CME/CNE ARTICLE • 2019 SERIES • NUMBER 5

Experience of Identity Change in People Who Reported a Diagnosis of Multiple Sclerosis

A Qualitative Inquiry

Alexander B. Barker, PhD; Kathryn Smale, PhD; Nigel Hunt, PhD; Nadina B. Lincoln, PhD; Roshan das Nair, PhD

CME/CNE Information

Activity Available Online:

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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 process of identity change following a diagnosis of MS.
2) Identify factors that may help a person with MS cope with identity change.

Accreditation Statement:

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Laurie Scudder, DNP, NP, has served as reviewer for this activity. She has disclosed no relevant financial relationships.

Alexander B. Barker, PhD, has disclosed no relevant financial relationships.

Kathryn Smale, PhD, has disclosed no relevant financial relationships.

Nigel Hunt, PhD, has disclosed no relevant financial relationships.

Nadina B. Lincoln, PhD, has disclosed no relevant financial relationships.

Roshan das Nair, PhD, has disclosed a relationship with Biogen and Novartis (speakers' bureau).

The peer reviewers for IJMSC have disclosed no relevant financial relationships.

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DOI: 10.7224/1537-2073.2018-069

Background: A diagnosis of multiple sclerosis (MS) can lead to changes to a person's sense of self. The aim of this study was to investigate the subjective experience of identity change and subsequent adjustment to MS.

Methods: Semistructured interviews were conducted with 16 people who reported having MS. Interviews were analyzed using thematic analysis.

Results: In the early stages of disease progression, participants wanted to compartmentalize the disease. Over time, through reflected self-appraisals, brought about by increasing symptoms and changed relationships with others, the disease became a part of participants' self-identity.

Conclusions: For people with MS, incorporating and accepting the disease as part of their self-identity can have positive implications for seeking and receiving support. *Int J MS Care.* **2019;21:235-242.**

Multiple sclerosis (MS) is a chronic, progressive, often degenerative condition that affects the central nervous system.[1] Multiple sclerosis affects approximately 100,000 people in the United Kingdom[2] and 2.5 million people worldwide.[3] The condition can lead to a wide range of symptoms, including cognitive and visual impairment; vertigo; sexual, bowel, and bladder dysfunction; fatigue; muscle weakness; ataxia; and spasticity.[4] Multiple sclerosis can have a devastating effect on a person's sense of self, with body and performance failures leading to feelings of loss of self and changes to identity,[5] which can have a negative psychological effect on an individual.[6,7]

One explanation for how individuals acquire their sense of self is through "reflected appraisal," which is the process through which people's self-views are influenced by their perceptions of how others see them.[8] Due to the impact of MS on a person's sense of self and identity,[5] people with MS may perceive that others view them differently because of their MS.

However, people can have multiple identities to represent themselves in different situations.[9] A person can respond to these identities and either incorporate them into their sense of self and think and act accordingly or have a complete lack of interest or motivation in an identity[10,11]; a person can choose to accept an identity as part of who they are or to reject it. It is possible that a person could have an identity that they have not internalized to their overall sense of self. Because MS is "imposed" on a person and causes changes to a person's identity and sense of self, it is possible that this MS identity may not be incorporated into a person's sense of self. A person may choose not to accept this identity as part of who they are, which could lead to negative effects of identity change[12] and an unwillingness to seek social support with others who share the MS identity.[10]

The Social Identity Model of Identity Change[12] posits that belonging to a large number of different groups before a life-changing transition, such as a diagnosis of MS, can protect individuals from the effects of this transition by providing them with groups to rely on.[6] These groups form a basis for drawing social support while providing a secure base for people to establish new identities, which are integrated and compatible with previous identities, enhancing a person's identity continuity.[12] This can reduce the negative effects of identity loss on psychological well-being.[6]

Although research demonstrates that individuals undergo a loss of aspects of identity after a diagnosis of

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From the Division of Rehabilitation and Ageing (ABB, KS, NBL) and the Division of Psychiatry and Applied Psychology (NH, RdN), University of Nottingham, Nottingham, UK; and the Institute of Mental Health, Nottingham, UK (RdN). *Correspondence:* Alex B. Barker, PhD, University of Nottingham, Clinical Sciences Building, City Hospital Campus, Hucknall Rd., Nottingham, NG5 1PB, United Kingdom; e-mail: alexander.barker@nottingham.ac.uk.

Note: Supplementary material for this article is available at ijmsc.org.

