

Therapeutic utilization of meditation resources by people with multiple sclerosis: insights from an online patient discussion forum

Jodi Millicent O'Donnell ^{a,b}, George Alexander Jelinek ^a, Kathleen Mary Gray ^c,
Alysha De Livera^a, Chelsea Rae Brown^a, Sandra Leanne Neate^a, Emily Louise O'Kearney^a,
Keryn Louise Taylor^a, William Bevens^a, and Tracey Joy Weiland^a

^aNeuroepidemiology Unit (NEU), Melbourne School of Population and Global Health, The University of Melbourne, Carlton, Australia; ^bSchool of Allied Health, Australian Catholic University, Fitzroy, Australia; ^cHealth and Biomedical Informatics Centre, The University of Melbourne, Carlton, Australia

ABSTRACT

We aimed to describe website traffic and qualitatively analyze an e-health community discussion forum.

Participants in this study were people affected by multiple sclerosis visiting the Overcoming Multiple Sclerosis (OMS) website.

This mixed methods study combined descriptive analysis of website traffic over 7 years and 1 month, and qualitative analysis of 1 week of posts in the meditation topic, coded into theme groups using qualitative thematic analysis.

There were 166 meditation topics posted with 21,530 initial views of primary post and 785 sub-post responses. Meditation posts and sub-posts received 368,713 replies. Number of views increased from 4,684 in 2011 to over 80,000 in 2017, a considerably greater rate of increase than overall traffic.

Qualitative analysis of posts on the meditation forum identified themes of barriers and enablers to utilization of meditation resources. Enablement themes dominated, observed across six of the seven theme groups with various forms of positive social and emotional support to learn and practice meditation. One theme, negative emotion, was identified as a barrier.

The OMS peer-to-peer patient online discussion forum serves important functions in encouraging, educating and enabling its growing online community. Our analysis may help improve and innovate online support for lifestyle management in many chronic diseases.

KEYWORDS

Multiple sclerosis;
meditation; online social
networking; self-
management

Introduction

Patient-centered online communities have been identified as critical for reciprocal patient empowerment and health-related knowledge exchange.¹ Evidence to date suggests that such communities may improve health literacy and overcome perceived barriers to accessing health networks and care.² Given the estimate that seven in 10 people in America with a chronic condition access online resources and information, and network with similarly affected peers,³ there is significant potential for online patient communities to facilitate patient self-care and disease management.

There is evidence of the broad benefits of online patient communities. For example, an investigation of participants within virtual health communities reported that health knowledge and empowerment were valued alongside such emotional supports as empathy, encouragement, affection, and reciprocal

CONTACT George Alexander Jelinek  g.jelinek@unimelb.edu.au  Neuroepidemiology Unit (NEU), Melbourne School of Population and Global Health, The University of Melbourne, Building 379, Level 3, 207 Bouverie Street, Carlton, Australia
Manuscript Tracking System ORCID ID: <https://orcid.org/0000-0002-5211-2771>

 Supplemental data for this article can be accessed [here](#).

© 2020 The Author(s). Published with license by Taylor & Francis Group, LLC.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

social support.¹ A 2016 review of six randomized controlled trials reported a positive impact from patient-centered e-health interventions; human factor issues such as patient behavior, self-efficacy, and health-related outcomes were found to influence and mediate the effectiveness of online communities.⁴

However, the evidence base is not as strong as it could be. For example, one systematic review of depression-specific support group studies found that analyses of online posts predominantly described user characteristics and online use patterns⁵; another systematic review across a range of health conditions found that low numbers of included patients, and unreliable methods of data collection could undermine the validity of the findings.⁶ The provision of online communities to support people with specific health conditions needs to be better informed about how these groups work for people across different social and cultural settings, and how they support and enable people's use of recommended methods and tools for self-care.⁷

Multiple sclerosis (MS) is a chronic demyelinating disease of the central nervous system affecting at least 2.5 million people worldwide, mostly young adults. MS is thought to be autoimmune in etiology, with a range of environmental factors implicated in both triggering the disease in genetically susceptible individuals and in its progression. Stress has consistently been shown to be one of these factors, with stress management a promising potential treatment.⁸ MS produces a variety of neurological symptoms usually leading to progressive disability.

