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Managing Psychological Stress in the MS Medical Visit: Patient Perspectives and Unmet Needs

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Abstract

Psychological stress can negatively impact multiple sclerosis (MS). To further understand how stress is addressed in the MS medical visit, 34 people with MS participated in focus groups. Transcripts were analyzed by inductive thematic analysis. The majority of participants did not discuss stress with their provider, citing barriers to communication such as lack of time, poor coordination between specialties, physician reliance on pharmaceutical prescription, and patient lack of self-advocacy. Participants recommended several ways to better manage psychological wellbeing in the clinical setting. These findings provide a foundation for future studies aimed at minimizing the detrimental effect of stress in MS.

Keywords

health psychology; patient satisfaction; psychological distress; qualitative methods; verbal communication

Introduction

People with multiple sclerosis (MS) have long reported their belief that stress worsens neurological symptoms (Ackerman et al., 2002) and meta-analyses show a consistent association between stressful life events and subsequent MS exacerbations (Artemiadis et al., 2011; Mohr et al., 2004). Stressful life events have been found to predict increased MS lesions in the brain (Burns et al., 2013; Mohr et al., 2000; Yamout et al., 2010; see Lovera & Reza, 2013 for review), and a stress-management intervention has been shown to reduce the appearance of new brain lesions on MRI (Mohr et al., 2012).

Because evidence shows that stress impacts the disease process in MS, the patient's experience of chronic or severe stress should be acknowledged in the medical context. Several evidence-based interventions enable clinicians to incorporate stress-management

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into treatment plans (Artemiadis et al., 2012; Firth, 2014; Grossman et al., 2010; Mandel and Keller, 1986; Mohr et al., 2012; Walker and Gonzalez, 2007), and coordinated referrals to mental health practitioners can create a team-based approach to care. Indeed, the complexities and challenges of MS dictate that optimal treatment is best achieved through a team of physicians and allied professionals (Rieckmann et al., 2012). Furthermore, teaching patients stress management techniques can encourage autonomy and improve self-management (Senders et al., 2012). However, it is unclear whether individuals with MS and their providers are actively communicating about psychological stress. Do doctors and patients dialogue about the experience of stress? If not, what barriers exist to having these conversations?

To better understand how stress is handled in the medical visit, we invited people with MS who scored > 15 on the Perceived Stress Scale (Cohen et al., 1983) to take part in focus groups. The objectives of this study were to 1) describe clinician-patient communication about stress in the medical visit, and 2) identify patient preferences for dealing with stress in MS care. Results may not only be applicable to MS but have broader implications for clinicians and patients managing other chronic neurological conditions, as well.

Methods

Study Participants and Setting

People with any type of confirmed MS (Polman et al., 2011) who scored > 15 on the Perceived Stress Scale (range 0 - 40) during a prior study conducted at Oregon Health & Science University (Senders et al., 2014) were invited to take part in this study after Institutional Review Board approval. A list of 65 eligible participants was randomly ordered; invitations to participate were mailed sequentially according to this list and followed up with a phone call within the week. Between February and April, 2013, 34 people with MS were recruited, acknowledged consent, and completed the study.

Design

Five focus groups were conducted. A descriptive, qualitative approach was the most appropriate design because we sought information about people's thoughts, feelings, and experiences. We chose to conduct focus groups because the process of group interaction can support the exploration and clarification of personal experience that might not emerge from a one-on-one interview (Kitzinger, 1994). Focus groups were semi-structured in that each group was presented with the same main questions:

- **1.** Do you talk with your medical provider about stress, why or why not?
- 2. How would you prefer stress be handled in the medical visit?

Each group was asked the same overarching questions, although the facilitator allowed for flexibility of dialogue depending on the unique chemistry of the group, and follow-up questions were asked as appropriate to group discussion. The lead author facilitated all five focus groups, each of which lasted $1 - 1\frac{1}{2}$ hours.

Analysis

Focus groups were audio recorded and transcribed verbatim. The lead author read each transcript several times to gain a strong, overall sense of the data (Braun and Clarke, 2006). The approach to coding was inductive (Saldaña, 2013). Two authors (AS and KS) performed initial coding and applied descriptive labels generated by the data. These labels were continually refined and eventually hierarchically organized as parent and child codes. AS lead the development of the final codebook with the following categories: definition of code, brief description of when to use, brief description of when not to use, and an example quotation from the transcripts.

