

Reasons for Engaging in Complementary and Alternative Medicine Among Highly Educated Women With Multiple Sclerosis

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ABSTRACT

BACKGROUND: Previous research has shown that users of complementary and alternative medicine (CAM) among persons with multiple sclerosis are more likely to be women and to have a higher level of education compared with nonusers. This qualitative study was performed to explore the motivations linked to CAM use among highly educated women with multiple sclerosis.

METHODS: The study was based on a phenomenological approach, and 8 semistructured, in-depth qualitative interviews were performed. Data were transcribed verbatim and analyzed through meaning condensation and identification of recurring themes.

RESULTS: Regarding the informants' motivations for CAM use, 3 main themes emerged: (1) Self-reliance is essential in disease management, (2) conventional health care lacks a holistic approach, and (3) personal experience is the primary guide.

CONCLUSIONS: The interviewees wanted approaches to health care that supported their desire to actively participate in the management of their disease. They were critical of the conventional health care system, and they emphasized the importance of letting their own personal experiences, as well as those of others, guide their decisions.

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Multiple sclerosis (MS) is an incurable, chronic autoimmune disease affecting the central nervous system and resulting in various symptoms and impairments. Medical treatment may slow disease progression or reduce symptoms, but it is not always effective and may be associated with severe adverse effects.¹ To supplement conventional treatment and rehabilitation, many individuals with MS turn to complementary and alternative medicine (CAM) to relieve symptoms and strengthen the body's ability to manage the disease.² No precise definition of CAM exists. We follow the overall interpretation as presented by the US International Center for Complementary and Integrative Health suggesting that CAM covers health care approaches that are not typically part of conventional medical care or that may have origins outside of usual Western practice (eg, *Ginkgo biloba*, reflexology, magnet therapy, cannabinoids, certain diets).

Studies among individuals with MS find CAM use at 46% to 59% in Nordic countries and as high as 82% in Germany.^{3,4} Some of the most frequently used CAM modalities among individuals with MS in Denmark are natural medicine, dietary supplements, special diets, and therapies such as acupuncture, reflexology, yoga, and meditation.⁵

In most cases, CAM use is not associated with health risks, and recommendations can be made in the area of MS symptom management.⁶ However, the effects of most types of CAM are not well documented in the MS field, and CAM use may be associated with adverse effects.^{6,7} In addition, the use of natural medicines and dietary supplements in combination with conventional medicine may lead to negative interactions.⁸ Although many individuals with MS benefit from CAM,^{7,9} potential risks and related costs should be considered. It is generally recommended that patients discuss CAM with their conventional practitioners, but many do not.^{4,9,10}

Previous research among individuals with MS found associations between educational level, sex, and CAM use,

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TABLE 1. Interviewee Demographics

Interviewee	Age, y	Diagnosis, y	Education	DMT	CAM treatments
Ann	58	PPMS, 2010	Medium-cycle	No	Natural medicine and dietary supplements, reflexology, qigong, yoga, holistic lifestyle
Betty	42	RRMS, 2017	Medium-cycle	Yes	Acupuncture, natural medicine and dietary supplements, body SDS, healing, special diets
Celine	49	RRMS, 1995	Medium-cycle	Yes	Acupuncture, homeopathy, natural medicine and dietary supplements, healing, LDN, special diets, mindfulness
Denise	54	RRMS, 1998	Long-cycle	No	Special diets, holistic mind-set
Elsa	42	RRMS, 2016	Long-cycle	No	Special diets, natural medicine, dietary supplements
Fiona	39	RRMS, 2020	Medium-cycle	Yes	Craniosacral therapy, special diets, natural medicine, dietary supplements
Gina	37	RRMS, 2018	Long-cycle	No	Special diets, acupuncture, meditation
Hannah	38	RRMS, 2012	Medium-cycle	Yes	Craniosacral therapy, acupuncture, special diets