MS,[5] the individual's experience of this change is less well understood. There are also differences in the extent of detrimental effects of having MS that people with MS experience[13,14] and in how they live with an unpredictable disease,[15] suggesting that some factors may prevent the negative effects of identity loss, such as psychological factors, including perceived stress and emotion-focused coping.[16] A person's response to the disease could have an effect on how they manage their illness and may explain why empirical studies evaluating the effectiveness of therapies for depression and anxiety in people with MS have mixed results.[17,18] The aim of this study was to investigate the subjective experience of identity change over time to provide insight into this process.

Methods

Participants

Participants were identified from a feasibility randomized controlled trial of an adjustment intervention for people who reported a diagnosis of MS.[19] The trial compared individual versus group delivery of the same adjustment intervention.[20] Participants from both arms of the trial who consented to be interviewed were contacted 4 months after randomization. Sixteen of the 21 invited participants were interviewed (Table 1). Ethical approval was granted as part of the feasibility randomized controlled trial.[19]

***Table 1.* Demographic characteristics of the 16 interviewees**

Characteristic	Value
Age, y	47.3 ± 11.9
Time since diagnosis, y	8.1 ± 6.6
Sex	
Female	11
Male	5
MS subtype	
Relapsing-remitting	9
Primary progressive	0
Secondary progressive	2
Benign	1
Neuromyelitis optica[a]	1
Unknown	3
Ethnicity	
White British	14
Asian	2
Relationship status	
Married/partner	10
Single/divorced	6

Note: Values are given as mean ± SD or number.
Abbreviation: MS, multiple sclerosis.
[a] One participant who originally reported having MS diagnosis was later found to have neuromyelitis optica diagnosis.

Data Collection

Semistructured interviews were conducted by two researchers (nine by A.B.B. and seven by K.S.) using the same interview schedule (Table S1, which is published in the online version of this article at ijmsc.org). Open-ended questions were asked that allowed for exploration of participants' thoughts and feelings on their social relationships before and after diagnosis, and changes to social relationships over time, as well as any effect these changes may have had on participant mood. Interviews took place either at the University of Nottingham (Nottingham, UK) or at the participant's home, depending on their preference, and lasted 20 to 60 minutes. Interviews were audio recorded and transcribed verbatim.

Where it facilitated discussion, eco-mapping techniques[21-25] were used to help elicit information about an individual's previous and current social identities. Eco-maps allow a graphical representation of the relationships that people have and their connection to larger social networks.[22] This can provide us with valuable information about a person's social network, including the structure, size, and function of the network and individual connections.[23] Eco-maps are useful for mapping and tracking changes to people and their social relations and contacts over time, capturing the participants' own perceptions[24] in a visual, standardized manner.[21] The use of eco-maps allowed us to gain insight into participants' social lives before and after the MS diagnosis. A fictitious example of an eco-map can be found in Figure S1.

Data Analysis

To understand and gain further insight into the process of subjective identity change, an interpretive epistemological stance[26] was taken to collect multiple realities from participants. A thematic analysis was conducted,[27] applying the Social Identity Model of Identity Change[12] as a lens for understanding and structuring the data. The interview data were examined to identify categories most pertinent to the research question. Once this had been achieved, the process of sense making was used to find connections and relationships in the data. This was achieved by successive reading of the texts, critical reflection, and persistent immersion in the text. After recognition of themes, with the support of quotations, these were discussed and compared and contrasted within the research team to ensure a consensus.

Results

Overview

The themes identified in the data were as follows: concealing the disease, presenting a more positive identity, effects of increasing symptoms/changing relationships with others, social support, family as a secure base for identity reconstruction, self-reflected appraisal, integration of the MS identity into changing sense of self, compartmentalization of the MS identity, and assimilating the MS identity into self-concept.

The analysis revealed patterns of adjusting to MS over time, with different factors affecting identity changes at different stages. The patterns of adjustment all began with participants concealing their disease by denying their diagnosis and/or compartmentalizing the MS while retaining a positive social identity. Due to progressing symptoms that resulted in the MS being more visible to others and subsequent changed relationships, participants began to experience the negative effects of identity change and sought social support, which led to a self-reflected appraisal and an acknowledgement of MS as an identity that they hold. After this realization, participants either incorporated their MS into their self-concept or did not accept MS as part of their self-concept and kept this identity compartmentalized.

