be unnecessarily prolonged and emotionally taxing. In a study applying standard qualitative research methodology, interviews were conducted and analyzed for 30 parents and 21 patients (aged 8–17 years old).<sup>3</sup> Families reported frustration with primary care physicians who lacked the knowledge base to handle the topic or efficiently make appropriate referrals, particularly if presenting symptoms were nonspecific (e.g., paresthesias). Given that pediatricians often rely on different consultants before a diagnosis is established, the providers' delay in making appropriate referrals further aggravated the situation.

Interviewing individual patients about their experiences not surprisingly reveals a wide range in responses as well as the degree to which they understand the information provided. Some experience a great sense of loss.<sup>2</sup> Others are relieved to receive a diagnosis from an informed clinician.<sup>3</sup> However, stress secondary to miscommunication can occur. For example, the authors recall one 20-year-old man who had been given the diagnosis of MS at age 16. He shared that at the time when he was told that he had the “disease MS,” he was convinced that his condition was fatal. He explained that he had not known anyone “with a disease” and to him “disease meant death.”

Individual interviews conducted by a psychiatrist with 23 pediatric patients diagnosed with demyelinating diseases, including 14 with MS, revealed common fears of getting worse, as well as worries about the future, fear of going blind, and concerns about not being able to walk.<sup>4</sup>

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Initial and ongoing care should include awareness of these fears and providing reassurance and support as concerns arise.

While the optimal approach to rendering the diagnosis and discussing management differs according to the child's age, in the majority of situations it is best to share the diagnosis with the child or adolescent concurrently when the diagnosis is discussed with the parents. The level of detail shared and terms used in discussion will obviously vary according to the patient's and family's educational level but having the child leave the room (as some parents request) when the diagnosis is offered can lead to additional anxiety. Overall, discussing the diagnosis requires a flexible approach and should involve both the patient and parents.

**ADOLESCENT PATIENT PERSPECTIVES** Most published information about the patient experience comes from adolescents, who report they often feel left out of consultations, which tend to focus on parental issues.<sup>5,6</sup> These adolescents want their own time with the doctor and more confidentiality. Adolescents report being frustrated when they perceive that they are not part of the consultative process.<sup>7,8</sup> Further, certain disease topics are best raised with the adolescent directly. For example, based on feedback provided during open sessions among counselors, a nurse, and adolescent MS camp participants, the adolescents reported feeling very uncomfortable discussing bladder problems in front of others. Taking the patient aside for selected private questioning may yield more meaningful responses than asking sensitive questions when parents or other family members are present.

Some authors have concluded that, relative to their parents, pediatric patients with MS tend to cope reasonably well. For example, a study of patients with pediatric MS evaluated by a psychologist in 1999 noted that "these youngsters did not describe themselves as being different from their peers ... Almost without exception, they were confident about the care they were getting and optimistic about the future."<sup>9(p14)</sup>

Messmer Uccelli et al.<sup>10</sup> found that parents of patients with pediatric-onset MS scored higher on a scale of depressive symptoms compared to parents of healthy children. The relatively confident reaction observed among some teens in contrast to their parents may be due in part to an adolescent perception of invulnerability.<sup>11-14</sup> Further, adolescents may be limited in their ability to predict future outcomes, have a lower perception of risk than adults,<sup>12</sup> and are more willing to accept conditions in which outcomes are ambiguous.<sup>15</sup> In comparison, adults may be more challenged by ambiguous situations.

**PARENTS' PERSPECTIVES** In a community-based participatory qualitative research program carried out in 2 pediatric MS centers in Boston,<sup>1</sup> a focus group with 6 parents was convened to identify key concerns and appropriate questions that could be posed to a larger number of parents of patients with pediatric MS. Subsequent to the focus group, and over the course of 12 months, a convenience sample of 21 families (with one or both parents) was recruited to undergo individual interviews with a psychologist. The parents' reactions to the diagnosis and their concerns were recorded and the transcripts analyzed according to accepted methods.<sup>16</sup> One common reaction pattern noted was initial emotional distress upon learning of the diagnosis, and feeling a threat to their child's well-being, which often was accompanied by a sense of devastation.<sup>1</sup>

Several parents communicated their sense of devastation through the metaphor of feeling they were in a nightmare. "I don't want to believe it. It's like a bad dream. That I'm going to wake up and it's there ... You ask why? Why your kids? Why do we have to go through all this? It's like when [is] this nightmare going to finish?"

Parents also projected the impact of the diagnosis well into the future, expressing concerns regarding the uncertain course of the disease. "What is going to happen next, we don't know. We don't know if you'll have another relapse or how far apart they'll be or how bad they'll be or anything. And it was just like a blow to you. But then it made us stop and think we don't know what tomorrow brings anyway."

Fortunately, as the parents and families gained more experience with pediatric MS, most adapted and found ways of living with their child's MS, and managing the many challenges presented to them by the illness. There are many possible routes to positive family adaptation. Most families found a way to return to the activities and organizations in which they participated before the diagnosis, albeit with some modifications. Some families reported that it was helpful to become involved in the MS community, and particularly the pediatric MS community when possible. "The answer for us was we are educating. We are fundraising. We are explaining to the rest of the world what MS is."

