

# Self-Management in Youth With Multiple Sclerosis During Transition to Adult Care and Adulthood: A Qualitative Study Using Interpretive Description

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### LEARNING OBJECTIVES:

- Describe the key self-management skills and life areas that youth with MS prioritize during the transition to adult care.
- Use knowledge of youth self-management priorities and skill development to provide developmentally appropriate, patient-centered care before and after transition to adult MS services.



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## ABSTRACT

**BACKGROUND:** Supporting effective self-management is essential for successful transition from pediatric to adult care. There is a limited understanding of the experiences, priorities, and challenges faced by youth with multiple sclerosis (MS) during this time, so we investigated youth perspectives on MS self-management and the development of self-management skills during transition.

**METHODS:** We conducted a qualitative study with individual interviews using the methodological framework of interpretive description. Participants were recruited from pediatric and adult MS care centers in Toronto, Canada. During interviews, participants described their experiences with self-management during transition. The research team, including youth patient-partners, used constant comparative analysis to identify themes from interviews.

**RESULTS:** Seventeen youth were interviewed (median age 18 years; range, 13-24 years; 12 girls/women). From the interviews, we identified themes about self-management during transition: a need for support and skills regarding MS diagnosis disclosure or concealment, utilization of safety nets, setting expectations, and delegating tasks. We also identified themes on the development of self-management skills: observation, knowledge exchange, explicit guidance and direction, and trial and error. Finally, the interviews highlighted that effective self-management involves self-management of medical, social, and emotional aspects of life, particularly at school and work.

**CONCLUSIONS:** In this study, youth with MS identified key self-management and skill development priorities and processes for the transition to adult care. These insights should inform comprehensive health care practices.

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The past 5 decades have seen a rise in the global incidence and prevalence of pediatric-onset multiple sclerosis (POMS), which is the onset of multiple sclerosis (MS) before the age of 18.<sup>1</sup> This has led to growing numbers of youth with POMS transitioning to adult care. People with POMS, their families, and their health care providers need tailored resources and education to support them during this transition, as it can be a challenging period.

Transition can be defined as a process that addresses the medical and psychosocial needs of youth as they move to adult-oriented systems,<sup>2</sup> usually at 18 years of age in Canada. Poor outcomes in various diseases have been observed during transition.<sup>3</sup> For example, increased rates of complications and hospital admission have been observed in youth with diabetes and cystic fibrosis after transfer to adult care.<sup>4,5</sup> Among the few studies that have addressed transition in MS, high rates of medication nonadherence, difficulty navigating appointments, increased mood symptoms, self-management difficulty, and a need for dedicated transition care support have been reported.<sup>6-9</sup> To improve outcomes during transition, the Canadian Paediatric Society recommends flexible age cutoffs based on youth readiness and prioritizing youth-centered approaches to care.<sup>10</sup> Although gaps remain in optimal transition practices for MS, emerging recommendations focus on self-management support, drawing from studies in other chronic neurological diseases like epilepsy.<sup>11</sup>

Fostering self-management knowledge and abilities during the transition to adult care can support the development of independent health care decision-making and confidence in youth.<sup>12</sup> Self-management is a conscious process where an individual manages symptoms, treatment, and lifestyle changes in conjunction with family, community, and health care professionals.<sup>13-17</sup> Importantly, transition is an inflection point for self-management behaviors, as pediatric care often has a shared approach to decision-making between youth and their caregivers, while adult care places a greater emphasis on patient autonomy.

Supporting youth in their development of self-management skills during their transition is essential to ensure they feel confident and capable to independently manage their MS in adulthood. Following the framework described by Lorig and Holman,<sup>15</sup> skills related to self-management can be classified into 6 categories: problem-solving, medical decision-making, resource utilization, patient-provider partnership, action planning, and self-tailoring.<sup>8</sup> Although these skills are the focus of many adult MS self-management interventions, it is unknown whether they are relevant to youth with MS.<sup>18</sup>

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Supporting youth who are transitioning to adulthood requires a holistic view of self-management that addresses the interplay between MS and psychosocial development during adolescence; however, what self-management truly entails for youth with MS remains poorly defined. Corbin and Strauss identified medical, emotional, and social self-management as essential to living with a chronic illness.<sup>16</sup> Medical management is management of aspects of the disease, including appointments, treatment adherence, and symptom control with prescribed therapies. Emotional management involves managing emotions related to the disease like anger, fear, or depression. Social management involves maintaining, changing, and creating new, meaningful social behaviors or life roles, for example, changing the way one participates in sports or contributes to household chores.<sup>15</sup> Transition to adult care coincides with adolescent development, which is marked by challenges relating to social and emotional management, including pursuing education beyond high school, entering the workforce, and evolving relationships with parents, caregivers, and romantic partners.<sup>2,19</sup> To address challenges related to both MS and adolescence, medical, emotional, and social self-management need to be concurrently supported.

Given gaps in knowledge about self-management in youth with MS, the objective of this study was to investigate youth perspectives on MS self-management and the development of self-management skills during the transition to adult care and adulthood. We had 3 research questions, as follows:

1. What skills do youth develop during transition to achieve self-perceived effective self-management?
2. How do youth describe the development of self-management skills during transition?
3. What life areas do youth identify as highly important for effective self-management during transition, and what do they identify as the associated facilitators and barriers?