Each transcript was independently coded in duplicate by two authors (AS, KS, or HW) using Dedoose web-based qualitative data analysis software (Dedoose, 2013). Prior to coding, each author completed at least one inter-rater agreement test through the training module provided by Dedoose. Discrepancies in coding were discussed amongst the research team and any disagreements were resolved by consensus. These discussions supported the refinement of codes and determined when authors where ready to participate in final coding of the transcripts. Authors were blinded to each other's work until all coding was complete. Discrepancies in final codes were discussed and resolved by consensus.

Thematic analysis according to Braun and Clarke (Braun and Clarke, 2006) was used to group repeated patterns of codes into meaningful categories/themes. Thematic analysis was chosen because it can provide a straightforward yet rich description of participants' beliefs and experience. All three coders contributed to this portion of the analysis. In addition, a neurologist familiar with each of the coded transcripts (AP) contributed content expertise and ensured an inter-disciplinary team approach to evaluating the data.

Results

Of the 65 people who qualified and were recruited for this study, we were unable to reach eight and 16 declined due to scheduling conflicts or lack of interest. Forty-one people signed up for a focus group and seven did not show; 34 people participated in this study. Demographic information is presented in Table 1.

Facilitators and Barriers to Discussing Stress in the Medical Visit

When asked whether participants talk with their MS medical provider about stress, eight people specifically said "yes" but the majority of participants across groups said "no". The medical provider was a neurologist for all participants in this study. From this discussion, two major themes were developed: 1) facilitators to talking about stress in the MS medical visit, and 2) barriers to talking about stress in the MS medical visit. Each theme was further categorized into three sub-themes: aspects of 1) the medical system, 2) clinician behavior, and 3) patient behavior that facilitate or inhibit communication about stress. Illustrative participant comments regarding barriers to communication are presented in Table 2.

Facilitators and barriers to discussing stress: The medical system

Elements of the medical system that facilitated communication about stress between clinicians and patients included a local educational series open to the community and hosted by Oregon Health & Science University (OHSU). Monthly lectures given by local specialists provide information about MS management and lifestyle options, and participants stated that because this program has addressed stress-management, it signals to them that the OHSU MS medical community is open to discussing stress in the medical context.

Another feature of the system that not only encouraged participants to discuss stress with medical personnel but also served to connect them with supportive community resources was the case manager. Two participants were assigned a case manager who would call every two months, answer questions and provide resources. One of the recipients of this service was frustrated by a high turnover of case managers and having to regularly reestablish the therapeutic relationship. Under ideal circumstances, however, several participants agreed that this would be a welcomed addition to their treatment team. To this point, some participants acknowledged unease about "asking too much" of their neurologist, and favored "a secondary person to be inserted into the clinical setting."

Participants who weren't talking about stress with their providers cited not enough time to cover physical and psychosocial issues during a visit as a barrier. Others suggested that a medical system that so readily separates physical and mental health by specialty inherently discourages "whole-person" conversations. The separation of specialties left one woman frustrated. While a number of specialists within the same health care organization attended to her care, these providers lacked coordination. Instead of feeling like she had an integrated health care team, she felt more like a "ping-pong ball", bouncing from neurologist, to urologist, gastroenterologist, and psychologist.

Ideally the primary care physician (PCP) would serve as a unifying clinician for those who receive multiple types of specialty care, but some participants agreed that once diagnosed with MS, their PCP deferred the majority of care to the neurologist, further complicating the sentiment above.

Facilitators and barriers to discussing stress: The physician

Eight of the 34 participants stated that they have discussed stress with their neurologist, and a few participants reported that their physician actively dialogues about stress and engages the patient in conversation. Participants also stated that they were more likely to engage in dialogue about stress with physicians who openly express that diet, exercise, and lifestyle choices can impact health.

Barriers to communication included physicians who are visibly not interested in the patient's experience of stress. Participants reported that stress was important to them but when they brought it up they were ignored or even chastised by their physicians: "I had a neurologist in the past that really kind of belittled me when we did talk about it, like 'What do you have to be worried about? You actually are doing really well compared to other MS patients.' So I just suck it up." Across all focus groups, participants had experienced a physician who

conveyed the sentiment, "Well, this is MS. What did you expect?" which left them feeling insulted and rejected.

Another barrier to communication about stress was the clinician who is too eager to offer a pharmaceutical solution. Participants across all groups stated they are not interested in taking another medication for stress-related symptoms, but felt that their physician had little else to offer in terms of support. "...I take ten prescriptions a day, just incredible. So I think it has to be more systemic, there needs to be a change of thinking..." Throughout this discussion was a strong overarching sentiment of "what can they do about it?" Participants who felt their clinician had little to offer other than medication were reluctant to discuss their experience of stress.