Pseudonyms are used for the quotations provided in the following sections. The information in parentheses is sex (male [M] or female [F]), age (in years), and type of MS (RR, relapsing remitting; SP, secondary progressive; B, benign; DU, diagnosis unknown; and NO, neuromyelitis optica).

Themes

Concealing the Disease

Diagnosis was often seen as an identity marker and signaled the start of the adjustment process. However, the time between first acknowledging symptoms and receiving a diagnosis might have made it difficult for some participants to come to terms with their MS. Dawn (F, 58, RR): "…I struggled with MS when I was first diagnosed with it, and I struggled with the idea of having it and the fact that I'd had it an awful long time but wasn't diagnosed."

Some participants felt that they should attempt to preserve their prediagnosis identity and to hold on to their established sense of self and identity. They also felt that they should keep their diagnosis private. Rebecca (F, 42, RR): "I've not gone around announcing that I have MS."

Some participants felt that they needed to preserve their previous identity due to the perceived stigma they attached to the MS identity. Because of their perceptions and worries associated with having MS, participants were unwilling to accept their MS identity due to the implications this has on their idea of their future self. Rosie (F, 59, RR): "It is a bit early days. But as I mentioned before I have avoided certain situations where there are MS meetings, because, you know, it is hard to think that, you know, personally that I might be in that, in a wheelchair so many years down the line."

Some social relationships reinforced the prediagnosis identity, which may have led to participants seeing their identity as unchanging. Rebecca (F, 42, RR): "There's erm, one or two [friends], that treat the MS as though it's never happened."

Being treated in a way in which the MS "never happened" reinforced the prediagnosis identity. To maintain high self-esteem, Rebecca appeared to acknowledge positive aspects of herself as important and unchanging while attaching low importance to aspects of identity related to negative self-beliefs, such as the feared consequences of MS. In a similar way, participants attempted to regain aspects of their previous identity that may have been lost due to the effects of MS. This externalization of MS was a way of coping and provided an avenue to vent their frustrations. Another example of the externalization of MS can be seen in the initial concealment and relative secrecy regarding a diagnosis of MS.

Presenting a More Positive Identity

In the data, participants articulated numerous identities. One participant attempted to preserve a prominent marker of her prediagnosis identity, work, despite increasing symptoms having an effect on this. Kelly (F, 28, RR): "One year when I got ill I was going in [to work], going in, going in and I was pushing through, pushing through, pushing through, and I got told off by HR because I shouldn't have been in in the first place."

Because of the highly valued nature of this (work) identity, Kelly attempted to hold on to this identity despite the increasing symptoms. Kelly downplayed markers of an identity that she saw as unimportant and stigmatized (MS) while acting in accordance with an identity that she saw as highly valued (work). Exchanging a stigmatized negative identity for something that the participant saw as valued was one technique for coming to terms with the diagnosis.

Effects of Increasing Symptoms/Changing Relationships with Others

The physical symptoms of MS were perceived as markers of illness progression and changing sense of self. As symptoms became more prominent, participants found that their sense of self was not consistent with markers of their own identity, or how others saw them, and these inconsistent views led to a reevaluation of what the participants viewed as their self. This reevaluation triggered a subjective shift in self-perception. Evelyn (F, 60, SP): "I had to put on an act of being OK, even when I wasn't."

Intrusive symptoms of MS often led to perceived changes in their relationships with other people. This led participants to reevaluate their sense of self, and they began to see the MS as part of who they were. William (M, 47, RR): "And they [friends], they probably don't realise there's a difference but, cause, there is a difference, because I'm not, I'm not the same person. On the outside I am, but not on the inside. I can't always do the same things that I used to be able to do."

Social Support

Participants saw social relationships as a way of dealing with the problems associated with MS. Participants chose the type of support that they felt they required by actively choosing which identity and reflected appraisal they needed at that moment in time. Beth (F, 56, B): "[Friends] haven't really changed, it's been more about me finding out which friend can offer me the right support at the right time."

Social support in general seemed to be closely linked to participants' mood and seemed to help participants come to terms with their diagnosis. Dawn (F, 58, RR): "She [friend] almost brought me back into the fold, so to speak."

Social relationships also caused negative emotions due to the conflict they caused between a person's previous identity and their new emerging one, such as struggling to explain to friends that they are tired. A number of relationships were lost or disrupted after the changes to identity due to MS. The loss of social relationships due to identity change had a negative psychological effect on participants' mood.

Receiving social support from other people with MS seemed to normalize the emerging MS identity. Kelly (F, 28, RR): "There's actually people out there that have, are doing, have done, have experienced what I've gone through, have been through."