## METHODS

### Study Design

Interpretive description was used with semistructured, individual interviews.<sup>20</sup> This applied qualitative methodology focuses on describing and interpreting variations in experiences and contexts. It also integrates prior health disciplinary knowledge (ie, prior clinical experience and research) into the interpretive process to generate further insights that can be applied to health care practice. This study was codeveloped and conducted with youth patient-partners. To inform our findings, we drew on our prior health disciplinary knowledge as MS clinicians, as well as prior research on self-management frameworks.<sup>13-17,21</sup> Youth patient-partners drew on their knowledge attained from experience with the health system as people with a chronic disease. This manuscript is reported according to the Consolidated Criteria for Reporting Qualitative Research (TABLE S1).<sup>22</sup>

The study was approved by the research ethics boards at The Hospital for Sick Children (SickKids) (10000880343), St. Michael's Hospital (23-109), and the University of Toronto (45438).

### Participants

We purposively sampled youth from the pediatric MS clinic at SickKids, and from the adult clinic at St. Michael's Hospital, both in Toronto, Canada. All youth with MS are transferred from SickKids to St. Michael's Hospital at age 18. Currently, there is no standardized transition process.

In this study, we defined transitioning youth as both those who experienced the transfer of MS care from pediatric to adult providers and those who experienced MS during the developmental shift from adolescence to early adulthood, with no requirement for prior pediatric care if they were treated at an adult center. Participants were required to have a diagnosis of MS, be between the ages of 13 and 24 years, and either speak and read English well enough to participate or speak a language for which we had access to professional translation. We excluded youth incapable of providing consent and youth who were within 6 months of receiving an MS diagnosis.

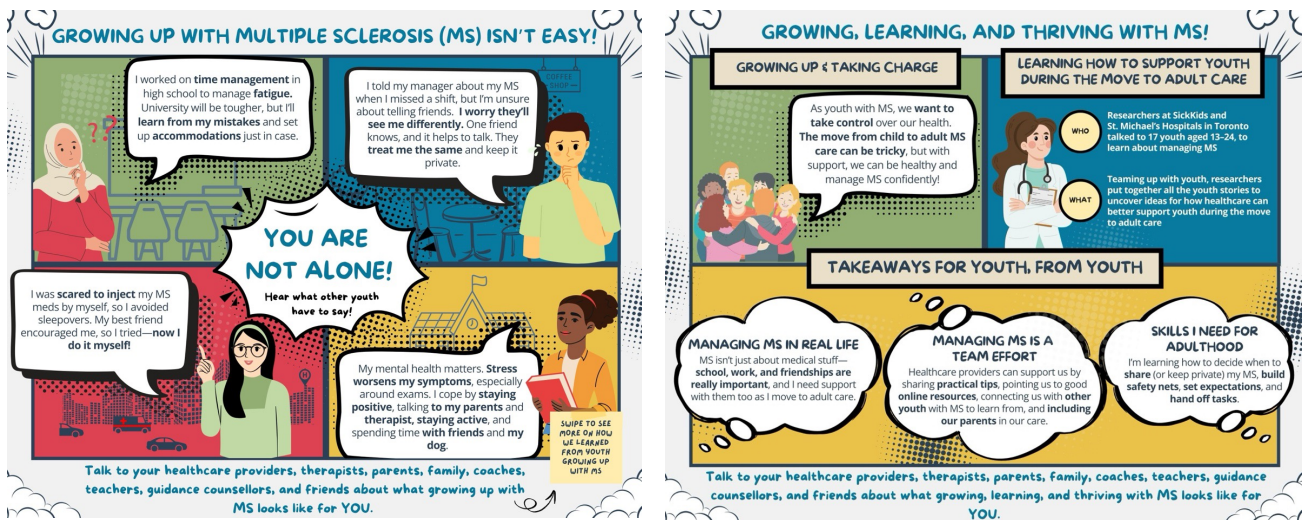
We aimed to recruit a balanced sample of female and male participants and a diverse sample according to visible minority status, socioeconomic status, education level, transition stage, and neurological disability. Participants were initially recruited during routine appointments. As the study evolved, purposive sampling was used to address gaps in sampling, knowledge, and experience. Additional participants were identified in collaboration with treating clinicians and recruited outside routine appointments. Purposive sampling criteria are detailed in TABLE S2.

### Data Sources

There were 3 sources of data for this study: self-report, clinical document review, and interviews. Gender, pronouns, visible minority status, household income, household composition (eg, living with parents), and education level were self-reported.<sup>23,24</sup> Clinical characteristics were collected from clinical document review. Participants were interviewed once, either online or in person. Participants were provided with the interview questions prior to the interview and were introduced to the interviewer (TABLE S3). K.M.S., a clinician-scientist in training, conducted all interviews as part of her PhD. She was supervised by her program advisory committee, who have extensive qualitative experience. She had no prior relationship with participants. Interviews were semistructured using an interview guide and field notes (TABLE S4). The interview guide underwent pilot testing with 2 youth volunteers outside of our study team to assess its developmental appropriateness. As interviews were analyzed, the interview guide evolved.<sup>20</sup> Interviews were audio recorded and lasted between 45 and 140 minutes.