One participant, however, felt medicine is changing to be more inclusive of nonpharmaceutical solutions. "I think what's interesting now is doctors are looking more at our diet and more at our minds, whereas before it was all medication, medication, medication. I think that something is changing, something is turning in the medical field..."

Facilitators and barriers to discussing stress: The patient

Participants also cited some of their own actions that inhibit communication. One participant said that memory issues frequently prevented her from addressing everything she would like to during a visit. Two others didn't feel comfortable discussing stress with their clinician, and shared that such conversations feel "too vulnerable". Finally, participants in two groups shared that they often don't realize they even need to discuss chronic symptoms with a practitioner because these symptoms have become the "new normal".

Participants also shared their strategies for facilitating conversations about stress. Keeping a list of important things to discuss at each visit helped some ensure that conversations covered topics meaningful to their experience. Some participants advocated for finding a physician that holds similar beliefs and for creating a health care team that practices in accordance with their own values. In concordance with this sentiment, other participants expressed that patients need to be their own advocates in insisting on the type of care and attention they prefer.

Patient Preferences for How Stress is Handled in the Medical Visit

When asked if they were satisfied with how stress is handled in medicine, almost all participants said "no". Recommendations for improvement were grouped into three categories, including those for the 1) medical system, 2) clinician, and 3) patient. Associated codes and comments are presented in Table 3.

Recommendations for the medical system

Every focus group protested the high financial cost of having MS and many participants found additional out-of-pocket expenses for stress-management services unacceptable. Affordability was a major barrier to resources like counseling, acupuncture, skills training, and meditation classes, and many people believe that insurance should cover such services, particularly when they are utilized to prevent worsening health.

Two groups endorsed regular screening of stress and stress-related conditions, and suggested that a certain score prompt communication between doctor and patient. These participants agreed that they wouldn't necessarily want their neurologist to directly manage stress-related issues, however they encouraged regular screening and referrals for appropriate services. There were also repeated desires for access to current listings of community classes, trainings, lectures, and practitioners.

Recommendations for the physician

Participants across all groups advocated for improved physician interpersonal skills when discussing stress in the medical visit. Above all else there were requests for compassionate, empathic listening and for the physician to 'act interested' in the patient's experience, even if there is no immediate solution. Because many people with MS tend to "look good" it can be difficult for others to fully grasp their experience. Participants across all groups shared that family, friends, and coworkers often don't understand MS: "You know, it's like having a cold. 'Well, You don't *look* sick -' 'But you look so *good*!'" In light of this universal challenge, having a health care team that actively listens and legitimizes the patient's experience with MS becomes even more important.

Many people were clear that they wanted something other than prescriptions from their medical encounter. Several desired referrals to classes, trainings, or support groups: "I'd like it if they suggested classes or support groups, because I haven't really been told those things." Others highlighted the value of just talking, asking questions, and being heard, including one woman who reported that these are the main reasons she seeks medical attention for MS.

Participants also recommended a more holistic, integrated approach to care. They recognize that while stressors such as family, work, or school might not be directly related to their MS, the consequences of stress reverberate throughout their lives and ultimately affect their wellbeing. Having a clinician who is willing to make these connections and see the patient as a "real human being" is crucial.

Two groups independently stated that making behavioral changes is challenging, and that sometimes they know what to do but the actual *doing* is difficult. Under these circumstances, people reported that they wanted their physician to hold them accountable in order to improve their motivation for making change. A doctor that holds the patient accountable in a consistent, caring way can improve participants' motivation for long-term behavior change.

Two other people reported that behavior change is difficult when it is unknown if efforts will truly make a difference in one's health. Participants agreed that if their neurologist made evidence-based recommendations for stress-management it would decrease uncertainty and support their efforts to manage stress.

Recommendations for the patient

Participants also had suggestions for their peers. As stated above, there was a sentiment that patients should advocate for themselves and that they should initiate conversations about stress and stress-related symptoms. "If [the doctor is] not asking, and we don't say, then

there is nothing, then there is a void there...So advocating for ourselves I think is one of the primary things we need to learn how to do."

Multiple groups acknowledged that advocating for one's needs is easiest done when the medical team and patient hold similar philosophical approaches to health and wellbeing. Thus the recommendation to be selective about which practitioners comprise the MS medical team is a theme worth repeating here.