Due to the reluctance to accept MS as part of their identity during the early stages of the adjustment process, participants may have been more inclined to seek social support from those who they saw as sharing their prediagnosis identity.

Family as a Secure Base for Identity Reconstruction

The family provided a source of social support for participants during the identity change. Family members were often the first people to know about participants' diagnosis of MS and were also seen as useful in providing support for some of the problems that occurred during identity change. Kelly (F, 28, RR): "Immediate family have to spend time with me no matter what … what mood I'm in, and what's going on yeah, that's the best support there is …."

The family can be quite a large social group. One participant, who before diagnosis had expressed strong ties with his wider family group, found that this diminished after diagnosis so that he only remained close to immediate family members. This change was due to the emerging symptoms of MS changing his outlook. Some participants found that not all aspects of their family initially provided a secure base for identity reconstruction. Evelyn (F, 60, SP): "My ex-partner began to resent me as soon as my disability became really apparent."

For the family to be an effective secure base for identity reconstruction, all members of the family need to work together to accept and adjust to the diagnosis. This narrative of the family not acting as a secure base suggests how important it is for coping strategies to be aligned between the family and the person with MS.

Self-reflected Appraisal

The emergence of symptoms may cause a person with MS to reexamine their identity and sense of self and be more open to self-reflected appraisals. Over time, participants often began to acknowledge the changed sense of self based on how others responded to them. Leonard (M, 46, DU): "If people see the [walking] stick, they've got a completely different attitude towards you."

Integration of MS Identity into Changing Sense of Self

Over time, the MS, which was externalized due to the negative identity connotations, could become integrated into a preexisting self-concept based on self-reflected appraisals. Participants began to view themselves based on how others reacted to them. Over time, symptoms may become progressively more visible to others, which led participants to reevaluate their sense of self. Leonard (M, 46, DU): "I knew for 3 years before I actually let it [MS] affect my life…And then it got to the point where it does, so you can't hide it anymore."

The ability to retain a sense of identity continuity seemed to be associated with positive psychological well-being. Indeed, participants used this as an early coping mechanism until the disease became more prominent, at which point they felt a need to incorporate this identity into their sense of self and engage in activities that were more representative of the MS identity, such as attending MS support groups. This was, however, not universal. Three participants continued to compartmentalize the disease after recognition of the MS identity. This may reflect differences in willingness or ability to incorporate the MS identity into the overall sense of self.

Compartmentalizing the MS Identity

The MS identity is one that is forced on a participant and not an identity developed through motivations or goals. The stigmatized nature of the identity often resulted in a lack of personal value being placed on the MS identity, and people with MS may not want to identify with or behave in a way that is consistent with the negatively judged MS identity. One pattern of adjusting to the MS identity was to continue to compartmentalize the identity and choose not to incorporate this into the overall self-concept. Alanah (F, 55, NO): "My way of coping is ... if I don't think it [MS] is happening, then it is not. If I ignore it, it is not there. It is like a tree falling in the forest, does anybody hear it, you pretend it's not there."

Compartmentalizing the MS identity presented a relative absence of internalization of the MS into the self-concept. Instead, participants presented identities that they considered to be more highly valued. Beth (F, 56, B): "Because my MS has got worse recently so that's why I've probably got a bit more proactive than I was, because I just didn't do anything for years because I have been diagnosed, what, 12 years, and I haven't done… I've just got on with it."

Assimilating the MS Identity into Self-concept

On acknowledging the MS identity, several participants began to assimilate this identity into their sense of self. Dawn (F, 58, RR): "Because it [MS] was mine and I wanted to control it. I didn't understand it, so how can I tell people what I've got if I don't understand it? I didn't understand it. I did lots of research and reading up, and that, and I still didn't understand it. I knew all the words, but they just didn't work for me then. It wasn't until 2 years after I was diagnosed, I suppose, that I actually got to grips with it and thought, 'This is ridiculous, make friends with it and stop worrying about it,' which is what I did."

A common theme in the data was that after an initial adjustment to the diagnosis of MS, participants acknowledged that they were more willing to talk about their disease. Participants may have been unwilling to talk about their diagnosis without first adjusting to their diagnosis and having incorporated the MS identity into their self-concept. Similarly, although social support can help a person adjust to his or her changing identity, acceptance of a changed identity can have implications for the social support a person seeks and receives in the future. Francis (F, 54, RR): "No, I probably wasn't ready [to talk about the MS]. The first year I couldn't get about anyway. I was quite ill for the very first year and then I ... sort of started just getting used to having problems and I probably ... no. I think, you know, people say, 'Oh, there's this you can phone' and I had always thought, oh I don't want to speak to other people, it's all the same thing and ... you know, I would always have that, sort of, attitude. I think I was just about ready now to have some contact."