### Data Management and Coding

Transcripts were verified and anonymized by the interviewer, and identifying information was replaced with generic phrases. Coding and thematic analysis were completed by the interviewer and 2 patient-partners, with input from all investigators. Patient-partners received training in patient engagement and qualitative methods from the research team (TABLE S5). Each interview was independently coded by 2 coders. Coding started with open coding (without a codebook). A codebook was

**FIGURE 1.** Study Infographic

Note: This infographic, intended for youth on social media platforms, illustrates prominent themes identified in this study through the use of graphics, modified quotes, and a lay summary, provided below.

Lay summary: Adolescence is a time when our role in managing our health changes. When we are children, our health is mostly managed by our parents. When we are adults, we mostly manage our health on our own. Adolescence is also the time when we move from child to adult health care. Research has shown that the move to adult health care can be a difficult and risky time for poor health in young people with chronic conditions. It is unknown how young people with multiple sclerosis (MS) manage during this time. This study was done in partnership with youth with MS as team members to learn more about managing life with MS during the move from child to adult MS care. This study was conducted in Toronto, Canada, at The Hospital for Sick Children and St. Michael's Hospital. In this study, 17 youth with MS, between the ages of 13 and 24 years, were interviewed about what it is like to manage life with MS. During interviews, youth also shared what it has been like, or what they think it is going to be like, moving from the child MS clinic to the adult MS clinic once they turn 18 years old. From these interviews, the research team learned about what's most important to youth for good self-management of their life with MS, like doing well at school and work. The interviews also revealed that young people with MS face challenges in managing their condition, including uncertainty about whether and how to tell friends, classmates, and coworkers about their MS diagnosis. Lastly, the interviews showed how youth learn the skills they need to manage life with MS, such as by reading about what other youth do online or by talking to their parents and then practicing the new skills and learning from mistakes along the way. The findings from this research will inspire ways for MS care providers to support youth in managing their lives with MS, especially during the move from child to adult MS care.

developed as interviews were coded and then used and refined in subsequent coding sessions.<sup>20,25</sup> As interviews were coded, coders also generated themes with reference to the research questions.<sup>20,26</sup> The iterative process between open coding, applying and refining the codebook, and generating themes was continued until thematic saturation was reached.<sup>20,27</sup> Coders used NVivo software to organize codes and interviews.

### Synthesis

For each research question, we created a topical survey, an inventory of the ideas discussed by participants.<sup>20,28</sup> Next, the terms from the topical surveys were transformed into thematic summaries of groupings and patterns that had been inductively derived.<sup>20,29</sup> Finally, where possible, relationships between themes and contexts were used to generate thematic descriptions identifying the concepts and latent patterns developed from the data and external sources.<sup>20,28</sup> During analysis, the frameworks by Corbin and Strauss and Lorig and Holman, Bandura's social cognitive theory, and Leventhal's self-regulation model became relevant external sources that informed our thematic descriptions.<sup>15,16,30-32</sup>

Willing interview participants were engaged as 3 additional patient-partners after analysis was complete. All patient-partners

and investigators contributed to a youth-facing infographic summarizing study findings.

## RESULTS

Between May 8, 2023, and January 17, 2024, we identified 59 eligible youth from both locations. A total of 26 were approached to participate before thematic saturation was reached after 17 interviews. Participants' demographic and clinical characteristics are summarized in the [TABLE](#). Our sample included a diversity of gender, education level, household income, visible minority status, and household composition. Participants were aged 13 to 24 years, 7 were still in the pediatric center transfer, 9 were in the adult center, and 1 was in the process of being transferred from the pediatric to the adult center. At the time of the interviews, participants had been experiencing MS symptoms for between 1 and 12 years. All had mild to moderate disability, and nearly all were prescribed a disease-modifying therapy. All interviews were conducted in English without the use of a translator.

Thematic summaries and descriptions by research question are detailed below. The infographic ([FIGURE 1](#)), cocreated with patient-partners and intended for youth with MS, illustrates the prominent themes in this study.

