

Experiences of Children and Adolescents Living with Multiple Sclerosis

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Abstract: About 5% of people with multiple sclerosis (MS) are diagnosed before age 18. Because pediatric MS is uncommon, little is known about the experiences of children and adolescents living with MS. The purpose of this qualitative study was to learn from these youth what it is like to live with the diagnosis of MS. Twelve patients with clinically definite MS between the ages of 8 and 18 years were interviewed. Initially, they were unfamiliar with MS and had a multitude of feelings about the diagnosis. Over time, they adapted to the temporary or permanent effects and incorporated changes caused by MS into their lives. Most described participation in social and recreational activities typical of their age group. Although they recognized their lives were different because they had MS, in many ways they felt unchanged. Most noted positive and negative changes in their relationships. They described common stressors unique to having MS that made life more challenging, but they used diverse coping strategies to address these stressors. They expressed the need to move forward with life and identified hopes and plans for the future. MS contributed to shaping their self-identities, but their disease remained only one component of who they were. The findings of this study provide a greater understanding of the experiences and views of youth with MS and offer guidance for nurses to enhance care.

Multiple sclerosis (MS) is an autoimmune disease that attacks the central nervous system and leads to demyelination, inflammation and destruction of axons in the brain, spinal cord, and optic nerves (Luchinetti, Brueck, Rodriguez, & Lassmann, 1998). MS usually begins with a relapsing-remitting course causing periodic neurological symptoms. Over time, the disease tends to become more progressive with persistent symptoms and disability. Typically, MS first presents in young adults between 20 and 50 years of age; however, retrospective reviews indicate that about 5% of individuals with MS are diagnosed before 18 years (Brett, 1995; Cole, & Stuart, 1995; Ghezzi et al., 1997; Iannetti, Marciari, Spalice, Spanedda, Raucci, & Trasimeni, 1996; Sindern, Haas, Stark, & Wurster, 1992). The incidence may be even higher than reported. Many adults with MS recount experiencing symptoms in childhood or adolescence that were possibly the initial manifestations of the disease. Improved diagnostic measures, the impetus to diagnose and implement treatment early and increased awareness of pediatric MS will likely lead to an ever-increasing number of patients diagnosed with MS in childhood and adolescence.

Children and teens with MS face an uncertain future with respect to disabling relapses, ongoing symptomatology and disease progression. Weakness, sensory changes, such as numbness and tingling, visual problems, ataxia, bowel and bladder dysfunction, speech and swallowing difficulties, spasticity, and dizziness can have a temporary or permanent effect on their lives. Fatigue, heat intolerance, cognitive deficits, headaches, seizures, tremors, and depression affect many of these children on an ongoing basis. Relapses that cause significant neurological dysfunction can also lead to school absenteeism and hospital admissions. Although some patients have few relapses and do not experience symptoms between relapses, others have repeated attacks or are bothered by persistent symptoms. Currently, the only treatments available to reduce the number of relapses and modify the progression of MS involve daily to weekly subcutaneous or intramuscular injections. All these aspects of having MS can affect quality of life.

Because pediatric MS is uncommon, little is known about the experiences of children and adolescents living with MS. To be truly empathetic, nurses need to understand the feelings, emotions, interactions, meanings, and responses of these patients (Annells, 1999). The purpose of this study was to learn from children and teens what it is like to live with the diagnosis of MS. With this increased understanding, strategies for optimizing nursing care will be identified.

