

# Perspectives of People with Multiple Sclerosis About Helminth Immunotherapy

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## CME/CNE Information

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**Target Audience:** The target audience for this activity is physicians, physician assistants, nursing professionals, and other health care providers involved in the management of patients with multiple sclerosis (MS).

### Learning Objectives:

- 1) Describe the proposed rationale for, use/logistics of, and concerns about helminth immunotherapy in the management of MS.
- 2) Identify the factors driving individuals with MS to contemplate using helminth immunotherapy.

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**Background:** Due to the chronic and incurable nature of the autoimmune disease multiple sclerosis (MS), some people with MS will seek out alternative therapeutic approaches. Helminth immunotherapy, the deliberate inoculation with helminthic parasites as an intervention to prevent, delay, or minimize progression of autoimmune disorders, is one such approach gaining traction in academic research and with the public. Herein, we explored the perspectives of people with MS regarding helminth immunotherapy and its use in disease management.

**Methods:** Interpretive description, a qualitative research approach, was applied to data extracted from online forums. Multiple investigators independently identified, extracted, and analyzed data to develop preliminary codes. Inductive thematic analysis and triangulation were then used to collaboratively establish themes.

**Results:** Four main themes were generated: experience of living with MS, influential factors in contemplating helminth immunotherapy, logistics of helminth immunotherapy, and concerns about helminth immunotherapy.

**Conclusions:** There was a general consensus in publicly available online forums that conventional therapies do not provide meaningful improvement for some people with MS. These people may seek alternative therapies such as helminth immunotherapy. Information on helminth immunotherapy from internet resources (eg, blogs and social media forums) can contain biased and scientifically unsupported opinions. Messages of efficacy and improved quality of life are readily available and may influence people with MS considering helminth immunotherapy as an alternative therapy. Although some people with MS are seeking helminth immunotherapy, clinical trial data do not currently support its use for people with MS. *Int J MS Care.* 2020;22:43-51.

**M**ultiple sclerosis (MS) is a chronic and disabling immune-mediated disease of the central nervous system. Although the cause of MS is unknown, there are both genetic and environmental risk factors associated with disease susceptibility.<sup>1</sup> Geographic location is a commonly cited environmental risk factor.<sup>2</sup> The low incidence of MS and other autoimmune diseases in equatorial regions suggests that there may be something protective about the environment in these regions. Increased sunlight exposure and production of vitamin D in equatorial regions could be protective.<sup>2</sup> An additional environmental consideration is the distinct difference in intestinal pathogen exposure between these regions.<sup>3</sup> Equatorial countries with lower socioeconomic status and infrastructure have significant-

ly higher rates of intestinal infections by helminths (ie, parasitic worms).<sup>3</sup> In contrast, helminth infections were essentially eradicated in North American and European countries that have high MS incidence.<sup>3</sup>

A variety of helminth species infect humans. They have typically been considered parasitic due to their ability to cause cognitive dysfunction, malnourishment, and anemia in infected children.<sup>3</sup> In recent years, however, the hygiene hypothesis, or old friends hypothesis, has emerged.<sup>3</sup> This line of thought highlights an association between the coincident decrease in microbial and helminth exposure due to sanitation and vaccination and the emergence of autoimmune diseases in industrialized countries and suggests that infection with helminths may not be completely detrimental.<sup>3</sup> Instead, helminths may represent “old friends” that have evolved alongside humans and play a key role in regulating our immune system.<sup>4</sup> The absence of helminth exposure may contribute to the dysregulated immune responses against self-tissue that drive the development and progression of autoimmune diseases such as MS.<sup>4</sup> As a consequence of this theory, it has been proposed that the immunoregulatory properties of helminth infection can be exploited to dampen autoimmune reactions and manage disease symptoms.<sup>3</sup> There are four published clinical trials that

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have evaluated helminth immunotherapy in the context of MS<sup>5-8</sup>; all of these administered ova of *Trichuris suis*, a whipworm that establishes persistent infection in pigs but is cleared from the human intestine. However, reports of self-administered helminth immunotherapy included exposure to ova of *T suis* and *Trichuris trichiura* (a whipworm that preferentially infects humans), and *Necator americanus*, a hookworm that is common in parts of Asia and sub-Saharan Africa.