People with multiple sclerosis (PwMS) as a group are particularly engaged with social media and the internet,^{9,10} with a 2012 study even suggesting PwMS use the internet in greater proportion than the general US population.¹¹ Studies have shown that PwMS use online social networks to hear others' stories and daily management plans, and to interact with information appropriate to the changing symptoms they experience if their disease progresses.¹² Online communities are known to provide PwMS with social, emotional, informational,^{13,14} and spiritual support.¹⁵ One major review showed that eHealth apps for people with MS improve outcomes and access to care, disease information, and support.¹⁶

Meditation for health

The practice of meditation has a long history. Fifth-century Vedic scriptures are the earliest reference to meditation for medical recovery and maintenance of human health,^{17,18} yet the effect of meditation on brain function and more recently neuroplasticity, has been of academic interest for only around 40 years and an area of research since the 1990s.¹⁹ Meditation has been described as a procedure that includes the use of a specific technique, muscle relaxation, relaxation of logical intention, a self-induced state, and a concentration on positive anchors for thoughts so as to avoid negative thinking or torpor.²⁰ Meditation is increasingly being recognized as a core component of optimal health, particularly for diseases that are exacerbated by stress; psychoneuroimmunology theorizes the mind-body connection as a mechanism for potentially negative effects on homeostasis, causing somatic disease.¹⁸ Medical practices have begun to include meditation as a component of mainstream therapies.¹⁹

Meditation for health may be helpful for a variety of conditions. A 2008 systematic review and meta-analysis of transcendental meditation demonstrated the effectiveness of meditation on psychosocial stress, myocardial ischemia, atherosclerosis, stress management, hypertension, and cardiovascular disease.²¹ Another systematic review found meditation to be a cost-effective, safe, and efficient practice to help treat pain and illness when incorporated into patients' medical therapy.²²

A prospective, non-randomized controlled trial determined that the effects of meditation on pain and quality of life for PwMS were significant. The authors cited studies supporting a helpful role for meditation in stress reduction, relaxation, and improvement of mood.²³ A large, international study of PwMS has shown a significant association between meditation, lower risk of depression, and improved health-related quality of life.²⁴

One systematic review found evidence for effects of mindfulness-based meditation on quality of life and mental health and potentially aspects of physical health for PwMS.²⁵ A recent randomized controlled trial of 139 participants with MS randomly allocated to an online mindfulness-based meditation course versus

active control showed the meditation group improving in quality of life, anxiety, depression, and sleep, although the effects had disappeared by 6 months without any follow-up input.²⁶

Online patient communities and meditation

There are many ways to access advice and support for meditation practice online and there is a small but growing body of research into their effectiveness.^{27,28} Notably, meditation resources have been diffused via online communities for people with chronic diseases. However, there is a gap in research examining the ways that online patient communities actually support the therapeutic use of meditation.

Aims/objectives

This study aimed to explore meditation-related information and communication exchanges in the discussion forum of an online platform for PwMS to determine whether and how this community provided support for meditation practices among PwMS.

Materials and methods

We utilized a mixed-methods study design combining quantitative analysis of website traffic and qualitative analysis of discussion forum topics and contents, from an online MS platform – research approaches previously used in a range of similar studies.²⁹ Insights were derived from combining analysis of (a) the volume of participant traffic in the meditation forum, and the frequency of follow-up postings to main messages posted there; and (b) themes discussed in the meditation forum generally, and themes specifically indicative of barriers or enablers in meditation practice.

Data used in this study were sourced from an open public discussion forum provided on the website of Overcoming Multiple Sclerosis (OMS) www.overcomingms.org, a not-for-profit organization based in the UK, USA, and Australia, established to support PwMS to make evidence-based lifestyle and medication choices. Individuals can post and edit new threads, reply to other members' posts, and send private messages to other members, but only if they register as members. Those who do not register can view any of the threads and posts, as this forum is in the public domain, but cannot comment.

Meditation is a key component of the OMS Program; the website provides 16 different audio-visual format guided meditation resources, at <https://overcomingms.org/resources/guided-meditation>. Activity by PwMS in the discussion forum over a period of 7 years and 1 month (from March 2010 to March 2017) formed the dataset for quantitative analysis. The OMS forum is moderated, and inappropriate or offensive content is subject to removal; however moderators do not censor posts on the basis of their positivity or negativity, nor do moderators create content, so the forum content appears to be a fair reflection of the diversity of PwMS' expressed ideas and sentiments.

Procedure

Part A: Quantitative Analysis

Descriptive and comparative quantitative statistics were obtained from two sources: the OMS forum demographics, topics and traffic counter; and Google Analytics accessed between 20 March and 3 April 2017, and for aggregate annual data again on 22 May 2018. Due to changes in data protection laws during the period of manuscript preparation, detailed aggregated website and forum traffic data were available for calendar years only. Quantitative and content data for the entire discussion forum were summarized, to provide context for the scope and scale of meditation-related activity in this forum.