TABLE. Participant Characteristics

	Age	Gender <sup>a</sup>	Visible minority <sup>a</sup>	Education level <sup>b</sup>	Employment status	Household income <sup>a,c</sup>	Lives with	Years since MS symptom onset	EDSS	DMT <sup>d</sup>	Recovery after most recent relapse
<b>Y1</b>	16-18	Girl/woman	No	Secondary	Student	> \$42,000	Parents	1	1.5 (Sensory: 1.0; sVisual: 1.0)	Fingolimod	Partial
<b>Y2</b>	16-18	Girl/woman	No	University	Student and working part-time	> \$42,000	Parents	2	1.0 (Pyramidal: 1.0)	Fingolimod	Complete
<b>Y3</b>	16-18	Boy/man	Yes	Secondary	Student	Unknown	Parents	2	Unknown	Fingolimod	Partial
<b>Y4</b>	22-24	Girl/woman	Yes	University (completed)	Working full-time	> \$42,000	Parents	12	1.5 (Unknown FS scores)	Ocrelizumab	Complete
<b>Y5</b>	16-18	Boy/man	No	Secondary	Student	> \$42,000	Parents	3	1.5 (Pyramidal: 1.0; Visual: 1.0)	Fingolimod	Partial
<b>Y6</b>	13-15	Boy/man	Yes	Secondary	Student	> \$42,000	Single parent	1	1.5 (Pyramidal: 1.0; Visual: 1.0; Cerebral: 1.0)	Natalizumab	Partial
<b>Y7</b>	16-18	Girl/woman	Yes	Secondary	Student	> \$42,000	Parents	4	2.0 (Pyramidal: 1.0; Visual: 1.0; Sensory: 2.0)	Natalizumab → fingolimod	Partial
<b>Y8</b>	13-15	Girl/woman	No	Secondary	Student and volunteer	Unknown	Parents	5	3.5 (Pyramidal: 2.0; Cerebellar: 1.0; Visual: 3.0)	Natalizumab	Partial
<b>Y9</b>	22-24	Girl/woman	No	University	Student	> \$42,000	Roommate	8	1.5 (Pyramidal – 1.0, Sensory – 1.0)	Ofatumumab	Complete
<b>Y10</b>	22-24	Girl/woman	Yes	University	Student	< \$42,000	Roommate	10	1.5 (Pyramidal: 1.0; Visual: 1.0)	Natalizumab	Partial
<b>Y11</b>	19-21	Boy/man	No	Technical college	Student and working part-time	> \$42,000	Single parent	3	1.0 (Unknown FS scores)	Peginterferon beta-1a → ocrelizumab or ofatumumab	Partial
<b>Y12</b>	16-18	Girl/woman	No	University	Student	> \$42,000	Alone	2	1.0 (Unknown FS scores)	Dimethyl fumarate	Complete
<b>Y13</b>	13-15	Girl/woman	No	Elementary/middle	Student	> \$42,000	Parents	2	1.5 (Pyramidal: 1.0; Visual: 1.0)	Peginterferon beta-1a	Complete
<b>Y14</b>	22-24	Girl/woman	Yes	University (completed)	Working full-time	< \$42,000	Parents	7	1.5 (Cerebellar: 1.0; Sensory: 1.0)	Cladribine	Partial
<b>Y15</b>	19-21	Girl/woman	Yes	University	Student	> \$42,000	Parents	6	2.0 (Sensory: 1.0; Visual: 2.0)	Ocrelizumab	Partial
<b>Y16</b>	22-24	Boy/man	No	University (completed)	Unemployed	> \$42,000	Parents	9	1.5 (Pyramidal: 1.0; Sensory: 1.0)	Fingolimod	Complete
<b>Y17</b>	22-24	Girl/woman	Yes	University	Student	Unknown	Parents	12	0.0	Dimethyl fumarate	Complete

DMT, disease-modifying therapy; EDSS, Expanded Disability Status Scale; FS, functional systems; MS, multiple sclerosis; Y, youth.

<sup>a</sup>These categories were self-reported.

<sup>b</sup>Elementary/middle school includes grades 1 through 8; secondary education includes grades 9 through 12.

<sup>c</sup>Household income status was self-reported as more or less than \$42,000 CAD per year. In Ontario, \$42,000 CAD is the threshold for low income, a surrogate for low socioeconomic status.<sup>16</sup>

<sup>d</sup>An arrow indicates the youth was switching DMTs.

**FIGURE 2.** Self-Management Skills<sup>a</sup>

Problem solving	Medical decision-making	Resource allocation and utilization
<ul style="list-style-type: none"> <li>Mitigating DMT adverse effects</li> <li>Knowing what to do if miss a dose of DMT</li> <li>Managing fluctuating day-to-day MS symptoms (eg, sensory, and visual disturbances)</li> <li>Managing chronic day-to-day-symptoms (eg, fatigue, cognitive difficulties, residual impairment from relapse)</li> <li>Managing mood and emotions (eg, stress, worry, anxiety, fear)</li> <li>Making a big task into multiple smaller ones</li> <li>Off-loading some tasks to others</li> </ul>	<ul style="list-style-type: none"> <li>Accessing, reviewing, and interpreting results (eg, blood work, MRI) on own</li> <li>DMT adherence</li> <li>Managing lifestyle choices (eg, daily vitamins, exercise, diet)</li> <li>Accepting help from others</li> </ul>	<ul style="list-style-type: none"> <li>Accessing emergency/urgent medical care</li> <li>Accessing routine medical care</li> <li>Reading and learning about MS</li> <li>Judging trustworthiness and relevance of resources</li> <li>Open communication with parents</li> <li>Creating safety nets</li> </ul>
Patient-provider partnership	Action planning	Self-tailoring
<ul style="list-style-type: none"> <li>Communication with HCPs at routine appointments</li> <li>Communication with HCPs outside routine appointments</li> <li>Communication with pharmacists, insurance, and patient support programs about DMTs</li> <li>Communication with clinic secretaries, MRI technicians, and blood laboratory</li> </ul>	<ul style="list-style-type: none"> <li>Setting and adjusting own expectations</li> <li>Identifying priorities/goals/needs</li> <li>Communicating expectations to others about needs and abilities</li> <li>Arranging formal or informal accommodations at school and work</li> <li>Thinking ahead</li> <li>Learning from mistakes</li> <li>Organizing/scheduling/establishing a routine</li> </ul>	<ul style="list-style-type: none"> <li>Engaging in self-reflection</li> <li>Self-soothe</li> <li>Positive thinking</li> <li>Knowing body (eg, physical and emotional limits)</li> <li>Normalizing and/or defining a new normal</li> <li>Finding the good side of things that “suck”</li> <li>Being nice to self</li> <li>Adjusting priorities/goals/needs</li> <li>Disclosing diagnosis or not</li> <li>Adapting strategies to meet current needs</li> </ul>

DMT, disease-modifying therapy; HCP, health care professional; MS, multiple sclerosis.

<sup>a</sup>This is based on the Lorig and Holman self-management skills framework.