Although helminth immunotherapy in the context of MS has been evaluated in a small number of clinical trials, there is currently insufficient evidence to support approval by regulatory bodies for its use in MS management.<sup>9</sup> Understandably, clinicians are unable to currently offer helminth immunotherapy to individuals with MS. However, as with many emerging therapies, word of the potential efficacy of helminth immunotherapy spans media coverage with a mix of evidence and falsities. As such, individuals with MS have begun to seek this unapproved therapy by travelling to other countries or purchasing these worms in the underground market.

The aim of this study was to explore the messages being conveyed via social media regarding the perspectives of individuals with MS on the use of helminth immunotherapy in MS management. This study focused on the experience of the individual contemplating, using, or deciding not to use helminth immunotherapy as an experimental, self-administered intervention to manage MS. This type of inquiry is well suited to a qualitative approach.

## Methods

### Overview

Interpretive description, an applied qualitative research approach, was used in this study.<sup>10</sup> Online forums, where multiple people share their personal experience and perspectives, including blogs and their discussion boards, were used as the data source. The internet can be a valuable tool for collecting participant-generated reflective qualitative data.<sup>11</sup> Blogs allow users to both generate and consume content while communicating and interacting with others through associated comment sections and discussion boards. These posts allow an unsolicited, spontaneous account of the user's offline world, offering rich first-person accounts of personal experience.<sup>12</sup> In accordance with the Tri-Council Policy Statement, this research is exempt from research ethics board review given that all information is sourced from publicly available or accessible records.

### Data Collection

Data collection used both a passive and an active phase.<sup>13</sup> The passive phase involved identifying and agreeing on appro-

priate data sources. This was done by searching the internet for public webpages related to helminth immunotherapy in the context of MS based on predefined sampling characteristics. Each investigator performed independent internet searches to identify appropriate sources (eg, blogs, discussion boards) created before January 2018 regarding helminth immunotherapy that were written by individuals with MS. Google searches with key word combinations and associated abbreviations of *multiple sclerosis, relapsing-remitting, progressive; worm, parasite, helminth; therapy, treatment, and immunotherapy* were used. Blog-specific servers (blog content management systems, eg, Blogster, Blogger, Journal Space) were also searched using keywords.

The researchers then met to discuss the independently identified websites and came to consensus on 20 data sources. Online commenters (either the original author of the blog or discussion board topic or a commenter) seemed to be users, nonusers, or people contemplating the use of helminth immunotherapy for MS management. The active phase involved data extraction, which was completed independently by two researchers, with a third researcher reviewing the two data extraction samples for consensus and creating the collated transcript.