Part B: Content Analysis

Posts to the meditation forum for the period from 27 March to 3 April 2017 were analyzed. Due to the great volume of posts overall in this forum and the meticulous nature of thematic analysis, 1 week of posts was sampled for review. These data were read and analyzed by a single researcher (JOD) and collated into post topics and sub-post replies and number of views. Qualitative content analyses of data were then undertaken by the same researcher employing a process of multiple readings of the data followed by the development of initial codes. Two senior researchers (GJ and TW) participated in research discussions and reflections and assisted in the development of themes through an iterative process. Themes classified as enablers were based on a well-established definition of e-health, which includes patients' use of the internet to enhance information exchange, find quality care, get access to medical knowledge, learn about preventive health, give and receive encouragement and support to take an active role in treatment decisions.³⁰ Themes were deemed to be barriers where negative language appeared to the researchers to reflect negative thought, potentially leading to a negative outcome.

Ethics

Ethics approval was not required as data obtained in this study represented autonomous online communication, accessible globally and publicly, and consensually contributed to the forum which was known to be in the public domain. Participants in the OMS discussion forum were anonymous and identified only by a chosen username, although this could be an individual's actual name if they chose, and they could interact in this anonymous or identified fashion on the forum as desired, or private message each other directly to arrange identified contact if desired. Usernames were removed to further de-identify these data for the purposes of this study, as an additional privacy precaution.

Results

The highest traffic-producing regions where forum users were located are shown in [Table 1](#). The top five countries where PwMS were accessing OMS were USA, UK, Australia, Canada, and New Zealand. All are English-speaking countries and countries without a long cultural tradition of meditation.

The traffic for each forum topic, categorized by views, posts, replies to posts, and average time spent on the page, is shown in [Table 2](#). Based on the activity for each topic, meditation was sixth in order of interest among specific topics, after diet, drug therapy, exercise, sunlight and Vitamin D, and mind-body connection. [Table 2](#) shows visitors spent an average of 1.05 minutes viewing the

Table 1. Overcoming multiple sclerosis forum highest traffic volumes by locations of PwMS.

Locations	Sessions	%	Topics	Posts
USA	1,756,265	40.03	35	148
United Kingdom	804,121	18.33	88	1174
Australia	500,302	11.40	36	191
Canada	264,559	6.03	12	38
New Zealand	149,038	3.40	5	52
Ireland	65,689	1.50	2	20
Germany	58,848	1.34	9	34
Netherlands	58,397	1.33	4	10
France	23,229	0.53	6	6
Switzerland	20,597	0.47	2	10
Denmark	31,005	0.71	4	34
Spain	27,353	0.62	3	8
TOTAL	4,387,436		206	1725

Data collected from Google Analytics on 20 March 2017 for the period March 2010 to March 2017

Table 2. Overcoming multiple sclerosis forum topics by volume of activity.

Forum	Views	Posts	Replies	Average time
(12 topics)	(1,191,859 views of primary posts)	(6,915 primary posts)	(46,054 replies to primary posts)	(spent on page)
Miscellaneous	458622	2068	13696	00:02:14
Diet	355100	2366	17180	00:01:43
Drug Therapies	188468	605	4130	00:02:11
Sunlight and Vitamin D	67423	408	2515	00:01:47
Exercise	54830	220	1821	00:01:48
Mind-Body Connection	27872	152	1022	00:01:51
Meditation	21530	166	785	00:01:05
Location	12256	225	1797	00:00:35
Parents and Children	9769	57	371	00:01:26
Recipes	9544	565	2002	00:00:22
Website	7305	77	722	00:01:02
Fundraising	670	6	13	00:00:53

Data for activity and sub-post replies were collected from OMS forum on 20 March 2017. Data for topics, views of first post and average time on page were collected from Google analytics on 20 March 2017 for the period March 2010 – March 2017. Note: Miscellaneous was removed from further analysis.

meditation home page. There were 166 meditation topics posted with 21,530 initial views of the primary post, with a further 785 sub-post responses. In total, meditation posts and sub-posts received a total of 368,713 replies, as shown in Table 3. Table 3 shows the increase in the number of page views of the meditation forum page, compared with overall forum pages, and with the overall website. Views went from just over 4,684 in 2011 to over 80,000 in 2017, a noticeably greater rate of increase than that in overall traffic.