CAM, complementary and alternative medicine; DMT, disease-modifying treatment; LDN, low-dose naltrexone; PPMS, primary progressive multiple sclerosis; RRMS, relapsing-remitting multiple sclerosis; SDS, self-development system.

showing a higher proportion of women and a higher level of education among CAM users compared with nonusers.^{5,7} Studies investigating perceptions of and reasons for CAM use among individuals with MS in general¹⁰⁻¹³ indicate that dissatisfaction with conventional treatment, a desire to play an active part in disease management, and a desire for holistic treatment are some of the main motivations. However, no previous studies have explored reasons for CAM use specifically among the typical adherents. To improve the dialogue between health care providers and individuals with MS about CAM, knowledge about the common reasons for CAM use is needed. Therefore, this qualitative study explores the motivations that may lead highly educated women with MS to use CAM.

METHODS

Recruitment Strategy and Interviewees

The interviewees were recruited through the official Facebook page of the Danish MS Society, where they filled out a form to register. The inclusion criteria were being a woman, having a bachelor's degree or higher education, having an MS diagnosis, and using a minimum of 2 CAM treatments during the past year. Of the 8 participants, 5 had bachelor's degrees and 3 had master's degrees. As shown in **TABLE 1**, the most-used CAM interventions were natural medicines and dietary supplements, special diets, and various therapeutic CAM methods (eg, acupuncture, healing, craniosacral therapy, "a holistic lifestyle"). Half of the informants also received conventional medical treatment to reduce disease progression and/or symptoms.

Data Collection and Analysis

In Denmark, studies that do not include biological material from humans cannot be reported to the National Committee

on Health Research Ethics. For this study, therefore, no approval was needed. However, the study adhered to the European Union General Data Protection Regulation and ethical principles for medical research as presented in the Declaration of Helsinki.¹⁴

The study consisted of semistructured, in-depth qualitative interviews that ranged from 35 to 60 minutes. All interviews were recorded and transcribed verbatim. The interviews took a phenomenological approach. An interview guide was developed to structure the interviews, as shown in **TABLE 2**, but the interviewer allowed for the informants' immediate perceptions to influence the interviews. Interview data were analyzed using a thematic analysis inspired by Attride-Stirling.¹⁵

RESULTS

Three themes emerged from the analysis regarding motivations for CAM use: (1) self-reliance in disease management, (2) lack of a holistic approach in conventional health care, and (3) one's own and others' personal experiences.

Theme 1: Self-reliance Is Essential in Disease Management

Interviewees used CAM to play an active part in the management of their MS, independent of the conventional health care system. To some extent, they ascribed their ability to navigate alternative approaches to disease management to their educational attainments.

Several interviewees said that playing an active part in their treatment and care was essential. Responsibility for one's own health was a commonly expressed value and was often identified as a necessary step to avoid being reduced to a passive recipient of health care. Elsa, who had chosen to discontinue conventional MS treatment, said, "People should make an active decision about what they think and