Literature Review

In light of its rarity, there is limited research on MS in patients younger than 18 years. A review of the pediatric MS literature indicates that the majority of research to date has focused on retrospective reviews or case reports describing the incidence, clinical and paraclinical features, and outcomes of

childhood onset MS (Banwell, Kennedy, Krupp, & Bar-Or, 2004; Belopitova, Guerguelcheva, & Bojinova, 2001; Boiko et al., 2002; Brett, 1995; Cole & Stuart, 1995; Duquette et al., 1987; Ghezzi et al., 1997; Hahn, Shroff, Blaser, & Banwell, 2004; Pinhaus-Hamiel, Barak, Siev-Ner, & Achiron, 1998; Selcen, Anlar, & Renda, 1996). Other studies have examined tolerance of pediatric MS patients to treatment with interferon-beta (Adams, Tyor, & Holden, 1999; Krupp et al., 2005; Mikaeloff et al., 2001; Waubant et al., 2001), explored potential risk factors for the development of early-onset MS (Alotaibi, Kennedy, Tellier, Stephens, & Banwell, 2004; Bager et al., 2004; Sadovnick & Scheifele, 2000), or identified the cognitive effect of MS on the pediatric population (Banwell & Anderson, 2002; Kalbet et al., 1999). There is no published nursing research on childhood MS or any studies describing the experiences of youth living with MS. Although a few studies explored adult experiences with having MS (Baker, 1998; Koopman & Schweitzer, 1999; Miller, 1997; Miller & Jezewski, 2001; Quinn, Barton, & Magilvy, 1995), the views and experiences of children and adolescents with MS are presumably unique.

Methodology

This exploratory qualitative study used a phenomenological approach to learn about the experiences of children and adolescents living with MS. Encouraging patients to tell their stories improves nurses' understanding of their lives (Koch, 1999). Studying children using a qualitative method enables care providers to better understand children's perspectives of health and illness, which further aids in improving their psychosocial and physical care and ultimately their quality of life (Woodgate, 2001). It also helps nurses discover the differences in perceptions between adults and children (Mishna, Antle, & Regehr, 2004). Children's or adolescents' expression of their views also supports their right to be heard (McPherson & Thorne, 2000). Phenomenological inquiry offers nurses the opportunity to find meaning in and understand everyday situations with patients, discuss and communicate their understanding with others, and, as a result, change their actions or the actions of others in subsequent situations on the basis of that understanding (van der Zalm & Bergum, 2000).

Sample

Patients followed in the Pediatric Multiple Sclerosis Clinic at the Hospital for Sick Children, Toronto, who were between 7 and 18 years and had the diagnosis of clinically definite MS for at least 3 months were approached to participate in the study. Appropriate ethical review and approval were obtained before commencing the study. Prior to data collection, parents provided written consent if a participant was younger than 16 years, and the child provided verbal consent after reading an assent form describing the study. Participants 16 years or older gave their own written consent.

Study Design

The study involved completing a brief demographic questionnaire and participating in an interview. The interviews took place without the parents present to avoid potential parental influence; foster honest, open answers; and maintain confidentiality. All verbal interactions were recorded on audiotape. A semistructured interview questionnaire guided the discussion about the participants' experiences living with MS. During the interviews, the participants told their stories by responding to a series of questions, probes, or prompts. The questions elicited their thoughts and feelings about MS, their views about the effect MS had on their lifestyles, relationships, and future plans, and their perceived stressors and coping strategies. Their knowledge of MS and their advice to others in a similar situation were also explored.

Data Analysis

Narrative analysis was used to inductively generate themes and subthemes (Reissman, 1993). The interviews were transcribed verbatim, and the NVivo software program, capable of retrieving and sorting information, was used as an adjunct to manage the narrative data (Richards, 2000). Themes were compared and integrated to describe living with MS as a child or adolescent. Because of the recognized developmental differences between school-age children and adolescents, the data from children 7–12 years and adolescents 13–18 years were also analyzed separately to reveal variations in experiences. The demographic information was reviewed and compared with the qualitative data to identify trends with respect to age, duration and severity of disease, and treatment regimen.