The Supplementary Table shows meditation forum topics, sorted into seven content themes: research, positive emotions, negative emotions, guided meditation, exercise, beginners, aids, and apps. Some irrelevant topics appeared in the meditation forum in error; this group was coded as misclassified and removed from further analysis. It included 10 posts, with 59 replies and 32,272 total views across the study period.

The seven content themes are classified in Table 4 as barriers and/or enablers to utilization of meditation resources. Enablers dominated the meditation forum. Barriers were observed across two of the seven themes, in posts that identified both physical and emotional barriers to meditation practice. Although barriers were shown to be second and third highest in volume of activity, this was not indicative of the qualitative nature of participant posts, nor sub-posts. Enabling factors such as positive language were observed across six of the seven theme groups and observed in all responses to perceived barrier themes. Below are summaries of the content of each theme, with sample quotes that illustrate the nature of the interaction.

Guided Meditation theme [Table 4] was coded an enabler to utilization of meditation resources. It included expert discussion about the OMS recovery program and meditation topics, with links to educational material, programs and techniques guiding the visitor to participate. This discussion shared meditation resources and motivational words of encouragement with each other. It shows the most activity with 60 posts, 234 replies, and 130,447 views [Supplementary Table].

1st Guided Meditation quote: Visualization

I imagine the golden orb moving up to my head, then dissolving, flooding my brain with golden light, which progresses throughout my brain and down my spinal cord and peripheral nerves

Table 3. Comparative change in number of page views of overcoming multiple sclerosis website, overall forum and meditation forum specifically, 2011–2017.

Year	2011	2012	2013	2014	2015	2016	2017
Website page views	978,144	1,793,590	2,615,260	2,872,503	2,878,594	3,167,752	2,825,630
Forum page views	507,568	929,907	1,175,950	1,242,478	1,177,403	1,190,041	1,133,094
Meditation page views	4,684	9,395	18,624	22,166	34,151	74,457	80,036

Data for annual page views collected from Google Analytics on 22 May 2018.

Table 4. Enablers and barriers to utilization of meditation resources.

Themes	Topics	Activity	Traffic	Barriers	Enablers
(Groups)	(166 posts)	(602 replies /sub-posts)	(359,069 views of replies)	2	6
Guided Meditation	60	234	130447		Enabler
Beginners	27	155	62780	Barrier	Enabler
Negative Emotion	14	59	42605	Barrier	
Research	17	33	31485		Enabler
Positive Emotion	16	97	28119		Enabler
Exercise	9	24	18771		Enabler
Aids and Apps	13	20	12590		Enabler
Misclassified	10	59	32272	Removed	Removed

Data were sourced and collated from Supplementary Table.

2nd Guided Meditation quote: Health Journey

I am just reviewing all my meditation materials, and found something that was really, really helpful for me in rough times. It's an audio by Belleruth Naparstek, with healing visualisation and affirmations. I practiced it for a long time, it gave me peace, hope, and I believe it helped me in my healing process. I still carry with me the thoughts and affirmation that moved my heart the most at that time. Love to all

Beginners theme [Table 4] was coded both an enabler and barrier to the utilization of meditation resources. It included posts from beginners exploring meditation, supporters, and discussion regarding help and tips on meditation from site visitors. This discussion had 27 posts, 155 replies, and 62,780 views [Supplementary Table].

1st Beginners quote: Why you should try meditation

Reasons keeping you from doing meditation – I can't sit still. I feel silly. I'm not spiritual. I can't sit there and say "Om". I'm doing the diet, isn't that enough? What I get out of it: A calm and clarity I never felt before. It's not as if it just tunes down the noise, but it's as if the other parts of me are now louder. I can hear myself think. My anxiety is manageable. My therapist noticed a big difference in just a month. I do the tapes while riding to work on the bus as well as during my workouts. Just give it a try. You may get so much out of it that you consider meditation the most positive thing you ever got out of this disease

2nd Beginners quote: Meditation anniversary

Exactly a year ago I was sitting in the meditation sanctuary at the ... (retreat) Centre. For me meditation has given me a safe and effective tool to deal with emotional trauma and stress

Negative Emotions theme [Table 4] was coded a barrier to the utilization of meditation resources. This discussion described a variety of emotional triggers such as stress, anxiety, and restlessness. Physical over-activity, pain or being interrupted contributed to an inability to meditate. There were 14 posts, 59 replies, and 42,605 views [Supplementary Table].