**BENEFITS OF MULTIDISCIPLINARY CARE** Given that MS is a diagnosis that affects the patient and family across multiple parameters, a multidisciplinary team offers many advantages for addressing the varied physical, psychological, and social issues that arise. A neuropsychologist can be helpful in identifying whether cognitive problems are present, determining the possible concurrence of mood disorders, and

providing concrete recommendations for the school. Psychologists can offer counseling. For motor problems, a physical therapist can provide an assessment and make recommendations. For the therapist and clinician, it is critical to emphasize to the family the importance of physical training and exercise. Individuals with pediatric MS engage in physical activity less often than their peers<sup>17</sup> and the benefits of exercise for adults with MS<sup>18</sup> with respect to building strength and endurance as well as enhancing quality of life, decreasing fatigue, and improving mood are likely to extend to children and adolescents. These benefits need to be clearly communicated as many parents worry exercise will worsen the disease course. Other key members of the team include social workers who can address the emotional stresses affecting the family and help arrange for needed services. Nurses, particularly when trained in pediatrics and MS, are valuable with multiple roles including providing additional education about the disease, assessing medication adherence, managing injection-related issues for those on such treatments, and providing psychosocial support.

#### **BENEFITS OF STRUCTURED OUTREACH ACTIVITIES FOR PATIENTS AND FAMILIES**

Given the rarity of pediatric MS, it is understandable that many patients and families experience a sense of isolation. Events that bring together affected families can address this need, as members of other pediatric MS families are uniquely able to understand, support, and share helpful information with each other. Supervised recreational outings and other group activities can give parents opportunities to connect with other parents and allow the children and teens to get to know each other. It is ideal to include an educational program provided by a health care professional and facilitation of group discussion built into the time together. These programs can serve as seeds of new, supportive social networks for children and families.

Summer camps developed for pediatric-onset MS are popular programs that take place in the United States and Canada. For example, the Teen Adventure Program is a 7- to 10-day summer camp for teens with MS that has run for 12 years and is organized by the Pediatric MS Center in Stony Brook, New York. Over the years, other camps (organized with the assistance of local MS chapters) in Texas and Alabama have provided social programs for families of children who have MS.

Supervised groups in the camp provide opportunities for teenagers to share the impact of MS symptoms on daily living and their feelings, including the need to protect their parents. For example, during a series of workgroups led by an MS nurse, a number of teens reported that they hide physical symptoms because they do not want their parents to worry,

while others hide their periods of grief, as noted by one adolescent at camp, who explained, “Sometimes, I just close my door, turn the music all the way up, and cry.” Sharing these experiences and working together in group activities helps enhance positive coping strategies and provides support, and can be empowering, as expressed by one adolescent, who reported that “Before I came to camp, I thought that I was sick. Now I know I am normal, it’s just that I have MS.”

**CONSIDERATIONS FOR SCHOOL** Navigating the education system may be particularly challenging for parents of children with MS. Parents are placed into a position where they must request accommodations at school at a time when they may not yet have a good understanding of what MS is and what it will bring for their child.

Many children and adolescents with MS benefit from educational accommodations (e.g., added time to get to class, allowed extra bathroom breaks, additional time to complete tests). However, school personnel are often unfamiliar with MS and unprepared to meet the patient’s needs. School personnel often need to be informed of the diagnosis and how to adequately provide support. School staff often need help understanding why some children have missed a large number of school days, particularly when relapses have occurred or for students who experienced a long period of symptoms prior to definitive diagnosis.

Parents are often unprepared to ask for accommodations, and members of the treatment team can help educate the parents how to advocate for specific services to be provided by school. In some cases, the team needs to take the primary role in helping secure appropriate services. Pediatric patients with MS residing in the United States are entitled to receive accommodations provided through a 504 plan or an individual educational program. These plans describe the individual needs of the student and range from preferential seating in the front of the classroom for those with visual disturbances or attention difficulties to extra time for tests, permission to leave class early to have sufficient time to make it to the next class, or reduced class schedules.

**DISCUSSION** MS in children presents many complications and considerations from both the patient and parent perspective. Care through an interdisciplinary specialized center and ongoing clinician support can help both the child and parent as they navigate the diagnosis. Given the potential for isolation, a priority should be facilitating connection with other children and their families to share experiences. Support at diagnosis and throughout management can facilitate a successful transition to adult care.<sup>19</sup>

## AUTHOR CONTRIBUTIONS

Lauren Krupp: contributed to the design and conceptualization of the study and drafting and revising the manuscript for intellectual content. David Rintell: contributed to the design and conceptualization of the study and drafting and revising the manuscript for intellectual content. Leigh Charvet: contributed to the design and conceptualization of the study and drafting and revising the manuscript for intellectual content. Maria Milazzo: contributed to the design and conceptualization of the study and drafting and revising the manuscript for intellectual content. Evangeline Wassmer: contributed to the design and conceptualization of the study and drafting and revising the manuscript for intellectual content.

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