Findings

Twelve children and adolescents with relapsing-remitting MS, 7 female and 5 male, participated

in the study. They ranged in age from 8 to 18 years; 4 were school-age and 8 were adolescents. They received their diagnosis as recently as 5 months to as long as 10 years prior to the interview. Age at diagnosis ranged from 6 to 16 years with 8 being diagnosed during their school-age years. Most experienced 2–6 relapses, but one participant experienced 17 relapses. All but one had been hospitalized at least once, and one was admitted to the hospital 13 times. Persistent symptoms of study participants are listed in Fig 1. All were on a treatment regimen involving regular intramuscular or subcutaneous injections or intravenous infusions. Despite varied experiences of the participants, common themes emerged during the interviews.

Learning the Diagnosis

When the participants first learned they had MS, they all indicated that they did not know what it was, though some stated they had heard of it before. Most expressed feeling scared or sad at that time. Many feared dying, believing they had a brain tumor or a rare terminal illness. This view was particularly prevalent if they were hospitalized at the time of diagnosis and recalled their parents' distress. Others felt confused by what was happening, while one stated feeling relieved that she finally had an explanation for her symptoms. Another felt self-pity and questioned why it had to happen to him. Some thought optimistically that the MS would "just go away" like a common cold. The following quotes illustrate some of the participants' thoughts and feelings when they were diagnosed.

I had symptoms but they went away in 1 month and when I was diagnosed with MS then of course I was scared. I didn't know what to expect. Right at the moment when the doctor told me I had MS, I wasn't as scared as I was when I came home and started thinking about it.

I thought, I wonder whether or not I could die from it. I wondered where I caught it from, like if my mom had it. I don't know. A bunch of different things ran through my head. I wasn't sure what exactly was going on, like I didn't know why my legs were so weak and why I couldn't move my left arm and I had no strength. It just didn't make any sense to me.

Um, I didn't really feel anything because I didn't know what it was. But then later when I realized what kind of type of disease that I had, I kind-of felt sad because of the disease that I had and I couldn't help about my future and stuff, and I was a little worried but it was OK.

Well it was "Why me?" Why did I have to have it? Why couldn't someone else have it?

They gradually learned more about MS through a variety of sources such as their parents, health-care professionals, printed information, and the Internet. Just living with the disease was another way they described how they learned about MS. Others mentioned completing a school project about MS that led them to research it. When asked how they preferred to receive information about MS, most responded that they wanted to read about it or talk to someone. Upon exploring their knowledge of MS, they tended to know basic information about the disease. They recognized that MS involved the brain and spinal cord, as well as antibodies, and that abnormalities in the central nervous system signal transmission caused their symptoms. They typically described MS in relation to their own experiences particularly when discussing disease symptoms and treatment. Only a few identified that MS could cause permanent disability in the future. In many cases, they acknowledged they did not remember a lot of details about what they had been told or read. However, they also indicated they had few unanswered questions, and several stated they were not interested in obtaining additional information. Some even felt pressured by family members and others to expand their knowledge of MS. Those with questions asked about when a treatment would be available that did not involve injections, when a cure would be found, what their personal prognosis was, why they got the disease (as opposed to someone else), and how others coped.

Noticing the Differences

Since their diagnosis with MS, most noticed that their lives had changed in certain ways. For example, many ($n = 12$) noted that their activities were occasionally limited by the following persistent MS symptoms:

- heat intolerance (6)

- fatigue (5)
- headaches (5)
- cognitive difficulties (5)
- sensory symptoms (numbness, paresthesias) (4)
- hand tremor (2)
- seizures (2)
- depression (1)
- none (2).

They described modifying their activities, such as discontinuing participation in competitive sports but remaining active in the same sport at a recreational level. Some felt they had decreased abilities and could no longer perform certain fine and gross motor tasks they were previously capable of performing. Others reported increased difficulties with school performance, relating to either new cognitive challenges or school absenteeism. The fact that they had the symptoms of MS also made them feel different, and, not surprisingly, they frequently cited their treatment regimen as a factor new to their lives. Several mentioned they needed to be more cautious than before, believing that they could have a relapse if they were not careful. Some perceived that others treated them differently now that they had MS. Finally, a few older teens talked about not taking life for granted anymore. As one teen stated...