1st Negative Emotion quote: Mindful meditation

I have always struggled with meditation and mindfulness, I have found if anything it made me worse (more anxious and panicky) and I couldn't explain it

2nd Negative Emotion quote: The impatient meditator

I have been meditating pretty much regularly for about 2 years. But I am always impatient. I follow the breath and it feels quite nice and relaxing, but man, I can't wait for it to end. I am an impatient person I think, and quite excitable about life. I always have so many things to do, to think about, to plan, to basically get on with

Research theme [Table 4] was coded an enabler to the utilization of meditation resources. It included posts about the health benefits of meditation. This included medical research and general health-related information about meditation used as a component of mainstream medical therapies. This theme had 17 posts, 33 replies, and 31,485 views [Supplementary Table].

Research quote: Transcendental Meditation – reduced stress, reduced attacks

I have had MS-related fatigue for about 10 weeks following a number of attacks, and transcendental meditation has already helped to greatly boost my energy levels for a few hours after each. The course I did was well taught (the Meditation Trust in the UK) and, importantly, the meditation is very easy to do, helped by the fact that it is not a 'concentration' meditation as such. Two major effects of continued practice are reduced stress and reduced fatigue

Positive Emotions theme [Table 4] was coded an enabler to the utilization of meditation resources. The posts reflected a positive experience being 'in the zone' and a desire to share the positive mind-body effects. Posts similarly described mind training from an athletic perspective. This discussion had 15 posts, 97 replies, and 28,119 views [Supplementary Table].

1st Positive Emotion quote: Overcoming MS is just like cricket!

It is very interesting to see how these top sportsmen approach such a challenge – so many parallels with our Overcoming MS journey. They talk about 'being in the zone' 'in the now or the present' 'each ball at a time, each hour at a time' 'determination and single mindedness'

2nd Positive Emotion quote: Enjoying today

Overcoming MS starts in the mind. I don't know how many times I have wept at some failing body part not performing the way it used to and then I start imagining a rapid descent into a miserable future. My despair is not only unhelpful but also inaccurate

Exercise theme [Table 4] was coded an enabler to the utilization of meditation resources. Posts observed meditation could be done as exercise, while walking and during yoga. This theme had 9 posts, 24 replies, and 18,771 views [Supplementary Table].

1st Exercise quote: Meditating on the elliptical

I go on the elliptical for 30 mins x 6 weekly. Instead of watching TV, I close my eyes and focus on my breathing. I've been doing this for years and it's doubly refreshing after I'm done. While I'm on the machine, I focus inwardly so I can feel my whole body without thoughts. If I am unable to stop the thoughts on any particular day, I just count my breaths, from 1 to 10. After 10, I start over at 1. If my mind wanders, I will count past 10. When I notice it, I just start again at 1. It's a way of focusing, noticing when your mind wanders and easily putting it back. Remember not to be hard on yourself if your mind wanders and just escort it back to the simple counting

2nd Exercise quote: Meditation – seated or lying

I have done a fair bit of meditation over the years, and a lot of yoga. I know that the general consensus is that you should be seated to avoid falling asleep, but I have been practising a lot of my meditations lying down in a yogic relaxation posture. Because I do my meditation in the evening (when the children go to bed) I feel that I need to lie down as I am pretty tired by then, and I then get a lovely meditation/relaxation and feel great afterwards

Aids and Apps theme [Table 4] was coded an enabler to utilization of meditation resources. It included discussion of tools, techniques, hints, tips, tricks and helpful online meditation applications, additional to the OMS site. There were 13 posts, 27 replies, 12,590 views [Supplementary Table].

1st Aids & Apps quote: Blind contour drawing

I sat down to meditate, and I couldn't. It was at that point when I remembered a drawing lesson I had in college called blind contour drawing. You draw the outline and details of an object without looking at your paper. I drew a set of cushions that were on the floor. I detailed every fold and line for about 15 minutes. Well, this did the trick. I was calmed and focused after this. I know there are a few people out there having a hard time with meditating, so I thought I would offer another method

2nd Aids & Apps quote: Meditation to Music

I'm having difficulty letting the thoughts come and go whilst meditating, but I do have relaxing music that when I close my eyes I just get lost in

Enablement quotes used positive language such as "I imagine, I believe, peace, hope, calm, clarity, nice, relaxing, focusing, noticing, reducing stress and fatigue." Negative language linked to negative

thoughts and barrier themes included language such as “not spiritual, I can’t, still struggling, impatient, excitable.” For example, [Supplementary Table, no. 43] shows a post in the meditation forum:

I don’t deserve to have MS. Fear, despair, hopelessness, worthlessness – I feel awful, really awful. My MS is progressing rapidly. I know it. How awful that will be – your mind then visualises the pain of it all. (13 responses, 8692 views).