TABLE 2. Interview Questions

Background and multiple sclerosis	
Research interest Who is the informant and how does the person in question feel about alternative treatment?	
Questions Can you tell me a little about yourself? How long have you had multiple sclerosis and how did it manifest in you?	Can you describe how your illness affects you in everyday life? Which medicine do you take? Does it work? Do you have any adverse effects? What thoughts do you have about taking medication?
Prompts Age, family, work, spare time Symptoms, course	Physical, mental, cognitive, symptoms, limitations Preparation, effect, adverse effects
Alternative treatment	
Research interest What are the interviewee's experiences with alternative treatments?	
Questions What types of alternative therapies have you tried? What is your definition of an alternative treatment? Why did you seek an alternative treatment? Can you describe a concrete experience with an alternative treatment?	How does the interviewee describe the effects and what effects does the informant experience? Did you experience any physical changes/effects after the alternative treatment? Can you describe how you experienced the effects and how they were expressed? Can you put into words whether you think that some of the treatments you mentioned have had a general effect on your illness? Is the effect different from conventional treatment? If so, how?
Prompts Dietary supplement, acupuncture, special diets Spiritual, holistic, knowledge, understanding Situation, feelings, influence, impact, motive Reactions, well-being, health	Outcome: physically, mentally enhanced or weaker; healthier, natural, short-/long-lasting effects Symptoms, daily life, mental, physical, positive, negative, well-being, health Which effects?
Knowledge, understanding, and critical thinking	
Research interest How is the interviewee affected in thoughts/feelings by others and by their actions?	
Questions How did you search for alternative treatments? How do you talk to others about alternative treatments? Do you recommend the treatments to others? If yes, what do you say about the treatments?	How does the interviewee understand that an alternative treatment works? (eg, evidence, anecdotes, credible knowledge, facts) What do you think about the knowledge that underlines alternative treatment methods? What is credible knowledge to you? Have you thought critically about alternative therapies? If so, which ones?
Prompts Acquisition of knowledge, conversations, communities, social circles Storytelling, conversations, relationships Description of effect, confidence, enthusiasm	Evidence, mechanisms of action in the body; energies, pleasure, personal experience Evidence, critical thinking, consequences, considerations, reflections, risks
Relationship with the conventional practitioner vs the alternative practitioner	
Research interest What is the interviewee's relationship with the doctor?	
Questions What do you think of your conventional practitioner vs your alternative practitioner? Is the relationship different? Are you satisfied with your treatment in the health care system?	Does the interviewee's relationship to conventional treatment affect their alternative choices? Can you tell us about a positive experience with the health care system in connection with your multiple sclerosis? Can you tell us about a negative experience with the health care system in connection with your multiple sclerosis?
Prompts Relationship with your practitioner, conversations, trust, confidentially, treatment, individual treatment, welcome, turn down	
Completion	
Question Do you have any concluding remarks or questions?	
Prompt Reflections, questions, final comments	



PRACTICE POINTS

Among individuals with multiple sclerosis, complementary and alternative medicine use may reflect their desire to approach disease management with an autonomous and holistic approach.

The dialogue between patients and health care providers should ensure that a patient's desire to play an active part in their treatment is acknowledged.

Lack of trust in the conventional health care system may lead individuals with multiple sclerosis to use complementary and alternative medicine exclusively, discontinuing conventional treatment altogether. ■

believe in, and not just let themselves be dictated [to] by a system. If I had done that, I would just be injecting myself in the leg.... They have just accepted that that's how the system works and that they 'are the disease....' I still have the will and the courage and the energy to fight for a long, good life without medicine."

Elsa's opinion reflects a common attitude among the interviewees: Playing an active, decision-making part in disease management is essential to be more than just a patient with MS. Not letting oneself be passively "dictated [to] by the system" was a goal. In her quote, Elsa implies that uncritically following the conventional recommendations for treatment is equal to not fighting for a good life, and that a good life is a life without conventional medicine.

Most interviewees also indicated that taking personal responsibility for one's life and health requires a critical appraisal of conventional medicine and doctors' opinions. For example, Ann stated, "I'm not the type of person who goes to the doctor and believes it will help me.... I just think that I can do a lot myself.... I think that we can do other things than what is traditional.... Many people think 'I'll just go see my doctor and then he will know what I should do' and then you receive a pill." The skepticism of conventional treatment was also reflected in the fact that 4 of the informants had declined conventional medical treatment for their MS.

Several interviewees emphasized that their high educational level was an important factor when making decisions

that did not necessarily follow a doctor's advice. Academic training was an important qualification for navigating the many different approaches to treatment as well as for seeing through conventional recommendations. Denise said, "I was sure as hell not letting him [the doctor] decide that [ie, on use of CAM treatments]. He may be a doctor, but I have studied religion and sports, and I know how much I don't know. I'm always trying to optimize.... I have used everything from my academic studies to manage well."