But the difference can also be a good thing in a way. Like, it allows me to like, understand more like, not take as much things for granted. But I'm not able to do a lot of things that other people do, but also I have to be more careful than other people. I have to be a lot more cautious.

The differences in their lives were not always perceived as negative and some participants even struggled with identifying ways their lives had changed, especially if they were diagnosed several years earlier. Although some of the participants noticed a major effect on their lifestyles after being diagnosed with MS, others perceived little change. "Physically it doesn't really stop me from doing anything." They reported participating in many of the same activities as their peers and as they had done prior to their diagnosis. A few mentioned modifying their activities, such as decreasing participation in competitive sports, not staying up late, or not going out as often because of fatigue. Several, however, found they were now more careful, took fewer risks, and did not push themselves as much, primarily because of their concern that this would worsen their condition.

Staying the Same

Despite the changes in their lives after the onset of MS, all of the participants described numerous ways in which life remained the same. They continued to attend school, participate in sports, play or "hang out" with friends, and take part in other social activities like going to movies, dances, or sleepovers. They also remained involved in personal interests such as reading, listening to music and playing on the computer. They described experiencing the same emotions, having the same personality, and feeling like "the same person." They still enjoyed having fun.

Coping with MS

Stressors. MS created unique stressors for the youth interviewed. They had to deal with issues related specifically to having MS that their peers did not need to face:

- treatment regimen—"Just the needles and getting tired a lot more."
- intermittent and ongoing symptoms—"Uh, just like having symptoms, like I don't like having symptoms, having them come and go and having new symptoms."
- unpredictability of relapses—"The not knowing when you're going to get sick and there's no warning."
- being treated differently by others because of the diagnosis—"Oh they just like, like if I can't do something, they say something about my MS."
- missing school and getting behind in school work—"It keeps me from being who I am as far as going to school, taking full classes like normal people."
- restrictions on lifestyle (limitations of activities)—"It puts restrictions on my life, and that I can't go out and do what I want to do because I have to watch that I'm not going to get too tired or just everything."
- effect on family (parental worry and sacrifices)—"How it affects my mom is the worst part. She's

so worried and it hurts me to see her so worried. She's more worried about me than I am. It hurts her so much she can't handle it, she's worried sick all the time and she's always tired and she always frustrated and I hate her having to be like that."

- uncertain future and potential disability – "It's a fear that at one point everything can be perfect in my life, the next being lost, or being a lawyer or someone with MS and I'll never being able to walk again."

Although the researchers predicted that the participants would identify receiving injections as their greatest stressor, several mentioned other stressors such as ongoing symptoms, unpredictability of relapses, and missing school as the worst part about having MS. Their treatment regimen was cited as a stressor by all participants but not necessarily as the greatest stressor. Notably, some teens remarked on the effect having MS had on their parents, describing their parents worry and the sacrifices they made for them as a negative consequence of the disease. Only older adolescents mentioned concerns about the future and the potential for permanent disability. All perceived stressors of the participants are listed in Fig 2.

Strategies. The youth reported numerous coping strategies. Many talked about maintaining a positive outlook on life and continuing to strive for their goals. Some made downward comparisons, acknowledging that others had more serious illnesses or disabilities. A few identified positive role models with either MS, or a disability who helped them see that they could continue to do what they wanted despite having a chronic illness or disability. Incorporating the effects of MS, such as symptoms and treatment, into their lifestyles and making adaptations as needed were used to normalize their situation and carry on with regular activities. They recognized that having MS was just one part of their identity. A teen who was diagnosed with MS 10 years previously said...

Seems like I was born with it. So it's there. It's almost like having brown hair. It's like it's supposed to be there.

Remaining busy distracted them from thinking about having MS and dwelling on the disease. They also described using active coping strategies because they believed it would help them, such as accepting treatment even though they did not like taking injections. For example, one school-age child stated...