This post received responses of positive support, for example, two enabling sub-post responses were:

Everything in life takes time, nothing happens overnight, and so does healing from such complex unhealthy process that is MS

I think allowing yourself the luxury of a good cry is really cathartic. Isn’t it amazing what you learn about yourself in adversity

Discussion

Literature reporting benefits of patient online support groups is limited. The American-based Pew Internet Health Tracking Survey 2012, looking at e-health networks, found that people living with chronic conditions stood out online; in addition to looking for formal information sources, they were sharing questions, reading and watching health journeys similar to their own. Eight in 10 people said they posted on e-health forums to reach others.³ The present study of a substantial number of online interactions by PwMS over a period of some years provides an inside look at the positive and negative use of ideas and language by visitors to an online patient discussion forum, and at the dynamics of peer-to-peer interaction between people who expressed despair and those who shared their experiences of overcoming it.

More specifically, these findings offer insights into ways that PwMS interact in online patient communities and interact with each other about online meditation resources. A recent study, looking at the design of electronic MS patient management systems, reported that the highest potential for improvement included patient education, for example, MS e-health platforms where information measures were integrated with easy-to-use approaches.³¹ Our analysis showed that the OMS website and forum supported education about meditation in keeping with this goal, providing considerable research-based information aligned with practical advice and audio-visual resources, through co-production by the OMS organization and PwMS who contributed to the forum.

Notably, analysis of the themes revealed many enablers of utilization of the OMS website meditation resources, through positive language in positive messages. Functioning effectively as a peer support community, PwMS using a variety of forms of expression of social and emotional support guided each other to learn to practice meditation and stay engaged in the practice. Enabling themes dominated the meditation forum; this is in keeping with systematic review findings where primary aspects of social support were identified to be emotional support, information sharing, and offering social companionship.⁵ It is also consistent with the characterization of e-health environments as enabling and encouraging.³⁰ Further, the act of responding to expressions of barrier themes has been reported to be of great importance in online patient communities¹; our analysis yielded examples of PwMS who took this essential role among their peers, by replying to such posts and initiating related posts from more positive perspectives. This peer support function, a key enabler of the utilization of the OMS meditation forum, is suggested as an important component of any online platforms that seek to provide better support for MS communities.

Limitations of study

This study was observational and descriptive, rather than interventional, and it relied on patient posts that self-reported personal experiences with MS qualitatively. There is no requirement for people

registering with the forum to show they have a diagnosis of MS, so some participants may not have had MS or been family members of someone with MS, raising the potential for inclusion bias. Analyzing the nuances in asynchronous online posts is necessarily subjective because additional posts and replies to posts may appear from moment to moment, or over longer periods. Additionally, the record of views of primary posts remained unchanged over time and could be used as a reliable indicator of primary interests of visitors to the forum. While participants could delete their own posts if desired, this suggests that no primary posts were deleted; however, some replies may have been deleted, raising the possibility that we did not analyze all posts to this forum.

OMS website upgrades and re-launch in 2015 may have resulted in lost visitor data meaning that quantitative analysis could not be certain of accounting for the entire forum content. Retrieval of traffic data was hampered to some extent by changes to data protection laws during the period of manuscript preparation.

While different cultures approach meditation and various health conditions differently, our data did not allow analysis of differences in content themes or traffic patterns across users of differing cultural backgrounds. We also analyzed only a single forum. Although other MS forums are available and could also be explored in relation to meditation practice, this was not felt to be feasible given the painstaking and time-consuming qualitative analysis of hundreds of posts and replies on this forum alone. While numerous, this sample of posts from 1 week may not have been representative, potentially introducing bias.

It was also out of scope in this study to explore many other aspects of interest in the dataset, such as correlations of traffic and content with other variables like age, gender, health condition, and so on; or temporal variability in traffic and content over the 2011–2017 period. Further, as [Table 1](#) shows, the population of people posting in the forum was predominantly English-speaking. This limits the generalizability of our results to non-English-speaking communities. Lastly, newer methods for analyzing online discussion content, such as natural language processing and social network analysis, were out of scope here. All are noted as promising areas of further research.

Conclusion

The peer-to-peer patient online discussion forum within the Overcoming Multiple Sclerosis website demonstrably serves important encouragement, education and enablement functions for a growing online community of people affected by MS. This study suggests that the interest among PwMS in the therapeutic use of meditation has grown substantially over a number of years and it shows that an online discussion forum can be effective for people to share their knowledge and experiences of meditation practice. By applying insights from this study – about the qualities of the interactions among PwMS, and the interplay between emergent discussion topics and formally structured resources – we suggest that it is possible to improve and innovate the provision of online support for many dimensions of lifestyle management, for greater numbers of people in a wider range of circumstances.