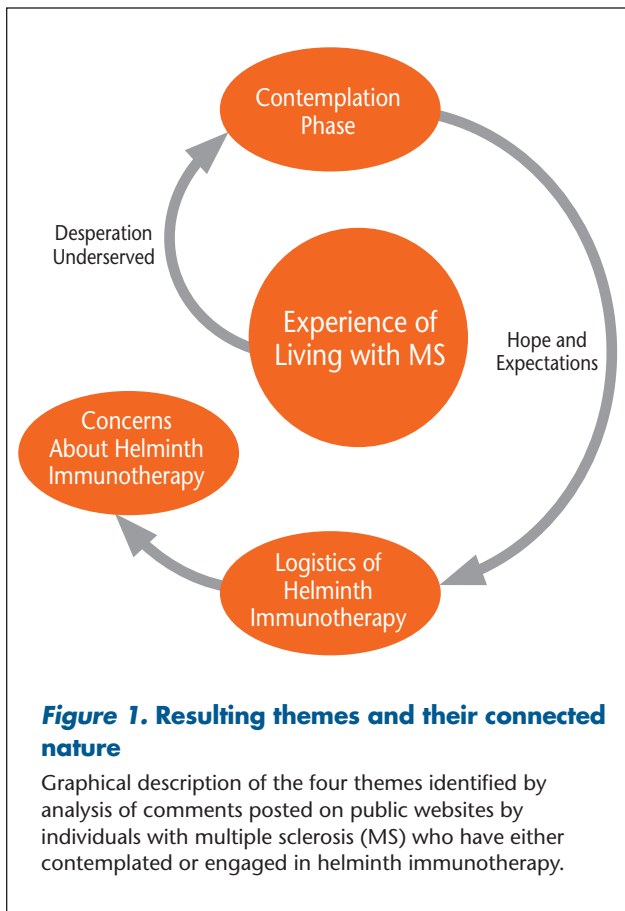
### Data Analysis

Data collection and analysis were inductive and iterative. Transcripts were independently analyzed by two researchers (S.J.D. and M.C.K.) using whole data immersion.<sup>10</sup> Preliminary codes were then discussed as a group. Using the preliminary code, three researchers (S.J.D., M.C.K., and M.C.) independently went through transcripts again before further group discussion to share and resolve any discrepancies. Triangulation was used both in data generation (transcripts and reflective accounts) and in data analysis (three researchers' independent coding). To facilitate data management, transcripts were imported into NVivo 11 (QSR International Pty Ltd, Melbourne, Australia) for formal coding and analysis. Through comparative and iterative analysis, codes were added and adjusted as needed.<sup>14</sup> Researchers (S.J.D., M.C.K., and M.C.) discussed and labeled four resulting themes.

## Results

### Overview

Four main themes were created: 1) experience of living with MS, 2) influential factors in contemplating helminth immunotherapy, 3) logistics of helminth immunotherapy, and 4) concerns related to helminth immunotherapy. Figure 1 outlines the connected nature of these themes. The experience of living with MS (theme 1) and the current paucity of effective treatment options may trigger a sense of desperation. This highlights the concerns of individuals with MS being an underserved population in terms of health care. Their sense of desperation and being underserved are driving factors that may lead to a contemplation phase (theme



2) in which they begin to search for alternative ways to manage their MS, including helminth immunotherapy. This contemplation phase is, in part, informed by the hope and expectations found in the shared perspectives of others with MS regarding the logistics of (theme 3) and concerns about (theme 4) helminth immunotherapy.

## Themes

### *Experience of Living with MS*

The primary research question was regarding the use of helminth immunotherapy, but the most apparent theme was commenters' expressed reality of the challenges of living with MS. A dominant message about the chronicity of MS and frustrations with lack of mainstream treatment options was conveyed, as demonstrated by this quotation: "If you are stricken with a terrible disease for which medicine has little to offer, then what, really, do you have to lose by turning to a parasite?"

There is currently no cure for MS, and quality of life (QOL) can be significantly affected by MS symptoms. There was a strong sense of desperation and eagerness for any intervention that might improve QOL:

"Although [helminth immunotherapy] sounds unusual, anything that could potentially help to alleviate the symptoms of MS is a positive step. As long as it's effective in helping the horrible symptoms, I don't think people mind where it comes from." Several commenters expressed feeling that they had no medical options when disease-modifying therapies (DMTs) were unsuccessful or no longer worked. The lack of pharmaceutical options for individuals with MS diagnosed as having a progressive form was also emphasized. Others expressed frustration with lack of treatment options or advice from their primary health care providers (HCPs) outside of pharmaceutical management. This may contribute to developing a strong drive to self-seek alternative therapies: "If someone is struggling with conventional medicine then parasites could be a great treatment approach. In many autoimmune diseases, it is not the disease that gets you, it's the symptoms."

Online forums were used as a means of overall social support for individuals with MS. Independent of a person's standpoint on helminth immunotherapy, there was an apparent consensus on a need for better disease management in partnership with conventional HCPs. Thus, although helminth immunotherapy was the topic of interest on these forums, it was considered as perhaps only one component of a larger management plan for MS. Our data suggest that individuals with MS who are contemplating helminth immunotherapy may do so because they want a more holistic approach to health care, one that emphasizes the patient-perceived need for healthy lifestyle changes and the desire to have wellness addressed as a routine part of MS management.

The hope for efficacious alternative management strategies seemed to be a motivating factor toward using helminth immunotherapy. Greater hope gained from reading others' accounts of success with helminth immunotherapy can fuel expectations for the therapy's efficacy. Although the present analysis identified barriers and concerns associated with helminth immunotherapy (theme 3), a prevailing sense of hope was evident: "For me, I decided that the risks associated with getting inoculated with hookworms [helminth immunotherapy] were very minimal. If the treatment worked, I could obtain important gains in the quality of my life. The hookworms were easy to get rid of if I decided that I did not benefit from them. The financial risk was the only real risk I could see and compared to what I was suffering this seemed to me to be a very small risk."