I mean I would suffer the injections instead of not being able to walk and write and play piano and all that.

The participants commonly mentioned gaining support from others as a coping strategy for dealing with the MS.

Although they employed many positive coping strategies, several discussed using arguably less adaptive coping strategies. These included denial, manipulation, unhealthy distractions, such as eating sweets and smoking marijuana, avoidance, and concealing aspects of their MS such as symptoms and treatment.

Gaining Support. All the children and adolescents in this study named people in their lives who supported them around the diagnosis of MS and the ongoing effect of the disease. In particular, they cited their parents as strong sources of support. A teen showed appreciation of her mother's support by saying: "She makes me feel like gold when I feel like silver."

They also mentioned other family members', such as siblings, grandparents, and other relatives, role in helping them cope by showing affection, reassurance, empathy, and merely listening. They viewed their parents as protectors and advocates for their needs. Some people supported them by ensuring activities were adapted, allowing full participation as much as possible. Parents and health-care professionals gave them information they wanted. Friends kept them distracted, encouraged them to do fun activities, and accepted them even though they had MS. People who gave them their injections were also described as helpful.

Dealing with Treatment. For some, the worst part about having MS was the treatment regimen. Injection discomfort, side effects, as well as, cosmetic changes such as redness and bruising at the injection sites bothered them. Even when they described the discomfort as minimal, just the "thought of the needle" was mentioned as stressful. However, they recognized the potential benefits and rationale behind the treatment. A few indicated that it was a parental expectation that they take the treatment for their MS. Although they disliked the injections, many discussed making the treatment regimen part of their routine, recognizing it as necessary. Others saw the injections as a regular reminder of their diagnosis. As one teen stated:

It's just so annoying to take it every night because it's such a big reminder. Like you forget about it and you're all like relaxed, and you're all like okay, you know you're not thinking about the MS or anything, and then mom says 'You forgot to take your shot.'

All preferred another option if it became available.

Interestingly, some of the participants described hiding the fact that they needed to take injections. School-age children in particular perceived that it might upset their friends if they knew they were given injections. One school-age child even stated that he and his mother discretely go to his room where she gives him his injections without the rest of his family knowing.

Changing Relationships. Since of their diagnosis, many of the participants reported changes in their relationships with others. On a positive note, several felt closer to their family. Others believed parental worry and overprotectiveness created a strain in their relationships. They admitted that they sometimes did not divulge symptoms to avoid increasing their parents' worry and give credence to their overprotective approach. As one teen said: "I don't really talk to my mom about it because she's more afraid than I am."

After learning they had MS, some recognized that people now treated them as "special." They received favors and allowances that they normally would not receive. This favoritism led to manipulation at times because they knew their behavior would not be challenged to the extent that it was in the past. When friends or family members appeared to ignore their problems, deny the diagnosis, or display insensitivity to their needs, a distance in the relationship developed. Similarly, a few perceived that others misunderstood them or their needs, especially teachers. Adolescents in particular discussed testing new relationships with diagnosis disclosure. They felt uncertain about how people new to their lives would respond and treat them once they learned they had MS. However, several of the participants stated that they felt everyone treated them as before. One school-age participant said: "My school and all people treat me like a regular boy."

Peer Response. Developmentally, peer acceptance is a strong desire in school-age children and adolescents; therefore, the response of their peers to the fact they have MS is important to them. In general, the participants believed most of their friends were supportive and treated them as they would others their age. A school-age child stated... "But even though that my friends don't have a condition I know that I'm accepted for one of their friends."

Many close friends expressed the desire to provide any necessary help. A few indicated that some friends seemed to deny or downplay the diagnosis, believing that if they looked after themselves they would remain healthy and recover from MS. Peers who were not viewed as close friends sometimes treated them differently. For example, they blamed their lack of ability in a particular sport or activity on MS, even if there was no correlation. At times, they perceived that peers excluded them from activities, expressing fear of them suddenly having MS symptoms or inducing symptoms. A school-age boy described what he believed some of his peers thought.