Discussion

Objective evidence continues to demonstrate that psychological stress can worsen MS symptoms (Burns et al., 2013; Mohr et al., 2000, 2004, 2012), and thus we assert that stress should, in some way, be addressed in the medical context. This study explored how stress is handled in the MS medical visit from the patient perspective and is the first we are aware of to address this question directly. Participants cited some aspects of their current experience that support communication about stress. They also acknowledged gaps in care and recommended actions to better manage psychological wellbeing in the clinical setting.

Our data may appear to suggest that patients want their neurologist to take on an entirely new role, yet this was not our experience. Overall, participants were quite satisfied with the MS specific care they receive and appreciated the specialty training their physician has in MS. In addition to their appreciation for excellent care focused on physical wellbeing, participants also expressed their interest in a more patient-centered/biopsychosocial approach to care. In general, participants wanted their experience of stress to be 1) acknowledged with screening or inquiry, 2) validated with empathy and concern, and 3) managed with referrals to community resources. Additionally, a physician who holds the patient accountable at each visit to receive support and make appropriate behavioral changes lends motivation and strengthens the therapeutic relationship, even if those visits occur only bi-annually or less frequently.

Our findings echo previous research that investigated the needs of 353 people with MS. Koopman et al. (2006) developed 75 needs statements covering seven categories: physical, psychological, accessibility, health, financial, employment/leisure, and information. Participants ranked needs statement in order of importance. Seven of the top ten needs of MS patients were psychosocial in nature, and three of the top ten needs specifically related to knowing that "clinicians are interested" and "being heard by the MS clinic". This sentiment, that just "being heard" can be therapeutic, was echoed by many of our participants, yet this idea may be challenging for practitioners trained in a system that is designed to offer concrete "fixes". Participants across all groups felt that clinicians are often too quick to offer a pharmaceutical solution, and this may be a difficult mindset for physicians to disengage. Medical school curriculum traditionally lacks detailed instruction in behavioral health and social sciences (Skochelak, 2010; Smith et al., 2014) and clinicians may need additional support to meet these needs.

Physicians were not queried in this study, yet other studies have found a major perceived barrier to adopting health behavior change counseling is a lack of time (Forman-Hoffman et

al., 2006; Spring et al., 2013). In addition to face-to-face time with the patient, the physician has a myriad of documentation, care coordination, and institutional responsibilities. Any increased demand on a tight schedule can seem unrealistic and sometimes unacceptable. However, primary care research on practice style and doctor-patient communication has shown that a biopsychosocial approach does not require more face-to-face time than a strictly physical approach (Roter DL, 1997), and patient satisfaction is highest among those that receive this type of care (Michie et al., 2003; Rathert et al., 2013; Roter and Stewart, 1997). Again, brief trainings might be necessary to instruct some physicians as to how to adopt a biopsychosocial approach within the limits of a busy clinic schedule.

The American Academy of Neurology recently published evidence-based guidelines for screening and treating psychiatric disorders in MS (Minden et al., 2013). The authors state that improved detection of emotional disorders would help ameliorate the negative sequelae of untreated mental illness, such as reduced quality of life, decreased treatment adherence, and increased risk of suicide. In light of these guidelines, routine doctor-patient communication about stress might not only help patients feel validated in their experience, but could signal to physicians when a more thorough screening of stress-related mood disorders like anxiety and depression is necessary.

Stress is a difficult construct to measure (Cohen et al., 1997) and there is a dearth of screening tools for generalized stress that have been validated for clinical use. Instruments should account for the subjective nature of stress appraisal and coping, thus measures of perceived stress are most likely to represent the most patient-centered assessment. The most widely used instrument in research is the Perceived Stress Scale (Cohen et al., 1983), although it is not designed for clinical assessment and does not have associated cutoff scores. There are a variety of instruments that are used clinically to assess emotional distress and in actuality measure an amalgam of depressive, anxiety, and other psychological symptoms (Andrews and Slade, 2001; Bryan et al., 2014; Derogatis and Unger, 2010; Goldberg et al., 1997). The lack of perceived stress screening tools for clinical use is a limitation that should be addressed with future research. Even still, clinicians can gain valuable information by directly asking patients about their experience and whether some kind of support would be welcomed or not.