### What Skills Do Youth Develop During Transition to Achieve Self-Perceived Effective Self-Management?

**FIGURE 2** uses the Lorig and Holman framework to show the skills that participants described as important for effective self-management. They are detailed below and aligned with the self-tailoring, allocating and utilizing resources, action planning, and problem-solving framework categories.

#### Self-Tailoring Disclosure and Concealment of Diagnosis

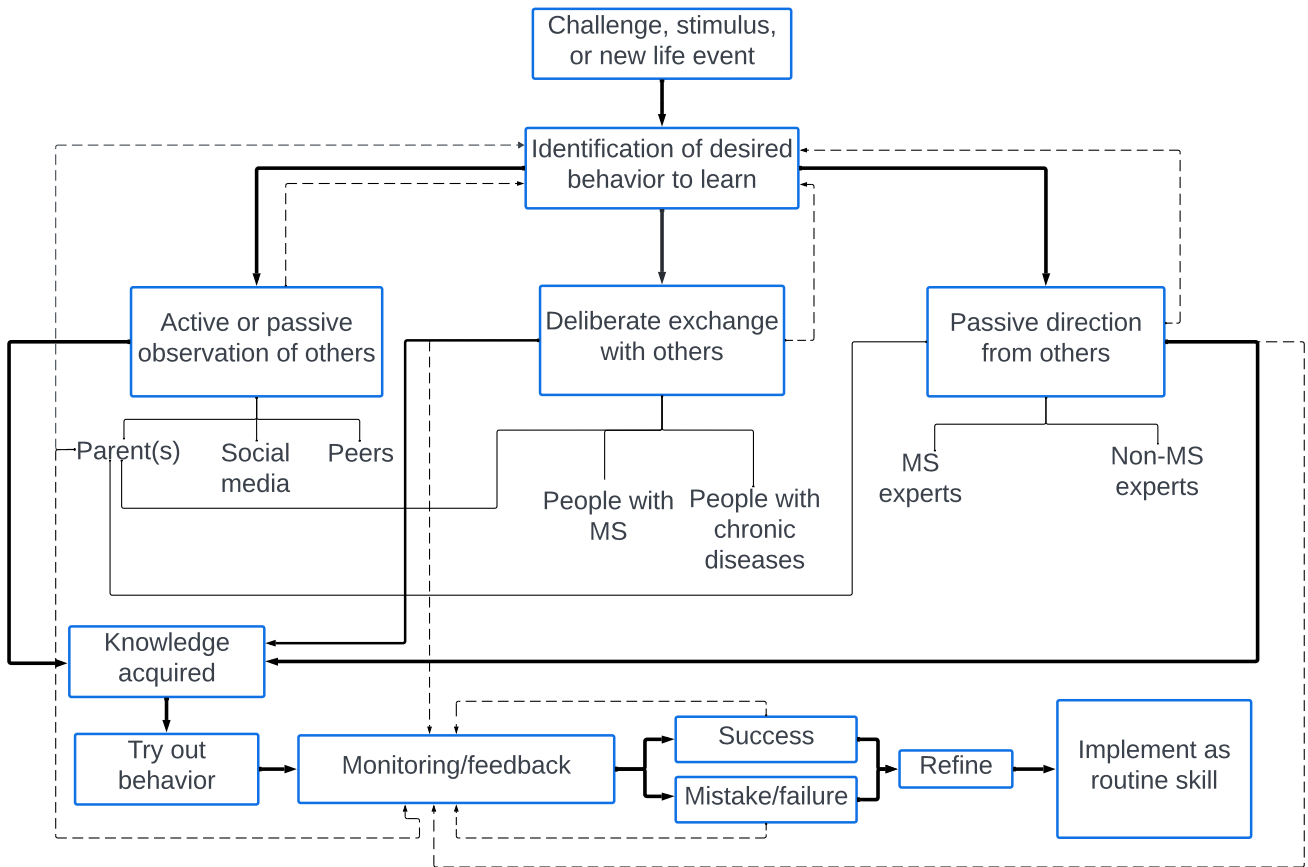
Participants identified the skill to decide when, if, and how to disclose their diagnosis as very important. They highlighted their need to be able to tailor disclosure according to different situations to effectively manage their life and disease. Contexts where this was emphasized were work, sports teams, university, and new relationships. Participants favored keeping their diagnosis private and only disclosing when there was a “good reason to,” like “in an emergency” or “to get accommodations.” They also highlighted the importance of balancing disclosure to get support with keeping the number of people who know they have MS to a minimum. Youth (Y) 15 said, “I only told my manager because I had to miss work for an appointment. I still have no confidence in letting my coworkers know, and to be honest with you, none of my friends know, and I would like to keep it that way.”

Some participants felt that developing disclosure skills is more important the further along one is in the transition process. Y16 said, “I wrote a speech and spoke to my whole high school [to raise awareness about MS]. I found myself less open to share my personal health when I got to university.”

#### Allocating and Utilizing Resources as Safety Nets

Participants provided examples of creating safety nets or strategies that provide stability and redundancy in case something does not go as planned. These included academic accommodations, parents keeping track of appointments and medications, informing coaches about MS, and parents attending MS appointments even after their transfer to the adult center. Youth highlighted that, in the later stages of transition, safety nets were used less often but were still important to support their personal growth. Y2 said, “I’ve been slowly starting to take it on [management of appointment scheduling] more and more over the past 6 months. Just because I am 18 now, [and] I am moving out. I’ll have to take on those responsibilities on my own, but it’s a slow process. We’re [ie, the youth and her parents] easing me into it. I have all the appointments on my school calendar, but my parents also have them in theirs, you know, just as backup, in case.”