### *Influential Factors in Contemplating Helminth Immunotherapy*

It seems that individuals with MS contemplate alternative options, such as helminth immunotherapy, in hopes of improving QOL. An initial component of contemplation is seeking out information. It was evident that online forums are being used as an information source for contemplators. Some even commented on this themselves: "Users read about the 'science' [of helminth immunotherapy] in online forums where people share their experiences, and learn where to get helminths ... they even trade incubation methods in discussion groups."

It seemed that most commenters considering helminth immunotherapy thought that clinicians were not a valuable resource in this contemplation phase. Some admitted that they hid using helminth immunotherapy from their HCP. Others felt that they could not discuss the possibility of helminth immunotherapy with their HCP for fear of being judged. This fear of discussing and/or disclosing use of helminth immunotherapy is perhaps perpetuated by other commenters' accounts of negative reactions from HCPs about their decision to try helminth immunotherapy.

Perception of scientific evidence validating helminth immunotherapy was another key factor during the contemplation phase. There was apparent disagreement on the quality and extent of existing research on helminth immunotherapy. Some commenters discussed helminth immunotherapy as a "well-proven" intervention for MS, whereas others expressed frustration with the lack of research and funding for research on helminth immunotherapy (and other alternative therapies). In some cases, the current state of the scientific literature regarding helminth immunotherapy in MS seemed oversimplified: "There are numerous animal studies and one landmark paper ... its results are unequivocal and stunning: helminthic therapy will slow or arrest the course of relapsing remitting multiple sclerosis in everyone who tries it." Many users commented on the hygiene hypothesis as the scientific basis for helminth immunotherapy. Individuals with MS who believed in the validity and abundance of scientific evidence supporting helminth immunotherapy seemed more likely to partake than those who questioned the state of the evidence.

Social acceptability was identified as an influential factor in the contemplation phase. Of concern was the social stigma associated with the "ick factor" of worm

inoculation. Although many commenters were themselves able to see past the ick factor in hopes of a successful therapy, concerns about others' perceptions were expressed. There were accounts by users of withholding using helminth immunotherapy from family, friends, coworkers, HCPs, and/or employers based on stigma associated with taking worms. Users advised contemplators not to tell others to avoid the ick factor stigma: "Some of my friends and relatives stopped inviting me to their houses after I announced my infection. I have been speaking to new people I meet or old friends, and seen them slowly start to lean away from me. Despite the fact that it is, for all intents and purposes, impossible to accidentally infect someone with these organisms ... a lot of people are terrified they will catch it from you."

Access to worms seemed to be an influential factor. Accessibility to enroll in a clinical research trial was a motivator to partake in helminth immunotherapy, perhaps because it requires less responsibility in logistical planning on the part of the participant. There was also a sense of safety and trust in participating in clinical trials that makes them an attractive option. Some users expressed jealousy of others who lived in geographic regions that made them eligible for these trials, and some even considered moving: "Oh I am so jealous I wish I lived in Wisconsin and could join that trial! Really. Worms are yuk but the potential results on MS sounds very promising." If not acquired through participation in a clinical trial, helminth immunotherapy has to be acquired individually through private enterprise, which leads to many logistical concerns after the decision to partake in helminth immunotherapy.

#### *Logistics of Helminth Immunotherapy*

Following and informing contemplation, those who want to engage in helminth immunotherapy face many additional decisions about the logistics of acquiring, administering, and monitoring the therapy. There is no helminth immunotherapy standard protocol or best practice. Based on stories shared by helminth immunotherapy users, there was no consistency in species of helminth, how often or how much should be administered, or how to best care for the worms once inoculated. This creates variety in applications of helminth immunotherapy, which commenters expressed poses a decision-making dilemma. One of the most prominent concerns expressed was choosing and accessing the therapy. With a lack of scientific evidence to inform a recommended method of helminth immunotherapy,

acquiring and administering helminths are often based on accessibility and others' subjective and potentially biased recommendations.

An issue when considering purchasing worms through private companies is that each company offers different types of worms to choose from (eg, ova of the roundworms *T trichuria* or *T suis*, or the hookworm *N americanus*), with different dosages, routes and timelines of administration, and costs. As an unconventional therapy, health insurance does not cover the cost of helminth immunotherapy. Therefore, it must be funded directly by the participant. The worms themselves are expensive to purchase privately, and additional expenses may include travel cost for administration abroad and cost of testing stool to ensure that the worms remain in the gastrointestinal tract. The only way to avoid these expenses is to participate in a clinical research trial, but many commenters expressed geographic constraints as well as not meeting the inclusion criteria for the studies, leaving private purchase as the only available option for this therapy.