In a consensus statement intended to guide patient management, the *MS in the 21st Century Steering Group* states that "....affording patients psychological and social support as part of their treatment package is likely to ensure the greatest possible mitigation of the potential financial, social, and psychosocial burdens associated with MS." (Rieckmann et al., 2012, p. 464). Our preliminary findings suggest that many MS patients and physicians are not communicating about stress, casting doubt as to whether patients are receiving adequate care in this arena. Future research should establish physician perceptions about how stress is handled in the medical visit, as their understanding may be different than patients. Indeed, others have highlighted dramatic differences in patient-physician perspectives regarding MS care. The MS Choices study surveyed 331 people with MS and 280 MS physicians and found 47% of physicians thought that patients were fully involved in deciding their treatment, whereas only 23% of patients felt that they had actively participated in these decisions (Riñon et al., 2011). Future investigations should query physicians and patients

across practices and geographic regions in order to provide a more comprehensive understanding of psychological stress in the medical context. The results of such investigations may then inform interventions that address specific gaps in care and physician-patient communication.

It is possible that providers are unaware of evidence-based behavioral interventions for their patients. Several stress management programs have been shown to be effective in MS. Mindfulness-based stress reduction is an eight-week program during which participants are instructed in mindfulness meditation, breath work, yoga postures, self-reflection and awareness (Kabat-Zinn et al., 1992). The addition of this program to usual care has been shown to improve depression, anxiety, fatigue, and quality of life for people with MS (Grossman et al., 2010). Stress Management Therapy for MS is a manualized, validated stress management program that teaches problem solving skills, relaxation techniques, and cognitive restructuring (Mohr, 2010). The addition of this program to usual care has been shown to decrease the development of new lesions on brain MRI (Mohr et al., 2012). Cognitive behavioral therapy helps participants increase a sense of control and self-efficacy by shifting destructive thought patterns, teaching effective problem solving and coping skills, and teaching relaxation techniques. While specific MS studies have not assessed stress as a primary outcome, several trials have demonstrated effectiveness in improving stress-related outcomes (see Hind et al. 2014 for review). Again, future studies should assess provider knowledge and perception of available programs for stress management in MS.

Limitations

The generalizability of our findings may be limited as most participants receive their MS care from a single center. Nonetheless, participants in the study have seen multiple physicians in varied care settings across the country over the course of their disease; their experiences are influenced by, but not necessarily limited to, their current physician. Thus, it is impossible to tell exactly how many providers contributed to the experiences reported here. In addition, it is a common sampling strategy to continue to conduct focus groups until no new concepts emerge in a category (Crabtree and Miller, 1999). Because participants in this study were recruited from a previous MS study, the participant pool was limited and our data may not have reached saturation. Finally, the Pacific Northwest may not reflect other regions of the world as there is a higher use of complementary and alternative medicine in this area and patients may be more exposed to a holistic medical paradigm. Future studies should recruit from the general MS public in varied geographic regions.

Conclusion

In summary, the majority of participants in this study were not talking with their neurologist about stress. Our analysis identified obstacles to these conversations, including barriers in the medical system, in the physician interaction, and from the patient. The majority of participant recommendations to improve how stress is addressed in the medical visit were directed toward the physician, and future research should examine physician perceptions to gain a more thorough understanding of how psychological stress is managed in the medical context.

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References

- Ackerman KD, Heyman R, Rabin BS, et al. Stressful life events precede exacerbations of multiple sclerosis. Psychosomatic Medicine. 2002; 64(6):916–920. [PubMed: 12461197]
- Andrews G, Slade T. Interpreting Scores on the Kessler Psychological Distress Scale (K10). Australian and New Zealand Journal of Public Health. 2001; 25(6):494–97. [PubMed: 11824981]
- Artemiadis AK, Anagnostouli MC, Alexopoulos EC. Stress as a Risk Factor for Multiple Sclerosis Onset or Relapse: A Systematic Review. Neuroepidemiology. 2011; 36(2):109–120. [PubMed: 21335982]
- Artemiadis AK, Vervainioti AA, Alexopoulos EC, et al. Stress management and multiple sclerosis: a randomized controlled trial. Archives of Clinical Neuropsychology. 2012; 27(4):406–416. [PubMed: 22491729]
- Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006; 3(2):77–101.
- Bryan CJ, Blount T, Kanzler KA, et al. Reliability and Normative Data for the Behavioral Health Measure (BHM) in Primary Care Behavioral Health Settings. Families, Systems, & Health. 2014; 32(1):89–100.
- Burns MN, Nawacki E, Kwasny MJ, et al. Do positive or negative stressful events predict the development of new brain lesions in people with multiple sclerosis? Psychological Medicine. 2013; 44(02):349–359. [PubMed: 23680407]
- Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. Journal of Health and Social Behavior. 1983; 24(4):385–396. [PubMed: 6668417]
- Cohen, S.; Kessler, RC.; Gordon, LU. Measuring Stress: A Guide for Health and Social Scientists. New York: Oxford University Press; 1997.
- Crabtree, B.; Miller. Doing Qualitative Research. 2. Thousand Oaks: Sage Publications, Inc; 1999.
- Dedoose web application for managing, analyzing, and presenting qualitative and mixed method research data. (Version 4.1). Los Angeles, CA: Sociocultural Research Consultants, LLC; 2013. Retrieved from www.dedoose.com
- Derogatis LR, Unger R. Symptom Checklist-90-Revised. Corsini Encyclopedia of Psychology. 2010:1–2.
- Firth N. Effectiveness of psychologically focused group interventions for multiple sclerosis: A review of the experimental literature. Journal of Health Psychology. 2014; 19(6):789–801. [PubMed: 23520348]
- Forman-Hoffman V, Little A, Wahls T. Barriers to obesity management: a pilot study of primary care clinicians. BMC Family Practice. 2006; 7(1):35. [PubMed: 16756673]
- Goldberg DP, Gater R, Sartorius N, et al. The Validity of Two Versions of the GHQ in the WHO Study of Mental Illness in General Health Care. Psychological Medicine. 1997; 27(1):191–97. [PubMed: 9122299]