Discussion

Social Identity Theory[28] posits that people have multiple identities depending on how they see themselves in the social situation they are in. Although the MS identity may be imposed on an individual due to the diagnosis, the participants in this study articulated multiple identities, highlighting a pattern of recognizing their MS and choosing to either assimilate it into their social identity or compartmentalize it. In the early stages of disease progression after diagnosis, participants wanted to compartmentalize and conceal the disease and continue with their prediagnosis identity, a similar finding to recent research[29]; however, over time they came to accept and acknowledge their MS and learned to cope with the everyday problems associated with living with MS. Compartmentalization of the MS identity could reflect early coping strategies,[9] and it appears that individuals can assimilate the MS identity into their self-concept at a later time.

Presenting a more positive identity in social situations seemed to be beneficial for some participants. This exchange of identities can be a stressful process that requires considerable psychological resources,[30] and this pattern of compartmentalizing thoughts about the self could provide greater resilience in times of stress.[31]

Participants restructured their social resources in an attempt to adapt to the MS. By receiving social support from close family members and friends, participants were able to acknowledge their emerging identity in a supportive environment, consistent with the Social Identity Model of Identity Change.[12] The family was a secure base for identity reconstruction, in line with previous research.[32,33] This suggests that there are stages to adjustment; however, these did not seem to be the same across the sample. However, most participants initially did not acknowledge the MS as part of their identity and instead saw this as a stigmatized identity, which led to an initial concealment of the diagnosis and a period of withdrawal. Presenting a more positive self-image and compartmentalizing the disease allowed participants to cope with the early stages of adjustment, allowing them to present an identity that they saw as more highly valued to maintain self-esteem.[28] However, as symptoms became more prevalent, people around the participants began to treat them differently, causing a self-reflected appraisal and a changing self-concept. The use of social support during this time seemed to be beneficial for coming to terms with this change in identity. The increasing presence of MS symptoms combined with social support and positive interactions with others seemed to help people recognize the MS as an identity that they hold.

PRACTICE POINTS

- MS may cause changes to a person's sense of self.
- Using a previously held social identity, such as the family identity, can allow a person to acknowledge his or her changed self-identity and accept social support, which can positively affect mood.
- People with MS may be more willing to accept social support from others once they assimilate their MS into their social identity.

A person's identification with their MS, and therefore assimilation of this identity into their self-concept, seems to be linked to the coping strategies they use. Acting in accordance with an identity that individuals identify with can result in autonomous behavior in line with this identity, such as increased motivation to communicate with other people who share the MS identity. This has implications for the delivery of interventions for mood problems in people with MS in that these interventions may be more beneficial once a person has started to come to terms with the diagnosis and incorporate the MS identity into their self-concept.

These findings need to be considered in light of the study's strengths and limitations. To ensure the quality of the research, data were rigorously analyzed. Once the themes were drawn out, with the support of quotations, these were discussed and compared across members of the research team. The participants were a unique group of people at a certain time speaking in a certain context with a particular researcher, and this should be considered in the transferability of results and conclusions. One participant who originally reported having a diagnosis of MS was later found to have a diagnosis of neuromyelitis optica but was retained in the study.

In conclusion, this study has provided us with insight into how people with MS acknowledge and incorporate their MS into their self-concept over time. It seems that people with MS do incorporate their illness into their identity over time, and this seemed to have a positive effect on mood. The availability of social support and the coping strategies a person uses may affect the time it takes for a person to come to terms with this change of identity. Multiple sclerosis is more readily accepted as part of a person's identity if it is not stigmatized and is seen as only a part of a person's identity. If the diagnosis is stigmatized, people may not readily acknowledge MS as a significant part of their identity, which may restrict their willingness to receive social support, which could then affect their mood. Using a previous social identity, such as the family identity, can allow a person to acknowledge their changed self-identity and accept social support, which can have a positive effect on their mood. □

Financial Disclosures: Dr. das Nair discloses a relationship with Biogen and Novartis (speakers' bureau). The other authors declare no conflicts of interest.

Funding/Support: Dr. Barker received a studentship from the MS Society (966/12).