They pity me. They don't invite me anywhere and I think they're scared that I'm going to drop to the ground, or just have all my parts go numb.

Disclosing the Diagnosis. A salient theme revealed during the interviews was the desire to remain selective about to whom to disclose their diagnosis. All felt it was important for certain people to know they had MS, such as their family, close friends, teachers, employers, and coaches. They believed these people were in the position to be understanding and supportive of their needs and provide assistance when required. A teen described it this way...

Before I didn't like, I don't go up to someone and be like 'Hi, I have MS' kind-of thing. And before I'd never tell people and even if they asked me I wouldn't tell a lot of them. My close friends know, but I didn't just tell people. But now if the situation comes up and I have to, and like, I openly talk about it because I'm not ashamed of it. It's me. I think in a way it's important that people know that I'm around a lot. Like, I make sure that people I'm around a lot know that if something happens they should know and they should be aware of what to do.

The participants commonly perceived that more people were aware of their diagnosis than they preferred. Adolescents diagnosed in their childhood years frequently recalled the whole class, school, or neighborhood knowing they had MS. This was a source of embarrassment at times and left them vulnerable to possible teasing, pity, or ostracism. Those diagnosed with MS as an adolescent were better able to limit disclosure. Disclosing to others that they had MS tested both existing and new rela-

tionships as illustrated in the following quote.

It's something I say right away kind-of, like in a week or two, because it's a part of my life and it might strike me anytime and I want that person to know that and I want him to be able to deal with it and be with me if that happens. It's kind-of like a test.

Effect Learning. Although many of the participants observed minimal effect of MS on their lifestyle, most readily identified the effect on school participation and learning. Relapses and medical appointments caused them to miss school, which they felt interfered with their academic achievement. Many described increased learning problems and difficulty with memory and concentration. Others believed they required increased effort to receive comparable marks. One teen stated...

I don't know how much it affects my studies. I still get high marks but maybe that's because I'm putting more effort now, because maybe it's harder for me with MS. But sometimes I do find myself, you know, hard to concentrate, um, forgetful, but recently I began to notice that.

One mentioned that her mood affected her motivation to participate in school. Those bothered by fatigue sometimes reduced their course load to enable them to complete the required work. Whether it was absenteeism, learning problems, impaired memory, reduced concentration, fatigue, or all of these, MS affected the school experience for most of the participants.

Looking Toward the Future. All the participants described moving forward and feeling hopeful about the future. Some of the older teens expressed uncertainty about the future effects of MS on their lives.

That's what I always wanted to do and I just hope that it's not going to interfere. If it does well then I'll have to just struggle with it and fight it to the best of my ability.

One reported frustration with others trying to dictate her future plans in light of the fact she has MS. When asked what they would like to do in the future, all participants had ideas about career choices and usually mentioned more than one interest or option. None of the participants believed MS caused them to change their career goals. Their eclectic career aspirations included teacher, social worker, doctor, psychologist, community caregiver, lawyer or judge, masseuse, fireman, actor or actress, music producer, sports administrator, rocket scientist, and engineer.

Advice to Peers with MS. Inquiring about the advice the participants would give a peer newly diagnosed with MS potentially reveals what participants have learned about having MS, what is important or significant to them, what others have done to help them cope, and how they personally cope with having MS. Most advised of the need to remain optimistic and hopeful. They suggested their peers continue to move forward, stay strong, and believe in themselves. Downplaying the disease was common, implying that they could have something worse and it was easy to carry on with life. Similarly, some wanted to assure their peers that they cannot die from MS. A few advised on the potential change in lifestyle and suggested implementing strategies to decrease stressors and fatigue. Recommendations included being more cautious and looking after themselves. They proposed that certain changes to their lives could actually be positive and improve their outlook on life. A description of MS symptoms, treatments, and diagnostic tests they may face, as well as the uncertainty of the disease, were also points they wanted mentioned. They advised that the injectable therapies were part of having MS and they needed to take them for valid reasons. A suggested way to help them cope included obtaining support from others.