- Grossman P, Kappos L, Gensicke H, et al. MS quality of life, depression, and fatigue improve after mindfulness training: A randomized trial. Neurology. 2010; 75(13):1141–1149. [PubMed: 20876468]
- Hind D, Cotter J, Thake A, et al. Cognitive behavioural therapy for the treatment of depression in people with multiple sclerosis: a systematic review and meta-analysis. BMC Psychiatry. 2014; 14:5. [PubMed: 24406031]
- Kabat-Zinn J, Massion AO, Kristeller J, et al. Effectiveness of a meditation-based stress reduction program in the treatment of anxiety disorders. The American Journal of Psychiatry. 1992; 149(7): 936–943. [PubMed: 1609875]
- Kitzinger J. The methodology of focus groups: the importance of interaction between research participants. Sociology of Health & Illness. 1994; 16(1):103–121.
- Koopman WJ, Benbow CL, Vandervoort M. Top 10 needs of people with multiple sclerosis and their significant others. The Journal of Neuroscience Nursing. 2006; 38(5):369–373. [PubMed: 17069266]
- Lovera J, Reza T. Stress in multiple sclerosis: review of new developments and future directions. Current Neurology and Neuroscience Reports. 2013; 13(11):398. [PubMed: 24104400]
- Mandel AR, Keller SM. Stress management in rehabilitation. Archives of Physical Medicine and Rehabilitation. 1986; 67(6):375–379. [PubMed: 3521538]
- Michie S, Miles J, Weinman J. Patient-centeredness in chronic illness: what is it and does it matter? Patient Education and Counseling. 2003; 51(3):197–206. [PubMed: 14630376]
- Minden SL, Feinstein A, Kalb RC, et al. Evidence-based guideline: Assessment and management of psychiatric disorders in individuals with MS: Report of the Guideline Development Subcommittee of the American Academy of Neurology. Neurology. 2013; 82(2):174–181. [PubMed: 24376275]
- Mohr DC, Goodkin DE, Bacchetti P, et al. Psychological stress and the subsequent appearance of new brain MRI lesions in MS. Neurology. 2000; 55(1):55–61. [PubMed: 10891906]
- Mohr DC, Hart SL, Julian L, et al. Association between stressful life events and exacerbation in multiple sclerosis: a meta-analysis. BMJ (Clinical Research Ed). 2004; 328(7442):731.
- Mohr, DC. The Stress and Mood Management Program for Individuals With Multiple Sclerosis: Therapist Guide. New York: Oxford Press; 2010.
- Mohr DC, Lovera J, Brown T, et al. A randomized trial of stress management for the prevention of new brain lesions in MS. Neurology. 2012; 79(5):412–419. [PubMed: 22786596]
- Polman CH, Reingold SC, Banwell B, et al. Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. Annals of Neurology. 2011; 69(2):292–302. [PubMed: 21387374]
- Rathert C, Wyrwich MD, Boren SA. Patient-centered care and outcomes: a systematic review of the literature. Medical Care Research and Review. 2013; 70(4):351–379. [PubMed: 23169897]
- Rieckmann P, Boyko A, Centonze D, et al. Future MS care: a consensus statement of the MS in the 21st Century Steering Group. Journal of Neurology. 2012; 260(2):462–469. [PubMed: 22936203]
- Riñon A, Buch M, Holley D, et al. The MS Choices Survey: findings of a study assessing physician and patient perspectives on living with and managing multiple sclerosis. Patient Preference and Adherence. 2011; 5:629–643. [PubMed: 22259240]
- Roter DL, Stewart M. Communication patterns of primary care physicians. JAMA. 1997; 277(4):350– 356. [PubMed: 9002500]
- Saldaña, J. The coding manual for qualitative researchers. Los Angeles: SAGE; 2013.
- Senders A, Wahbeh H, Spain R, Shinto L. Mind-Body Medicine for Multiple Sclerosis: A Systematic Review. Autoimmune Diseases. 2012; 2012:1–12.
- Shinto L, Yadav V, Morris C, et al. Demographic and health-related factors associated with complementary and alternative medicine (CAM) use in multiple sclerosis. Multiple Sclerosis. 2006; 12(1):94–100. [PubMed: 16459725]
- Skochelak SE. A Decade of Reports Calling for Change in Medical Education: What Do They Say? Academic Medicine. 2010; 85:S26–S33. [PubMed: 20736563]
- Smith RC, Laird-Fick H, D'Mello D, et al. Addressing mental health issues in primary care: An initial curriculum for medical residents. Patient Education and Counseling. 2014; 94(1):33–42. [PubMed: 24139540]