**FIGURE 3. Self-Management Skill Development**



MS, multiple sclerosis.

Note: This flowchart depicts the process of self-management skill development identified by youth with MS during their transition from pediatric to adult MS care and young adulthood in our qualitative study. The blue boxes with bold lines with arrows indicate the pathways youth identified. The dashed lines with arrowheads indicate feedback loops highlighting the iterative nature of the process; the solid lines identify people and resources used as part of self-management of these skills. The process begins with a challenge, stimulus, or new life event leading to the identification of behaviors to learn. Then youth acquire knowledge through 3 primary pathways: active or passive observation of others (parents, online media, or peers), deliberate exchange of ideas with others (people with MS or other chronic diseases), or passive direction from MS or non-MS experts and parents. Acquired knowledge is then applied through trying out behaviors, followed by monitoring and feedback. Success or failure during this stage leads to refinement of the behavior, ultimately resulting in the implementation of the skill as part of routine self-management.

**Action Planning by Setting Expectations for Self and Others**

Participants identified setting expectations for themselves and others as an important skill to manage their lives and disease. This skill was prominent when managing mood, emotions, and fatigue, and when participating in recreational activities. Participants who expressed higher confidence with setting expectations also had more confidence in diagnosis disclosure, and most were in later transition stages. Y4 said, “When I started telling friends I have MS, I told people, if I’m not feeling 100%, I might be more fatigued, and this is why I might be acting this way or don’t want to go out.”

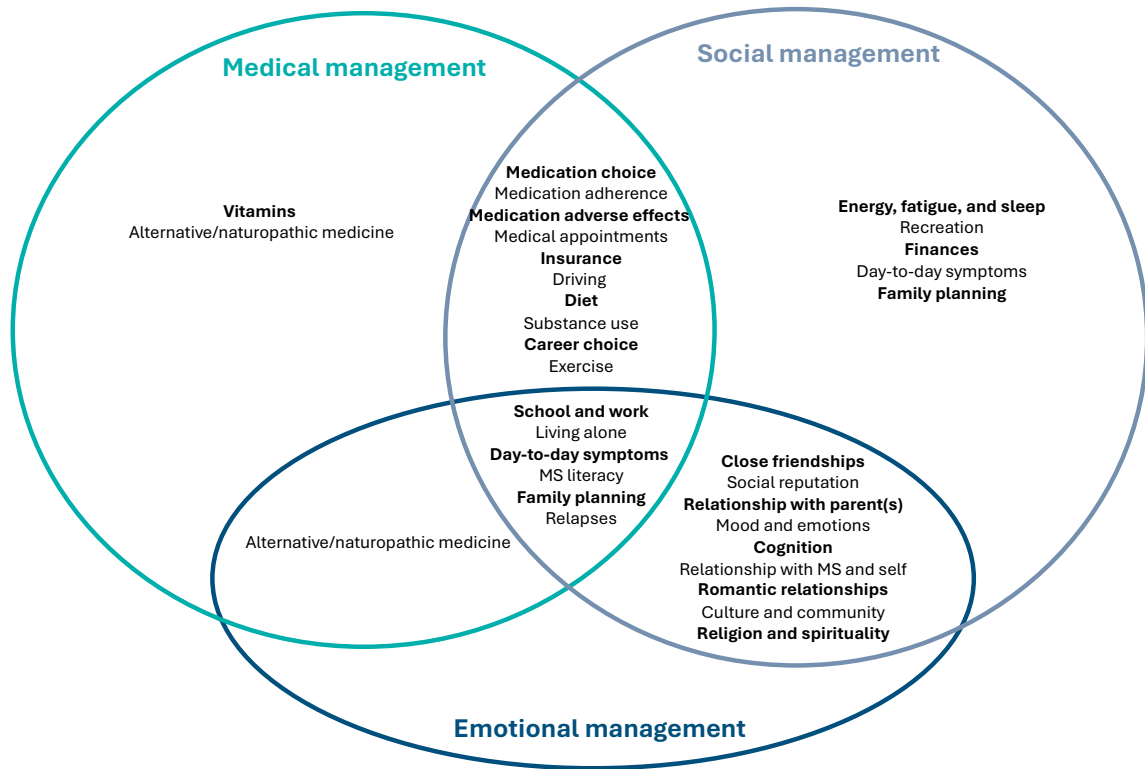
**Problem Solving by Strategically Offloading Tasks to Manage Priorities**

Participants described how they offload emotional, cognitive, physical, or logistical tasks to allow them to focus on other priorities, responsibilities, or interests. They described actively

delegating or passively allowing another person to assume responsibility for a task that they otherwise would have had to address themselves. When facing higher-priority or urgent tasks, participants offloaded future-oriented tasks to parents. They also recognized the need to eventually assume responsibility for multiple demands simultaneously. Y3 said, “I think it’s important for him to do it [for his dad to manage his appointments] because I’m in a special academic program and with all the work I have to do, it takes a weight off knowing that he’ll be doing that for me. Though if I ever do move, I’m assuming I’ll have to do it for myself.”