A few informants linked their way of navigating treatment approaches to their ability to search for and assess information in a meaningful way. Hannah, who was a health professional, said, "There must be substance in what I read. I am well aware that I can sit as a health professional and read and interpret an article better than others [with MS]."

Theme 2: Conventional Health Care Lacks a Holistic Approach

Generally, the interviewees found it important to view body and mind as a whole in the management of their disease. They felt that CAM offers a holistic approach to disease management, and the opposite was true of the conventional health care system. Thus, the lack of a holistic approach led to a loss of trust in conventional health care.

A few interviewees said that they had a satisfactory relationship with their conventional doctor, but most felt that their CAM practitioners provide a more holistic focus and are more present in the consultation. Betty said, "There is more presence with the alternative practitioner than with the doctor.... The doctor is more absent. They do the same tests every time. They ask standard questions.... I get a more holistic treatment [with the alternative practitioner] and take something valuable home with me."

Part of the appeal of the holistic focus is the integration of care for the mind and the body. Betty also said, "When you take medication, then it's all about the brain.... If the body is not brought into play, then I don't think it's going to work.... The 2 are interconnected more than what is recognized in the Western world.... The body also remembers our experiences and the things we go through."

Several informants were inspired by the Eastern way of thinking about disease management, which they characterized as more holistic and often encompassing more than conventional medical treatment. Eastern medicine was viewed as ascribing higher value to what patients can do for themselves, without judgment. Denise, who had been treated in a country in Asia, said, "Here I learned about the holistic way of thinking...which consists of different compositions, mental and physical. It's all interconnected.... The [holistic] doctor never told me what was right or wrong.... He never let me feel that I couldn't act [like] myself. He believed that what we do for ourselves has an effect...." Denise later explained how her conventional doctor reacted to her experience with the holistic doctor by calling her experience "mumbo jumbo," mocking her and laughing. This resulted in Denise losing her regard for conventional doctors altogether.

Similarly, Gina had wanted to discuss whether a certain diet could be beneficial to her health, but this idea was rejected by her conventional doctors, and her impression was that non-Western cultures often have more holistic approaches to health care and would be more open to such a discussion: "I've lost a lot of confidence in the system.... Not a single person has been willing to talk about diet beyond what the health authorities recommend. In my experience, some doctors from other countries are more open to new ideas. With Danish doctors, I am met with resistance.... The doctors prefer to look at trials, medicine, placebo." Doctors in the conventional Danish system were generally described as being closed-minded and unwilling to think beyond official guidelines and recommendations.

The interviewees generally thought that conventional treatment and conventional doctors overlooked their individual needs and the root causes of their symptoms by narrowly focusing on symptomatic treatment, a temporary and inadequate treatment plan. Gina recalled that instead of looking for the cause of her muscle tension she was offered a pill to relieve it: "A pill is just a temporary solution that doesn't really address the root cause. It just becomes symptomatic treatment instead of getting to the cause of why I have muscle tension.... That kind of treatment, it's just so microscopic, and there's a long way [to go] for the treatment to be about me [as a person]."

Some informants related the doctors' narrow focus on pills to financial incentives from the pharmaceutical industry. Ann said, "There is financial profit in it. Therefore, a neurologist will not consider anything besides pills.... I think because the pharmaceutical industry has such big financial interests that it limits what we are supposed to do and not do." Hannah also articulated that financial incentives were particular to conventional health care and did not play the same role in CAM: "The whole pharmaceutical industry...it's all about the money. It's not the same way in the alternative treatment industry."

There was generally a more positive attitude toward CAM practitioners earning money from treatments than conventional doctors earning money from treatments. Part of the reason for this was that participants considered CAM practitioners to be generally more invested in their patients' treatment, giving them higher credibility.

Theme 3: Use of Personal Experiences as the Primary Guide in Decision-making About CAM

The third theme is that the participants' decisions regarding the use of CAM are, to a large extent, based on their own or others' personal experiences. Scientific evidence regarding CAM was generally considered less relevant.