Acronyms

MS	Multiple Sclerosis
OMS	Overcoming Multiple Sclerosis

Disclosure statement

George Jelinek supported the foundation of the not-for-profit charitable organization Overcoming Multiple Sclerosis which administers the website www.overcomingms.org described in this paper; George Jelinek receives royalties for his

book *Overcoming Multiple Sclerosis*; George Jelinek, Sandra Neate and Keryn Taylor have received remuneration for conducting educational workshops for *Overcoming Multiple Sclerosis*. The other authors declare that there is no conflict of interest regarding the publication of this paper.

ORCID

Jodi Millicent O'Donnell  <http://orcid.org/0000-0002-5211-2771>

George Alexander Jelinek  <http://orcid.org/0000-0001-6157-0910>

Kathleen Mary Gray  <http://orcid.org/0000-0002-2163-3910>

References

- Kordzadeh N, Liu C, Au Y, Clark J. A multilevel investigation of participation within virtual health communities. *Commun Assoc Inf Syst.* 2014;34(26):493–512. doi:10.17705/1CAIS.03426.
- Mackert M, Champlin S, Holton A, Muñoz I, Damásio M. eHealth and health literacy: a research methodology review. *J Comput Mediated Commun.* 2014;19(3):516–28. doi:10.1111/jcc4.12044.
- Fox S, Duggan M. Internet health tracking survey, part two: sources of health information 2013. 7 April 2019. Washington DC: Pew Research Center.
- Wildenbos GA, Peute LW, Jaspers MW. Impact of patient-centered ehealth applications on patient outcomes: a review on the mediating influence of human factor issues. *Yearb Med Inform.* 2016;(1):113–19. doi:10.15265/IY-2016-031.
- Griffiths KM, Calear AL, Banfield M, Tam A. Systematic review on internet support groups (ISGs) and depression (2): what is known about depression ISGs? *J Med Internet Res.* 2009;11(3):e41. doi:10.2196/jmir.1303.
- Tengstedt MÅ, Fagerstrøm A, Mobekk H. Health interventions and validity on social media: A literature review. *Procedia Comput Sci.* 2018;138:169–76. doi:10.1016/j.procs.2018.10.024.
- Rogers MA, Lemmen K, Kramer R, Mann J, Chopra V. Internet-delivered health interventions that work: systematic review of meta-analyses and evaluation of website availability. *J Med Internet Res.* 2017;19(3):e90. doi:10.2196/jmir.7111.
- Lovera J, Reza T. Stress in multiple sclerosis: review of new developments and future directions. *Curr Neurol Neurosci Rep.* 2013;13(11):398. doi:10.1007/s11910-013-0398-4.
- Hay MC, Strathmann C, Lieber E, Wick K, Giesser B. Why patients go online multiple sclerosis, the internet, and physician-patient communication. *Neurologist.* 2008;14(6):374–81. doi:10.1097/NRL.0b013e31817709bb.
- Lejbkowitz I, Paperna T, Stein N, Dishon S, Miller A. Internet usage by patients with multiple sclerosis: implications to participatory medicine and personalized healthcare. *Mult Scler Int.* 2010;2010:640749.
- Nielsen AS, Halamka JD, Kinkel RP. Internet portal use in an academic multiple sclerosis center. *J Am Med Inform Assoc.* 2012;19(1):128–33. doi:10.1136/amiainl-2011-000177.
- Colombo C, Mosconi P, Confalonieri P, Baroni I, Traversa S, Hill SJ, Synnot AJ, Oprandi N, Filippini G. Web search behavior and information needs of people with multiple sclerosis: focus group study and analysis of online postings. *Interact J Med Res.* 2014;3(3):e12. doi:10.2196/ijmr.3034.
- Lavorgna L, Russo A, De Stefano M, Lanzillo R, Esposito S, Moshtari F, Rullani F, Piscopo K, Buonanno D, Brescia Morra V, et al. Health-related coping and social interaction in people with multiple sclerosis supported by a social network: pilot study with a new methodological approach. *Interact J Med Res.* 2017;6(2):e10. doi:10.2196/ijmr.7402.
- Steadman J, Pretorius C. The impact of an online Facebook support group for people with multiple sclerosis on non-active users. *Afr J Disabil.* 2014;3(1):132. doi:10.4102/ajod.v3i1.132.
- Masoumeh Abbasi S, Mohammad Ali M, Mohammad Taghi Abbasi S, Mirzaei M, Ali Mellat A. Online social support for patients with multiple sclerosis: a thematic analysis of messages posted to a virtual support community. *Int J Community Based Nurs Midwifery.* 2016;4:188–98.
- Marziniak M, Brichetto G, Feys P, Meyding-Lamadé U, Vernon K, Meuth SG. The use of digital and remote communication technologies as a tool for multiple sclerosis management: narrative review. *JMIR Rehabil Assist Technol.* 2018 Apr 24;5(1):e5. doi:10.2196/rehab.7805.
- Loizzo J. Meditation research, past, present, and future: perspectives from the Nalanda contemplative science tradition. *Ann N Y Acad Sci.* 2014;1307:43–54. doi:10.1111/nyas.12273.
- Sampaio CV, Lima MG, Ladeia AM. Meditation, health and scientific investigations: review of the literature. *J Relig Health.* 2017;56(2):411–27. doi:10.1007/s10943-016-0211-1.
- Braboszcz C, Hahusseau S, Delorme A. Meditation and Neuroscience: from basic research to clinical practice. In: Carlstedt R, editor, pp. 755-778. *Integrative clinical psychology, psychiatry and behavioral medicine: perspectives, practices and research.* New York (NY): Springer Publishing. 2010.