**How Do Youth With MS Develop Self-Management Skills During Transition?**

Participants described a recursive process of developing self-management skills: They were confronted with a challenge or stimulus that inspired the choice to develop a skill. Next, they identified learning from others using a combination of observing,

**FIGURE 4.** Youth-Identified Areas That Are Important for Effective Self-Management of Life With Multiple Sclerosis

MS, multiple sclerosis.

Note: This figure illustrates all the life areas identified by participants that need effective self-management during transition. The life areas are organized within the Corbin and Strauss self-management task framework. .

exchanging ideas, and getting explicit direction. Eventually, youth described practicing and refining the skill by assessing consequences and getting feedback. This process is illustrated in **FIGURE 3** as a thematic description, reflective of elements of social cognitive theory and the self-regulation model.<sup>31,32</sup> Each step of the process the youth described is detailed below.

### Challenge or Stimulus

Regarding the types of stimuli that drive self-management skill development, participants identified social pressures, social support, fear of relapse, new symptoms, and parental expectations as key factors, particularly as they grew older. Y13 said, “For the first couple of months, I never injected my own medication. I was too scared to do it, but then told myself I was just gonna do it and my friend was convincing me and saying, ‘Be brave!’ So then I finally did it. At the beginning, I was really nervous to go for sleepovers [be]cause I would have to ask their parents to do it for me, but now I can do it myself.”

### Learning From Others

Participants described developing self-management skills by observing and reading about others’ experiences online, as well as by engaging in discussions online and in-person. They learned this way from parents, close peers without MS, people with MS,

youth with other chronic conditions (eg, epilepsy, lupus), as well as influencers, celebrities, and youth with other chronic illnesses on YouTube, Instagram, TikTok, and TED Talks. A few youth mentioned exchanging ideas with their MS provider (in contrast to getting direction from them, as discussed below). Some also used community MS resources, but highlighted that most resources were not relevant to pediatric MS and were difficult to understand.

### Direction From Others

Participants learned self-management skills because someone “told me to do it this way,” usually their MS provider or parent. Some had hoped for more direction from their MS providers about self-management in areas beyond medical management. For example, in the context of managing new challenges in university, Y10 said, “I feel like if I had my health care team inform me of those things [strategies and accommodations] or sit me down and help me break down these basic tasks—having that information earlier on would have really prepared me for that transition to living on my own.”

### Practice, Assessment, and Refinement of New Self-Management Skill

Once knowledge was acquired, participants described the process of trying out a skill through trial and error, often followed by

soliciting feedback from their parents. Parents held a valued role, and their feedback was highlighted in all stages of transition and in many contexts. Y10 said, “I focused a lot on time management for my fatigue during my later years of high school. In university, it is gonna be a lot more challenging and stressful, but I think the practice I’ve had has led me on the right path. It’ll be new, but good for me to learn and experience the mistakes to do better next year.”

### **What Facilitators and Barriers Influence Self-Perceived Effective Self-Management in Life Areas That Are Most Important to Transitioning Youth?**

**FIGURE 4**, based on the Corbin and Strauss framework, illustrates the life areas that youth described as essential to managing life with MS. Self-management in these areas connects to medical, social, and emotional tasks and shapes overall MS management. Life areas emphasized as important are detailed below.

#### **Managing Social Reputation**

All participants expressed that effectively managing their life with MS involved maintaining control over their social reputation. A key aspect of self-management was ensuring they were seen as “normal.” They were worried about being seen as “a slacker,” “faking it,” “dying,” or “fragile and weak” if they disclosed their MS to peers. They also identified concerns about being treated differently as a barrier when choosing to tell someone they had MS. Some identified the ability to effectively explain and disclose their diagnosis as something that facilitated stronger social relationships and ameliorated their concerns about being stigmatized.

#### **Managing School and Work Performance**

Participants thought that performing well at school and work was essential for effective self-management. Difficulties with managing fatigue, absenteeism (ie, due to appointments or symptoms), cognitive difficulties, and diagnosis disclosure were reported as barriers to peak performance. Participants highlighted the need to learn skills to manage and communicate difficulty. Y2 said, “It took a lot to get me to approach my teachers. My parents wanted me to, and it did end up being helpful in the long run, but I don’t typically like telling people I have MS. If for some reason I wasn’t as comfortable with them, I’d send them an email, but if I was comfortable with them, I would stay after class and I’d talk to them and say, you know, I got diagnosed with MS recently, some days it’s going to be hard for me. Some days I will need to leave class early, some days I won’t be in class at all. Some days I’ll be sick. I’m gonna do my best to stay on top of my work, but there will be challenges.”

#### **Managing Mood and Emotion**

During transition, participants felt “anxiety,” “stress,” and “sadness”; had “mood swings”; and were “grouchy,” “scared,” and “overwhelmed.” Participants emphasized that managing their moods and emotions was an important aspect of managing their physical MS symptoms and vice-versa. Y10 said, “If I’m feeling really stressed out or I know that my MS symptoms are flaring, and there’s an assignment, I know that I’m not gonna do it to the

best of my ability, and that’s not an accurate representation of my intellect or of what I know about that topic. So I know that if I have a lot of assignments or if MS is not doing so great and I’m really stressed out, I really focus on lowering my stress.”

Participants identified engagement with parents, family, friends, and pets—often through exercise, video games, and sports—as facilitators of effective mood and emotion management. Some youth noted that therapists helped them manage their mental health, and noted that having a therapist with knowledge about MS was imperative.