In addition to decisions about helminth immunotherapy, commenters also had to make broader decisions about their MS, including whether to continue taking their DMT and/or other conventional therapies prescribed. The few helminth immunotherapy clinical trials that have been conducted included participants who are DMT-naïve, thus there is no evidence surrounding therapy interactions or the bidirectional impact of taking both therapies concurrently. Thus, these decisions were often based on information shared within these blogs and not discussed with HCPs. One commenter asked: "I assume I can't be on Tysabri when using it [helminth immunotherapy], but how long of a wash-out period do I need before I start it? I'm also on low-dose naltrexone and low-dose testosterone, would I also have to stop those treatments?"

With the variability of MS it is hard to compare the effectiveness of any intervention on an individual basis. In the present analysis, we note that commenters used self-reported measures around fatigue and severity of symptoms and length of relapse as attributes for effectiveness of self-administered helminth immunotherapy. In commenters who reported beneficial effects of helminth immunotherapy, affected parameters included reduction or withdrawal of their DMT, improvements on magnetic resonance imaging, and/or reduced relapse duration or severity. Most commenters noted whether this was a change from their MS experience before

helminth immunotherapy. However, not only did the type of results vary, but there was also variability in how much they attributed perceived changes in their MS to the helminth immunotherapy. For example, two commenters reported a shortened duration of relapse, but only one believed that this shortened relapse was a result of the helminth immunotherapy, whereas the other was skeptical and thought that it was the natural disease course independent of the therapy. Variability in both type of results reported and attribution of these results to helminth immunotherapy seemed to impact the perspective about helminth immunotherapy effectiveness.

Many commenters did not expect helminth immunotherapy to be a cure but instead an option to help manage symptoms. Results such as reduced fatigue or decreased relapse severity were perceived as positive and worthwhile results in favor of helminth immunotherapy. It was evident that symptom improvement and corresponding influence on QOL are valued by individuals with MS as determining factors in helminth immunotherapy effectiveness.

#### **Concerns About Helminth Immunotherapy**

The fourth theme was established as an extension of the logistics (theme 3) based on the number of concerns expressed regarding the current use of helminth immunotherapy, as well as the advancement in considering helminth immunotherapy as a treatment option for individuals with MS. Commenters expressed concerns regarding the cost of helminth immunotherapy, but another aspect related to cost is the potential business side of marketing and supplying parasites. Unless participating in helminth immunotherapy research, individuals with MS are able to access worms only from unregulated online suppliers. Some suppliers may use "worm farming" as a profitable business, capitalizing on the desperation and hope contributing to the decision to use helminth immunotherapy. Some commenters' solution to access and cost was to consider growing worms themselves. It seemed that even those who are using helminth immunotherapy realize how alternative it is and have concerns about its acceptance by regulatory boards.

Nonusers expressed concern that helminth immunotherapy is just another quick fix that people are looking to take without addressing lifestyle interventions such as diet and exercise in the management of MS: "Gimme a diet coke, a Macdonald's burger with super-size french fries and a big side of raw worm eggs" was reported by a cynic of helminth immunotherapy. Some fear that oth-

ers with MS may be jumping to interventions too soon without first evaluating the effect of other behavioral approaches that have more clinical support but may be more difficult to incorporate into daily life (eg, exercise and diet). This highlights the comprehensive approach to MS management that is needed on the part of both individuals with MS and HCPs.

Short-term safety concerns seemed to be eased by the positive experiences reported by other commenters with MS who had taken helminth immunotherapy, but the long-term effects remain unknown. We believe that ongoing interest in and use of helminth immunotherapy despite concerns further demonstrates the desperation and need for improved management in MS (theme 1). The value of an individual's concerns influences contemplation (theme 2), and, for those who go on to become users, hope/optimism ultimately outweighs concerns. A variety of concerns still exist regarding the logistics of worms (theme 3) that may hinder advancement and potential integration into mainstream management.