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The Consortium of Multiple Sclerosis Centers (CMSC) presents an annual award, the Herndon Award for Outstanding IJMSC Article, for the best article published in the *International Journal of MS Care* during a given calendar year. As announced at the Annual Meeting of the CMSC, the winners of the 2018 award are Nananda F. Col, Andrew J. Solomon, Vicky Springmann, Carolina Ionete, Enrique Alvarez, Brenda Tierman, Christen Kutz, Idanis Berrios Morales, Carolyn Griffin, Long H. Ngo, David E. Jones, Glenn Phillips, Ashli Hopson, and Lori Pbert for their article "Evaluation of a Novel Preference Assessment Tool for Patients with Multiple Sclerosis" (published in the November/December 2018 issue of IJMSC). The award is named in honor of founding editor Robert M. Herndon and carries a $1000 stipend.

PATIENT INVOLVEMENT IN MS MANAGEMENT

Evaluation of a Novel Preference Assessment Tool for Patients with Multiple Sclerosis

Nananda F. Col, MD, MPH, MPP, FACP; Andrew J. Solomon, MD; Vicky Springmann, MSc; Carolina Ionete, MD, PhD; Enrique Alvarez, MD, PhD; Brenda Tierman, RN; Christen Kutz, PA, PhD; Idanis Berrios Morales, MD; Carolyn Griffin, RN; Long H. Ngo, PhD; David E. Jones, MD; Glenn Phillips, PhD; Ashli Hopson, BA; Lori Pbert, PhD

Background: *We developed a preference assessment tool to help assess patient goals, values, and preferences for multiple sclerosis (MS) management. All preference items in the tool were generated by people with MS. The aim of this study was to evaluate this tool in a national sample of people with MS.*

Methods: *English-speaking patients with MS aged 21 to 75 years with access to the internet were recruited. Participants completed the preference tool online, which included separate modules assessing three core preference areas: treatment goals, preferences for attributes of disease-modifying therapies, and factors influencing a change in treatment. The tool generated a summary of participants' treatment goals and preferences. Immediately after viewing the summary, participants were asked to evaluate the tool. Rankings of preference domains were compared with rankings obtained in another study.*

Results: *In 135 people with MS who completed the tool and evaluation, the highest ranked goal was brain health (memory, thinking, brain), followed by disability concerns (walking, strength, vision). Rankings were highly similar to those in the referent study. Nearly all participants reported that the tool helped them understand their goals and priorities regarding MS and that the summary appropriately reflected what is important to them. Most participants (87%) wanted to discuss their treatment goals and priorities with their clinician.*

Conclusions: *This preference assessment tool successfully captured patients' goals, values, and preferences for MS treatment and could potentially be used to help patients communicate their preferences to their clinician.* ***Int J MS Care*****. 2018;20:260-267.**

Understanding patient values is crucial to shared decision making (SDM).[1] Shared decision making is essential for high-stakes decisions about multiple sclerosis (MS) when choosing the best treatment depends on how a patient values the risks and benefits of their options.[2] The essential elements of SDM include informing patients when they face a decision, ensuring that patients understand their condition and their options, eliciting patients' values and preferences, and helping them apply their values to the decision.[3] However, eliciting patient values is challenging and time-consuming, and there is no consensus on

From Five Islands Consulting LLC, Georgetown, ME, USA (NFC, VS, BT, AH); Neurological Sciences, University of Vermont College of Medicine, Burlington, VT, USA (AJS); University of Massachusetts Memorial Medical Center, Worcester, MA, USA (CI, IBM, CG); Neurology, University of Colorado, Aurora, CO, USA (EA); Colorado Springs Neurological Associates, Colorado Springs, CO, USA (CK); Harvard Medical School, Beth Israel Deaconess Medical Center, Boston, MA, USA (LHN); University of Virginia Health System, Charlottesville, VA, USA (DEJ); Biogen Inc, Weston and Cambridge, MA, USA (GP [now at Akcea Therapeutics]); Division of Preventive and Behavioral Medicine, University of Massachusetts Medical School, Worcester, MA, USA (LP). *Correspondence:* Nananda F. Col, MD, MPH, MPP, FACP, Five Islands Consulting LLC, 1119 Five Islands Rd., Georgetown, ME 04548; e-mail: Nanfcol@gmail.com.

Note: Supplementary material for this article is available at ijmsc.org.

DOI: 10.7224/1537-2073.2017-021
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International Journal of MS Care
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