Several informants indicated that their knowledge of alternative forms of treatment is mostly formed by their social communities, personal networks, and, to some extent, social media. Hannah explained, "I've been reading in Facebook groups. Some women who have MS write a lot about alternative treatments.... I think people are good at

recounting experiences." Generally, other peoples' experiences with CAM made an impact on their decisions regarding CAM use.

Several informants stated that their personal experiences are essential when it comes to deciding whether to continue or stop a CAM treatment. For 2 informants, the primary consideration was whether CAM increased their experience of overall well-being. Fiona said, "To me, evidence, in a way, is about well-being.... Perhaps it doesn't cure MS at all, but just 1 improvement of my condition in some form or other.... That alternative [practitioner], she is just really nice.... You can feel that she is compassionate and feels sorry for me. She cares for me, and I let her." Celine said, "I started with acupuncture. It made my body relax and feel good. Whether it's just placebo I don't know, but it helped.... Maybe it's just [lying] down for an hour and being taken care of that has an effect.... Just an hour to myself where I am in focus." The effects of CAM treatments were a sensory experience but also an experience of psychological well-being and care. Thus, CAM treatments were experienced as a form of self-care and as a personal health-promoting treatment.

Fiona believed that knowledge and evidence could never be truly objective, and for that reason, an individual had to rely on their own experiences: "You can seek a lot of knowledge in the places where you want to find the knowledge you are seeking.... Evidence can be fluent when it comes to [the impact of] nature and nurture and the persons that are selected. No study will ever be completely objective. It can never be 100%.... It just has to make sense, the things we do to ourselves. I think it makes sense to do things if they don't do more harm than good." While not articulating a strong opinion concerning evidence, the interviewees emphasized the importance of not being dictated to by the rules and characteristics of the conventional health care system.

DISCUSSION

Reasons for CAM Use

The interviewees in the present study expressed a strong desire to be an active part of their treatment and care, which they achieved largely through CAM. They were also critical of conventional health care, which they believe places the patient in a passive role and focuses too narrowly on medical symptom management instead of holistic treatment. CAM practitioners treated the whole person and not just the symptoms. These findings are in line with previous findings about individuals with MS and CAM. Mews and Zettl¹⁰ found that dissatisfaction with conventional treatment and a desire to play an active part in disease management were the main reasons for CAM use. Similarly, Nayak et al¹¹ found that the most common reasons for using CAM were a desire for holistic treatment and dissatisfaction with conventional health care.¹¹ Loraschi et al¹² also found dissatisfaction with conventional treatment to be a main reason for CAM use, and Skovgaard et al¹⁶ found active patient participation to be one of the main

reasons for CAM use among individuals with MS who used CAM exclusively.

The present study found that the interviewees mainly rely on their own and others' personal experiences to guide CAM decisions. In a study exploring CAM use among patients with cancer and patients with MS, Salamonsen¹⁷ similarly found that experience-based knowledge, such as bodily experiences, was perceived as a relevant source of knowledge for CAM decisions. Skovgaard et al¹⁶ found bodily sensations to be an essential tool guiding CAM use among exclusive CAM users with MS.

Some interviewees in the present study emphasized their academic backgrounds and linked them specifically to their critical stance toward conventional health care and their openness to alternative ways to improve health and well-being. This aspect is not widely present in the literature, which may be explained by the fact that the present study is based on data from a strategically selected sample of informants that allowed this specific perspective to be articulated. As women with high levels of education constitute the typical CAM user among individuals with MS in Denmark, the critical attitude toward conventional research practice may be relevant to understanding their underlying motives and choices as these choices may seem irrational to their conventional providers but represent a logical consequence of their critical approach.