Last, there is concern regarding the mismatch between some commenters' perspectives of "safe and effective" and "extensive review of the literature" versus what is actually available. The studies that do exist risk being overinterpreted by the lay community, especially a population such as individuals with MS, who have a vested interest in accepting the limited data to provide hope and assuage their sense of desperation. There is a need for more research into the effectiveness and mechanisms of helminth immunotherapy, as well as efforts to improve communication between individuals with MS and their HCPs regarding use of helminth immunotherapy and other alternative therapies.

## Discussion

This qualitative investigation exploring perspectives of individuals with MS about helminth immunotherapy provides a variety of important insights. The chronicity, lack of cure, and limitations with conventional treatment options for MS contribute to some individuals with MS pursuing alternative therapies such as helminth immunotherapy, despite the absence of standard and/or conventional parameters or regulations for its administration. Social media are currently used by some individuals with MS as a primary source to seek out and share information/opinion about helminth immunotherapy. Users of helminth immunotherapy are also sharing their experience online, reporting both short-term benefits and concerns. Online forums may then influence other

individuals with MS who are in the contemplation phase regarding the use of helminth immunotherapy.

Dissatisfaction with contemporary therapy was apparent in this study. It seemed to motivate the self-search for alternative therapies. This is not a new concept, and many researchers have documented that individuals with MS tend to have low levels of satisfaction with conventional treatment due to ineffectiveness.<sup>15</sup> Alternative therapy seeking is not necessarily a complete rejection of conventional medicine or an unrealistic search for a cure, but rather more of an action toward taking personal responsibility for their health and a pragmatic approach to living as well as possible with this chronic condition.<sup>16</sup> In the reports we analyzed, some people were considering helminth immunotherapy as a replacement for conventional therapeutics, as a last resort after exhausting other treatment options, or as an additional approach to symptom management.

Salamonsen et al<sup>17</sup> described the transition from recipient of conventional medicine to explorer of alternative therapy involving four stages: losing bodily competence, developing responsibility, taking control, and choosing alternative therapy. The factors influencing this transition can be classified as "push" or "pull" factors. Push factors turn people away from conventional therapy. It was evident through the online forums that commenters felt that current therapy methods were not effectively managing symptoms and QOL. Frustration with the ineffectiveness of conventional therapy to improve everyday QOL seems to be an ultimate push motivator to explore alternative therapies such as helminth immunotherapy.

Individuals with MS actively looking for alternative options may turn to support networks for information, such as the online resources explored in this study. Approximately 10 years ago, the chronic cerebrospinal venous insufficiency treatment procedure was emerging and many individuals with MS sought this procedure as an alternative therapy. Similarly dissatisfied with conventional therapy, those who underwent chronic cerebrospinal venous insufficiency treatment said that one of the largest motivating factors was the perception that they are in this together and the support they provided to each other through social media networks.<sup>18</sup> A similar support network regarding helminth immunotherapy seems to exist through the online forums used in this study. People open to alternative therapy are able to find a network that understands the lived experience and

empathizes with the motivations behind seeking alternative therapies, and supports the decision to do so. As demonstrated herein, these networks also address questions regarding logistics and concerns about a therapy to its contemplators in light of their experience of living with MS, thereby providing pull factors toward helminth immunotherapy.<sup>17</sup> Pull factors highlight the perceived positive aspects of alternative therapy and pair with the push from feelings that arise from dissatisfaction with contemporary therapies to draw individuals with MS toward options such as helminth immunotherapy.

It was evident that online forums are being used as an information source for contemplators, sometimes instead of seeking advice from a licensed medical professional. It is important for HCPs to be aware of alternative therapies that their patients with MS might be considering. A more comprehensive approach to the routine management of MS could create other avenues to discuss alternative therapies than just online forums. Although an important source of support, blogs and their discussion boards can present misinformation or misperceived messages about science. Discussion with HCPs could enhance the details and extent of push and pull factors and improve communication on patient-identified priorities. The HCP could also help to translate the findings on helminth immunotherapy relative to individual needs and use an evidence-informed approach to support individuals with MS regarding their treatment options, alternative or conventional.