Discussion

The children and adolescents who participated in this study expressed their unique experiences about living with MS and how they coped with and adapted to the changes and stressors in their lives since their diagnosis. It is evident that MS changed their lives, but in many ways how they view themselves and life remained the same. They still participate in age-appropriate activities, but sometimes to a lesser extent or with modifications. Changes are not necessarily viewed as negative. In fact, many recognize that having MS creates positive transformations in their lives such as closer relationships, special privileges, and a better appreciation for life. They also tend to be accepting of changing interests and do not necessarily attribute these changes to having MS. Children and teens appear to incorporate the consequences of having MS into their lives and attempt to normalize their situation as much as possible. Having MS creates new stressors for them, but they implement nu-

merous strategies to help them cope with these stressors. Relapses, persistent symptoms, school difficulties, treatment regimens, and disease uncertainty create challenges, but they still strive to be the person they want to be, continue to develop goals, and maintain hope for the future.

It became apparent during the interviews how having MS shaped these young people's lives. The onset of this disease occurred prior to or during the process of self-identity development. Erikson's (1963) psychosocial development theory purports that individual development occurs in relation to social and cultural environments. According to Erikson, school-age children are faced with the task of developing a sense of industry with the aim of learning responsibility, social and work skills, cooperation, and fair play; while adolescents are in the process of developing their sense of identity and learning who they are and their purpose in society by participating in social experiences, building their self-esteem, and increasing their independence. The onset of a chronic disease such as MS during childhood or adolescence presumably influences this process. The effect of MS on their ultimate identities is unknown but is expected to play a significant role. The longer the participants in this study had MS, the less they noticed the differences MS caused. They recognized it as just one component of who they are as a person and no longer remembered life without MS.

The role of development in shaping their experiences was apparent throughout. Age alone influenced their perspectives on stressors, and future plans, and disclosing their diagnosis to others. With a greater orientation to the future, older teens expressed more concerns about potential future disability and the effect of MS on future plans. With increased cognitive maturity, they have a greater capacity to understand the disease and its progressive nature. Adolescents were more selective about disclosing their diagnosis, whereas school-age children were more likely to conceal that they required injections. The fact that the participants were accepting of changing interests is understandable from a developmental perspective as well because the interests of all children and adolescents change as they mature, face new experiences, such as being diagnosed with MS, and move in different directions as a result of different circumstances. Their experiences mold their developing self-identities, and in this case, an influential experience is living with MS.

A comparison of the literature exploring the experiences of adults living with MS to the findings of this study reveals that the children and teens in this study shared several common experiences with their adult counterparts. For example, participants in Koopman and Schweitzer's (1999) study also feared they had a terminal illness prior to their diagnosis. Adults with relapsing-remitting MS in Miller's (1997) study identified similar issues such as worrying about the burden of the disease on their family, wanting to conceal symptoms from concerned family members, dealing with uncertainty, making minor changes to their lives, and limiting disclosure of the diagnosis to others. Furthermore, they had equivalent concerns about rejection from their peers because of their diagnosis. Coping strategies common to both adults and youth included gaining support from others, maintaining a positive attitude, avoiding stress, and sustaining hope. While the adults described conflict with medical professionals and lack of understanding by employers, the adolescents in this study described conflict with their parents typical of the teenage years and lack of understanding from teachers and certain peers. Unlike the participants in this study, the adults in Miller's study mentioned feelings of hopelessness, a sense of loss (e.g., relationships, independence, employment, abilities), and lack of information about MS and resources. Unique to the children and teens were issues relating to school such as academic performance and absenteeism. They also described using coping strategies not identified in the adult studies and appeared to be more hopeful about the future than the adults.

Implications

What the children and adolescents described about their experiences has many implications for nurses. Based on the study findings, nurses should consider the following actions when caring for youth with MS.