The Autonomous Patient

People with a higher socioeconomic position have higher health literacy, defined as the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.¹⁸ Health literacy is also closely linked to empowerment, defined as a process through which people gain greater control over decisions and actions affecting their health.¹⁹ The highly educated interviewees in this study expressed a need for self-reliance and not wanting to be "dictated" to by the system, emphasizing a skepticism of conventional health care. However, it may seem paradoxical that the interviewees did not seem to bear the same skepticism toward CAM and its practitioners as they did toward conventional treatment. They felt that CAM gave them holistic treatment for their disease and their well-being. This, combined with a feeling of being ignored, and in some cases having been ridiculed by medical doctors, may explain why their skepticism was mainly directed toward conventional health care. This is in line with previous research: CAM users have a higher level of health literacy,²⁰ and CAM helps some patients feel empowered.²¹ Understanding the desires to gain greater control over one's disease and to rely on one's own experiences may help providers understand their patients' motivations for using CAM.

Dialogue With Providers and Patient Safety

The women in the present study indicated that dialogue with conventional providers about CAM could be difficult and was associated with negative experiences. Lack of trust

in the conventional system and conventional medicine led a few to discontinue conventional treatment altogether. Gotta et al⁴ found that nearly half of individuals with MS replaced conventional treatment with CAM, and this could have increased the risk of disease progression. Other studies also emphasize the safety of CAM use among individuals with MS and the importance of continuously improving the dialogue between patient and provider regarding its use.^{6,10,13}

The literature points to several possible reasons why individuals with MS refrain from disclosing their CAM use to their providers. Gotta et al⁴ found that 37.6% doubted their physician's competence, and other studies found that a doctor's lack of interest in or knowledge of CAM or the individual's fear of a negative response may also negatively affect dialogue.^{13,16}

Skovgaard et al^{9,13,16} point to the importance of provider and patient reaching a mutual understanding of fundamental beliefs and assumptions about health and treatment, and the systematic review by Petersen et al⁸ covered possible interactions between herbal medicines and dietary supplements with disease-modifying or symptom-alleviating MS drugs. To strengthen the dialogue between providers and typical CAM users, including those interviewed in the present study, providers should be aware of and acknowledge CAM users' desires to be treated holistically: to play an active and autonomous role in their disease management and to be seen as individuals and not just as patients with MS. While acknowledging the potential benefits of CAM in holistic MS management, providers could clarify the MS disease process and how conventional medicine works to slow progression.

Providers may also benefit from recognizing that CAM may be embedded in alternative worldviews and acknowledging a patient's personal benefit from CAM while at the same time talking to patients about possible adverse effects and negative interactions between conventional treatment and CAM. A provider's greater awareness may serve as a constructive point of departure for dialogue.

Strengths and Limitations

The strategic recruitment of interviewees, focusing on female CAM users with high levels of education, dictated a certain limitation in the approach. Although providing insight into the perspectives of typical individuals with MS who use CAM, other themes could have occurred if the interviewees had been selected randomly from a broader sample. Similarly, the use of semistructured interviews produced reflections on specific, preselected issues but may have limited the range and variety of perspectives. Finally, the sample size of 8 was a result of the strategic recruitment, and additional themes may have been found from a larger sample of informants.

CONCLUSIONS

Among typical CAM users with MS, ie, highly educated women, active participation in one's own disease

management is essential: Conventional health care places the patient in a passive role and focuses too narrowly on medical symptom management instead of treating the whole person. With CAM, the interviewees found ways to treat their body and mind as a whole and practitioners who approached health care in ways that supported their desire.

Interviewees emphasized their academic background as an important basis for thinking critically about conventional health care and noted the importance of letting personal experiences, their own as well as others', guide CAM decisions. The interviewees generally did not articulate any strong opinion concerning the value of scientific evidence.

As shown in this study, patients who feel alienated from conventional health care may ultimately discontinue conventional treatment. Moreover, patients may be engaging in CAM that could be harmful or interact negatively with conventional treatment without speaking to their conventional practitioners. To avoid patients distancing themselves from conventional care and to avoid inappropriate use of CAM, providers should prioritize respectful dialogue where patients are encouraged to talk about their use of CAM and are also encouraged to play an active part in the management of their health and treatment. ■

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