- Spring B, Ockene JK, Gidding SS, et al. Better Population Health Through Behavior Change in Adults: A Call to Action. Circulation. 2013; 128(19):2169–2176. [PubMed: 24100544]
- Walker ID, Gonzalez EW. Review of intervention studies on depression in persons with multiple sclerosis. Issues in Mental Health Nursing. 2007; 28(5):511–531. [PubMed: 17613150]
- Yamout B, Itani S, Hourany R, et al. The effect of war stress on multiple sclerosis exacerbations and radiological disease activity. Journal of the Neurological Sciences. 2010; 288(1–2):42–44. [PubMed: 19892371]

Table 1

Demographic data for all study participants (n=34).

	n (%)			
Age (years, std)	53.3 ± 11.9			
Female	30 (88)			
Type of MS				
Relapsing Remitting	18 (53)			
Secondary Progressive	7 (20)			
Primary Progressive	5 (15)			
Unknown	4 (12)			
Time since first symptom (years, std)	19.4 ± 12.7			
Time since diagnosis (years, std)	12.9 ± 9.9			
Using Disease Modifying Therapy (DMT) ^a				
Yes	20 (59)			
No	13 (38)			
Missing data	1 (3)			
Using medication for stress, depression, or anxiety b				
Yes	20 (59)			
No	13 (38)			
Missing data	1 (3)			
Education				
HS Diploma	15 (44)			
College Grad	19 (56)			
Disability ^C				
None/minimal	1 (3)			
Mild	11 (31)			
Moderate	8 (24)			
Some support needed	8 (24)			
Walker or two handed crutch	2 (6)			
Unable to walk	3 (9)			
Missing data	1 (3)			
Have health insurance				
Yes	23 (67)			
No	10 (30)			
Missing data	1 (3)			
Ethnicity				
White	34 (100)			
Other	0			

 a DMTs used by participants included: glatiramer acetate, interferon-1b, interferon-1a, natalizumab, and fingolimod.

^bMedications for stress, anxiety, or depression used by participants included: alprazolam, aripiprazole, bupropion, citalopram, clonazepam, duloxetine, escitalopram, fluoxetine, lorazepam, sertraline, venlafaxine

^cDisability status was generated by a self-report scale previously shown to correlate with Expanded Disability Severity Scale scores (r=0.85) (Shinto et al., 2006).

Table 2

Participant quotes that illustrate barriers to communicating about stress in the medical visit. Quotes are divided by sub-theme: barriers encountered in the medical system, with the physician, and from the patient.