- Reassure them they are not going to die from MS.
- Give information they request in simple terms and anticipate common questions and concerns.
- Offer reeducation about MS periodically as they mature.
- Respect their right to limit the information they receive.
- Inform those who are newly diagnosed that some in a similar situation feel much of life stays the same.
- Acknowledge that they will note some differences in their lives and describe the possible differences most pertinent to them (e.g., treatment, symptoms).

- Recognize and support their various coping strategies and, if necessary, help them identify potentially useful strategies as described by their peers.
- Explore relationship and peer issues.
- Provide guidance around dealing with fatigue and heat intolerance and adaptations to lifestyle.
- Identify potential school issues.
- Review the benefits of treatment and the need to incorporate this into their routine.
- Discuss disclosing the diagnosis to others.

In addition, the participants in this study described issues that provide guidance on how nurses can counsel parents. For example, nurses should consider the following actions when dealing with parents whose child has MS.

- Identify children's perceptiveness of their parents' worries.
- Advise them not to overwhelm their children with extensive information but to provide them with requested information.
- Encourage creation of a routine and ongoing support of the treatment regimen.
- Describe possible feelings and stressors of their children and review appropriate strategies for addressing these.
- Discuss possible school issues and advocate for appropriate supports.
- Talk about disclosure of diagnosis to others and encourage discussion with their children about who needs to know they have MS.
- Suggest discussing with teachers the pros and cons of sharing the diagnosis with classmates.

Implementing these recommendations into practice has the potential to enhance adaptation of these youth but requires further study.

Limitations

Limitations of this study include a small sample size of 12, although this is an acceptable number to receive saturation of themes in qualitative research (Sandelowski, 1995). The participants were also limited to patients receiving care at a specific pediatric MS clinic. Conceivably, youth who receive care in other facilities not geared specifically to pediatric MS care may provide alternative responses. All participants in this study had relapsing-remitting MS and did not have physical disability at the time of the interview. Those with a more progressive form of MS and associated disability likely have different experiences living with MS. The youngest participant in our study was 8 years, therefore, the experiences of younger children were not identified. Lastly, seven patients approached to participate in the study declined participation. Their experiences and how they cope with their disease may be different than those who participated. Several parents indicated that their child did not want to participate because he or she was uncertain about their ability to respond to questions about living with MS or preferred not to discuss it.

Future Research

This study is an initial step in learning more about how MS affects children and adolescents. A quantitative study exploring quality of life of these youth would also be helpful. A follow-up study of these young people when they become adults living with MS may provide us further understanding of the experiential differences between adults and children. In addition, the experiences of parents whose children and teens have MS remain unexplored. Therefore, a qualitative study investigating parents' perspectives would be helpful for nurses who typically deal with the needs of both parents and children.

Summary

The children and adolescents living with MS who participated in this study had many common experiences. Initially, they were unfamiliar with MS and had a multitude of feelings about the diagnosis. They gradually learned about MS from a variety of sources including just living with the disease. Over time, they adapted to the temporary or permanent effects and incorporated changes caused by MS into their lives. Most described participation in social and recreational activities typical of their age group. Although they recognized their lives were different because they had MS, they felt unchanged in many ways. Most noted some positive and negative changes in their relationships after diagnosis. They described stressors unique to having MS that made life more challenging, but they used diverse coping strategies to help them address these stressors. All had supportive people in their lives who facilitated coping. They expressed the need to move forward with life and identified hopes and plans for the future. MS clearly contributed to shaping their self-identities, but their disease remained only one compo-

ment of who they are. The findings of this study provide a greater understanding of the experiences and views of youth with MS and offer guidance for nurses to enhance care.

Acknowledgments

This study was funded by an unrestricted research grant from Biogen Idec Canada. We also thank Dr. Brenda Banwell, medical director of the Pediatric Multiple Sclerosis Clinic at the Hospital for Sick Children.

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