#### **Managing Fatigue, Energy, and Sleep**

Self-management of fatigue, energy, and sleep was emphasized as important during transition. Participants said that difficulties with managing fatigue kept them away from sports, spending time with friends, and accomplishing goals. Y10 said, “Fatigue has worsened for me since transitioning to adulthood because of dealing with other things like being in university. I feel like when I was really young, the fatigue was present, but I was still able to do things on my own without asking for help.”

Participants identified social expectations to “stay out late” and “go to parties” as barriers to fatigue management and recognized setting expectations in their social group and planning breaks as facilitators for effective fatigue self-management.

## **DISCUSSION**

During their transition to adult care, the youth with MS in our study valued support, safety nets, setting expectations, delegating tasks, and learning skills to manage diagnosis disclosure. They developed self-management skills through observation, knowledge exchange (online and with parents), explicit guidance, and trial and error. For participants, effective self-management included medical, social, and emotional management with an emphasis on managing social reputation, mood, fatigue, and performance at school and work.

The youth-identified key skills and life areas highlight potential opportunities for counseling during appointments. Youth feared stigmatization but found that effective disclosure provided them with support, so deciding when, if, and how to disclose is a crucial skill for managing social reputation. Similar concerns about stigma have been observed in youth with other chronic diseases.<sup>33</sup> Studies in adults link confidence in diagnosis disclosure or concealment to better health, mood, and quality of life, but youth with MS remain underrepresented in these studies.<sup>34</sup> Our findings underscore the importance of empowering youth to learn disclosure skills during transition.

Our interviews highlight transition as a pivotal time with unique barriers and facilitators to effective self-management of fatigue, mental health, and cognitive difficulties. It is estimated that 50% to 76% of youth with MS experience clinically significant fatigue, approximately 30% fulfill criteria for affective disorders (eg, anxiety, panic, major depression, and bipolar disorders), and up to one-third experience cognitive difficulties.<sup>35-37</sup> Studies in adults with MS have shown the importance of self-management in these areas and the effectiveness of specific interventions.<sup>18</sup> Given our findings, we suggest that supporting

youth in the management of fatigue, mental health, and cognition requires developmentally appropriate resources and trained professionals familiar with chronic diseases and MS, including career counselors, therapists, and lifestyle coaches. Future research should explore interventions to support self-management during transition by addressing the barriers and facilitators identified in this study.

Our study participants also identified parental involvement as critical for self-management learning, especially when parents act as safety nets and resources for offloading tasks. Youth reported that this parental involvement is important even while in the adult health care system and living independently. While parental reliance could be a practical choice, it may limit the development of essential skills required in adult care, where youth may be forced to become more independent. Similar to findings in other transition research, our findings suggest that a gradual shift in autonomy and skill-building should be encouraged during clinic visits or with strategically-timed interventions.<sup>10,12</sup> They also indicate that MS providers should actively engage parents in routine care in early adulthood to facilitate self-management skill development, as parents can have difficulty relinquishing responsibilities to their child during transition.<sup>12</sup>

Our thematic summary of how youth develop self-management skills during transition reflects elements of Bandura's social cognitive theory and Leventhal's self-regulation theory. According to social cognitive theory, people learn by observing others, evaluating the consequences of their actions, and integrating those observations with their own beliefs and environmental factors.<sup>30</sup> According to the self-regulation model, patients manage their diseases by recognizing health threats, managing emotional responses, assessing risks and treatments, developing action plans, and then adjusting behaviors based on continuous feedback.<sup>31</sup> Our findings suggest these learning theories, the effective relationships youth have with certain sources online and their parents, and their desire to learn from providers should be used to inform development of skill-building material for youth with MS.

Our study has some limitations. Although we attempted to recruit a diverse group, our sample includes only volunteers from tertiary MS clinics, and almost all participants were prescribed disease-modifying therapy. Our participants are especially engaged in their MS care and potentially have higher levels of social support than the average youth with MS. Our sample included only English-speaking participants, so we could not examine how language proficiency might influence self-management, which is important with Canada's ethnically diverse population. Given that most participants were students and living at home, this limited our ability to draw specific themes about self-management in relation to employment and household composition. All participants had at least 1 adult they considered a parent; therefore, our findings may not be generalizable to youth with other family structures and types of caregivers. Future research could include investigating factors previously linked to self-management in adults with MS in transitioning youth.<sup>38</sup> Considering all of the above limitations, generalizations to the greater MS community may be

## PRACTICE POINTS



Youth-centered approaches are needed to support self-management-related concerns for youth with multiple sclerosis during the transition to adult care.

Providers should explore the unique pressures youth face in school, work, and social settings, as youth identified these areas as priorities for self-management growth during transition.

Providers can support self-management skill building during transition by encouraging youth to learn from others' experiences, offering clear and practical advice, sharing reliable online resources, and involving parents or caregivers in care discussions—even in adult care settings. ■

limited. Nonetheless, findings from this study can be used for future hypothesis testing on a larger scale.

## CONCLUSIONS

In this study, youth identified key self-management skills and priorities during their transition to adult care and adulthood. Findings highlight opportunities to enhance self-management support in routine MS care using youth-centered approaches—guided by social cognitive theory and the self-regulation model—that engage parents, online communities, and diverse providers. Understanding the skills, learning processes, and focus areas that youth with MS need provides valuable direction for enhancing future MS transitional care practices. ■

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