Codes	Quotes	
Medical system		
Lack of time	I have [talked about stress with my neurologist] a little. Not a whole lot because they are trying to fit as many patients in in a day as they can generally so there's only so much time and they usually separate the physical and the mental in terms of mental, it's completely separated, so.	
Poor coordination between specialties	Well, I have different symptoms and I feel like a ping-pong ball. You have this? Go here. You have that? Go there. And no one is putting it all together to make sense of thingsIt's frustrating because you feel like you're always missing a piece of the puzzle, like something's not quite coming together.	
Physician		
Displays lack of interest	[Stress] is the thing I complain about the most, and whenever I go to the doctor they never ask me about my stress issue, but I always mention it and it doesn't seem to go anywhereIf I had somebody that acted like they were interested in what I have to say it would be very comforting to me. I had a neurologist in the past that really kind of belittled me when we did talk about it, like "What do you have to be worried about? You actually are doing really well compared to other MS patients." So I just suck it up.	
Quick to offer prescriptions	I think that's one of the problems with MS, they do too much research on medication and not enough research on other alternative therapies for people with MS. Like diet makes a big, huge difference, and nobody talks about dietIf you have a complaint they'll say, "Ok, do you want this medication?" I'm not saying they need to know everything about it, but it would be nice to have some kind of resource for other kinds of things that you could do to help.	
Some PCPs defer care to the neurologist	It would be nice to have someone that knew you and knew what you were going through both mentally and physically to understand your symptoms and be like, "Okay, this your next step, this is your next step." And traditionally I think this was the role of primary care, but I swear once you get MS your primary care is just like, "Oh, it's MS."	
Patient		
The "new normal"	You don't really say what is going on because it's nothing new, it's just constantIt's like you live with it and after a while it's just part of your life. So when someone asks, "How are you?" I don't know, I'm fine, because if every - I always tell my husband if you actually knew how I felt on a day-to-day basis you'd be horrified, because it's just constant. So for us when the doctor says, "How are you?" You're like, "As I am every other day." It's just how you are.	
Lack of self-advocacy	And there's a lot of people who fall through the cracks who don't know how to be an advocate, and they are afraid of confronting the doctor because the doctor sits on some high throne in the sky. Well, that's not my world but there are other people who I've talked to who can't ask questions.	

Table 3

Illustrative quotes of participant recommendations for handling stress in the medical visit.

Codes	Quotes	
Medical system		
Accessibility	I think insurance should pay for these things. We know these positive therapies help with overall health in the long run, so why wouldn't the insurance company pay for this? You know, I'm on Medicare and they don't pay for anything other than meds [so] you have to pay for massage, acupuncture, classes out of pocket and that's frustrating.	
Regular screening	When I go in to see almost any doctor they start out pleasant, 'How are you doing today?' 'Oh fine.' But sometimes it might not get beyond that, so the depression inventory would be a good thing.	
Case manager or secondary person	This is like, we are expecting them to go from Joe Friday "Just the facts ma'am", to "You're stressed, now what is the problem?" you know, more of a therapy, psychology thing. And I don't think a neurologist is the right person. Maybe someone trained in that kind of listening would pick up on those cues, but I don't know that neurologists - maybe a secondary person to be inserted in a clinical setting to - I think we are asking too much of them.	
Physician		
Improved interpersonal skills	I think validation, it sounds obvious, but to me the validation right off the bat is stillso important, just as a starting point. Even if it seems obvious, for me emotionally it helps. And then being able to move on to suggestions	
A more holistic approach	Well I think the stress falls over into everything in your life. They need to be able to relate to everything you're going through, not sleeping because you're stressedeffects the rest of your day. So they've got to be aware of more of that kind of stuff.	
Something other than medications	The rush to quick fix it with a pill isn't generally what I'm looking for when I go to the doctor. If you've got a strep throat, well that's what you need, but other than that you want to talk, you want to find out, because with MS there's just so much to it.	
Understands community resources	I keep thinking of a list of programs that are available that could be given to people newly diagnosed, well to anybody really, because there are so many therapies pertaining to stress that are gaining popularity. I think that would be helpful, because like you say, you don't know, you don't have the time to look it up because you're just worried about trying to get your house clean, the regular stuff. Or even a mailer when new things become available.	
Holds patient accountable	[I would like for my physician to make] suggestions which may be obvious ones, but ones I still maybe haven't chosen to try or whatever, and for them not to give up on me because I may be stubborn.	
Patient		
Be an advocate	We have to advocate for ourselves because a doctor isn't going to know to ask you, "Are you crying 45 minutes a day in the bathroom by yourself?" And sothey can't fix what we're not telling them. If they're not asking, and we don't say, then there is nothing, then there is a void thereSo advocating for ourselves I think is one of the primary things we need to learn how to do.	
Be selective about practitioners	You have to connect with them, so finding a good neurologist and a good doctor, and good medical support team, you have to like them and they have to like you and it's important that they honor where you are and who you are and vice versa. That's a real challenge, finding that core team	