20. Cardoso R, de Souza E, Camano L, Leite JR. Meditation in health: an operational definition. *Brain Res Protoc.* 2004;14(1):58–60. doi:10.1016/j.brainresprot.2004.09.002.
21. Rainforth MV, Schneider RH, Nidich SI, Gaylord-King C, Salerno JW, Anderson JW. Stress reduction programs in patients with elevated blood pressure: a systematic review and meta-analysis. *Curr Hypertens Rep.* 2007;9(6):520–28. doi:10.1007/s11906-007-0094-3.
22. Arias AJ, Steinberg K, Banga A, Trestman RL. Systematic review of the efficacy of meditation techniques as treatments for medical illness. *J Altern Complement Med.* 2006;12(8):817–32. doi:10.1089/acm.2006.12.817.
23. Tavee J, Rensel M, Planchon SM, Butler RS, Stone L. Effects of meditation on pain and quality of life in multiple sclerosis and peripheral neuropathy: a pilot study. *Int J MS Care.* 2011;13(4):163–68. doi:10.7224/1537-2073-13.4.163.
24. Levin AB, Hadgkiss EJ, Weiland TJ, Marck CH, van der Meer DM, Pereira NG, Jelinek GA. Can meditation influence quality of life, depression, and disease outcome in multiple sclerosis? Findings from a large international web-based study. *Behav Neurol.* 2014;2014:916519. doi:10.1155/2014/916519.
25. Simpson R, Booth J, Lawrence M, Byrne S, Mair F, Mercer S. Mindfulness based interventions in multiple sclerosis—a systematic review. *BMC Neurol.* 2014;14:15. doi:10.1186/1471-2377-14-15.
26. Cavalera C, Rovaris M, Mendozzi L, Pugnetti L, Garegnani M, Castelnuovo G, Molinari E, Pagnini F. Online meditation training for people with multiple sclerosis: A randomized controlled trial. *Mult Scler.* 2019;25(4):610–17. doi:10.1177/1352458518761187.
27. Wahbeh H, Oken BS. Internet mindfulness meditation intervention for the general public: pilot randomized controlled trial. *JMIR Ment Health.* 2016;3(3):e37. doi:10.2196/mental.5900.
28. Wahbeh H, Svalina MN, Oken BS. Group, one-on-one, or internet? Preferences for mindfulness meditation delivery format and their predictors. *Open Med J.* 2014;1:66–74. doi:10.2174/1874220301401010066.
29. Allen C, Vassilev I, Kennedy A, Rogers A. Long-term condition self-management support in online communities: a meta-synthesis of qualitative papers. *J Med Internet Res.* 2016;18(3):e61. doi:10.2196/jmir.5260.
30. Eysenbach G. What is e-health? *J Med Internet Res.* 2001;3(2):E20. doi:10.2196/jmir.3.2.e20.
31. Ziemssen T, Kempcke R, Eulitz M, Großmann L, Suhrbier A, Thomas K, Schultheiss T. Multiple sclerosis documentation system (MSDS): moving from documentation to management of MS patients. *J Neural Transm (Vienna).* 2013;120(Suppl 1):S61–66. doi:10.1007/s00702-013-1041-x.