We found a mismatch between the scientific evidence supporting helminth immunotherapy and the portrayal of this evidence by the individuals with MS writing in these online forums. Currently, there is limited evidence regarding helminth immunotherapy in MS. From the limited number of clinical trials, only phase 1 and 2 safety data have been published.<sup>6,8</sup> These preliminary data indicate that helminth immunotherapy seems to be fairly safe in the short-term but has minimal effects on disease status.<sup>6,8</sup> However, in online forums regarding helminth immunotherapy for MS, the dominant messaging regarding the state of the literature was that there was an abundance of scientific support for helminth immunotherapy, including reported positive effects on MS disease markers. Therefore, contemplators using online forums are potentially being misled as to the quantity and quality of the scientific evidence-based efficacy of this treatment. There are a few potential rea-

sons for this mismatch, and all likely contribute. First, as with publishing bias, people tend to report the results that support their previous notions. Individuals with MS reading the scientific literature and looking for positive results will likely see and pick out only the positive results that support their belief. Furthermore, online forums for helminth immunotherapy may be dominated by anecdotal reports from a small sample of users reporting only the positive impact of helminth immunotherapy. Finally, some individuals with MS exploring the literature may not be familiar with the scientific process and are ill-equipped to critically appraise and interpret findings, including limitations and caveats of individual studies. The previous factors likely contribute to misinformation about the state of the scientific evidence supporting helminth immunotherapy being perpetuated through online forums. It was apparent that many people are using this information as a primary motivator for choosing alternative therapy. Thus, individuals with MS may choose to undergo this therapy under a false pretense of its efficacy, potentially leading to unintended adverse effects and uninformed risks that they may not have been prepared to take when making their decision.

Online forums offer spontaneous accounts unprovoked by researchers. However, they are typically written with a specific audience in mind, and are therefore acknowledged as a narrative representing an experience versus an objective truth.<sup>12</sup> We acknowledge that the limitations of using blogs as a data source include a

## PRACTICE POINTS

- Individuals with MS who are not satisfied with conventional therapy can seek alternative therapies, including helminth immunotherapy.
- Rather than discussing helminth immunotherapy with their health care providers, individuals with MS may consult online forums that provide anecdotal experience with and opinions about the scientific validity of helminth immunotherapy to inform their decision-making process.
- Given that some individuals with MS are using helminth immunotherapy, there is a need for more basic and clinical research on this alternative therapy in the management of MS and the role of conventional health care providers supporting people with MS considering this approach.



potential sample bias. Perhaps our select group of online commenters primarily comprises individuals with MS who have not had success with conventional treatment. Using this type of preexisting online resource limits the ability to further explore a point or ask commenters for clarification (eg, in an interview). Fitting with the aim of this study, an unsolicited account of subjective expressions of personal life experiences makes online forums a valuable data source. Unsolicited input can decrease bias that may be found in interviews because of the person-to-person interaction.

This study highlights a mismatch between what some individuals are looking for to help manage their MS and what HCPs are currently able to provide. Despite advancement in pharmaceutical management for MS, a population of individuals with MS remains for whom conventional therapy is failing. This can be a driving factor for self-seeking alternative therapies, including helminth immunotherapy. The present data suggest that HCPs are not a primary information resource or medical support when contemplating helminth immunotherapy, indicating an underlying problem with communication or support between HCPs and individuals with MS. This is worth further exploration because it represents missed opportunities for HCPs to be a supportive objective resource when their patients would like to discuss alternative therapies. There is a need for more research on alternative therapies in the management of MS and the role of conventional HCPs supporting individuals with MS through the decision-making process. There is much to be learned still regarding conventional treatment responders versus nonresponders in both conventional and alternative therapies. Individuals with MS who are nonresponders to mainstream management approaches represent a specific group that may self-seek alternative therapies. If some truly benefit from alternative therapies such as helminth immunotherapy, it becomes necessary to explore what can be learned from their success to better understand how to test, implement, and further improve the therapy in question for the good of all individuals with MS.

Some individuals with MS are interested in helminth immunotherapy as an alternative therapy in the management of MS and in using online forums to inform the decision-making process regarding its use. Information gathered from these sources can provide a valuable sense of support but also contains biased and scientifically

unsupported opinions. It is important to recognize that some individuals with MS are using helminth immunotherapy. Messages of efficacy and improved QOL are readily available and may influence decisions considering this alternative therapy. Improved communication between HCPs and individuals with MS regarding alternative therapies is needed. Individuals with MS desire more research and knowledge translation regarding the science and role of helminth immunotherapy in disease management. □

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