“I can’t control MS entirely, but at least I feel a sense of control”: A Qualitative Analysis of Individuals’ Perceptions of Control, Illness Coherence, and Self-Efficacy Following a Web-Based Lifestyle Program for Multiple Sclerosis

Rebekah Davenport, William Bevens, Sandra Neate, Pia Jelinek, Maggie Yu, George Jelinek, Jeanette Reece

Submitted to: Journal of Medical Internet Research
on: May 06, 2024

Table of Contents

“I can’t control MS entirely, but at least I feel a sense of control”: A Qualitative Analysis of Individuals’ Perceptions of Control, Illness Coherence, and Self-Efficacy Following a Web-Based Lifestyle Program for Multiple Sclerosis

Rebekah Davenport[1] BA(Psych), GradDipPsych(Adv); William Bevens[2, 3] MBiolSci, PhD; Sandra Neate[3] PHD, MD, MBBS; Pia Jelinek[3] MBBS, MD; Maggie Yu[3] MPH, MA; George Jelinek[3] MBBS, MD, PHD; Jeanette Reece[3] MPH, PHD

[1]The University of Melbourne Faculty of Medicine, Dentistry & Health Sciences Melbourne School of Psychological Sciences Melbourne AU
[2]University of California Institute for Clinical and Translational Science Irvine US
[3]The University of Melbourne Centre for Epidemiology and Biostatistics Melbourne School of Population and Global Health Melbourne AU

Corresponding Author:
William Bevens MBiolSci, PhD
University of California
Institute for Clinical and Translational Science
1001 Health Sciences Road
Irvine
US

Abstract

Background: Evidence suggests that illness perceptions, held by persons living with multiple sclerosis (plwMS), impact affective distress and physical health outcomes. In a randomized controlled trial (RCT), we developed two Multiple Sclerosis Online Courses (MSOCs) – the standard care course (SCC) and the intervention course (IC), adapted from an evidence-based lifestyle program. Modifying lifestyle risk factors presents an opportunity to positively influence individuals' perceptions of MS and improve health outcomes.

Objective: We undertook thematic analysis on qualitative interviews from participants who completed the MSOC across both RCT study arms. We aimed to identify motivations, experiences, and health outcomes, including changes in illness perceptions.

Methods: Participants were invited for a semi-structured interview.

Results: Mental-health themes dominated the IC arm, so only IC data informed theme development which included qualitative reports from 22 plwMS. Three themes were identified: 1) “Self-efficacy for disease management”; 2) “Personal control”; and 3) “Illness coherence”.

Conclusions: Lifestyle-modification may improve personal control over MS, illness coherence, and self-efficacy for disease management. Clinical Trial: This trial was registered prospectively with the Australian New Zealand Clinical
Trials Registry, www.anzctr.org.au, identifier ACTRN12621001605886

(JMIR Preprints 06/05/2024:60240)
DOI: https://doi.org/10.2196/preprints.60240

Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain v
Yes, but only make the title and abstract visible (see Important note, above). I understand that if I later pay to participate in <a href="http

Original Manuscript

Rebekah A. Davenport[1], William Bevens[2,3],Sandra Neate[2], Pia Jelinek[2], Maggie Yu[2], George Jelinek[2], Jeanette Reece[2]

[1]Melbourne School of Psychological Sciences, The University of Melbourne, Melbourne, VIC, Australia,
[2] Centre for Epidemiology and Biostatistics, Melbourne School of Population and Global Health, The University of Melbourne, Carlton, Australia
[3] Institute for Clinical and Translational Science, University of California, Irvine, Irvine, CA, United States

Author Identifier

Rebekah Davenport: https://orcid.org/0000-0003-0426-2158

William Bevens: https://orcid.org/0000-0003-0426-2158

Sandra Neate: http://orcid.org/0000-0002-0781-9848

Pia Jelinek: https://orcid.org/0000-0003-0426-2158

Maggie Yu: https://orcid.org/0000-0003-0426-2158

George Jelinek: https://orcid.org/0000-0001-6157-0910

Jeanette Reece: https://orcid.org/0000-0003-0426-2158

Trial registration: This trial was registered prospectively with the Australian New Zealand Clinical Trials Registry, www.anzctr.org.au, identifier ACTRN12621001605886

Date of registration: 25 November 2021

1.0 Introduction

Persons living with multiple sclerosis (plwMS) are tasked with adjusting to substantial prognostic uncertainty, in the absence of clarity regarding the aetiology of symptoms or access to a cure. Acute critical events, such as receiving an MS diagnosis, and ongoing illness stressors, can disrupt emotional equilibrium [1]. It is well established that depressive, anxiety, and stress symptoms are highly prevalent in the MS population [2]. Approximately 30% of plwMS report clinically significant depressive symptoms, while 34% experience symptoms of anxiety [2]. Lazarus and Folkman's [3-4] seminal work on cognitive appraisal proposes that the psychological impact of an event (e.g., MS diagnosis, relapse) is partly dependent upon an individual's appraisal of the event (i.e., perceived harm, intensity, duration, controllability) and their self-efficacy to access and employ effective coping responses. Empirical evidence provides support for this, highlighting the significant contributions of illness appraisals relating to perceived personal control over MS, a strong illness identity (attribution of physical symptoms to disease) and illness coherence (perceived understanding of MS) on depressive symptoms [e.g., 5-7]. Further, self-efficacy perceptions have been shown to impact symptom severity and disability [8] and quality of life (QoL)[9].

Identifying factors that are predictive of health outcomes, and are amenable to intervention, is critical for maintaining hope and positive disease-management, particularly in the context of a highly uncertain disease such as MS. Given their robust links to mental and physical health outcomes in plwMS, illness perceptions hold substantial clinical significance. Additionally, interventional data demonstrates the amenability of illness perceptions. Changes to illness perceptions, facilitated by cognitive-behavioural therapy, have been shown to coincide with decreases in depressive and anxiety symptoms [10].

The involvement of health-care practitioners, including mental-health workers, in MS care is crucial but has been regarded as time-intensive, challenging to access, and likely to incur large financial expense [11]. As such, there has been an emerging focus on lifestyle self-management as an intervention for plwMS, supplemental to clinician-administered psychological treatments and pharmaceutical disease-modifying therapies. Emerging evidence supports the effectiveness of lifestyle self-management interventions, encompassing improved diet quality, increased exercise, mindfulness practices, and stress management, in enhancing QoL [12-13], and improving depressive and anxiety symptoms [14]. Furthermore, self-management interventions place the patient at the centre of their own care, emphasising their responsibility and control over identifying and addressing health challenges.

According to the Common-Sense Model of Self-Regulation theory (CSM) for chronic disease populations [15-16], exposure to new and alternative information from expert sources is important in influencing the nature and severity of illness perceptions. When presented within the context of a programmatic, educational intervention, delivered by experts, lifestyle modification may provide plwMS with the required scaffolding to re-evaluate their mental representations of illness and efficacy to manage their own MS. To date, research into illness perceptions in the MS population has almost exclusively been conducted within a quantitative research paradigm. While quantitative findings provide important information on the group-level relationships between illness perceptions and health outcomes in MS, they are unable to address questions relating to the highly varied, individual experience of MS, or the effects of self-managed lifestyle modifications on illness perceptions. Few studies have explored the patient perspective of MS using a qualitative approach [17]. This information holds considerable value for medical and allied health professionals involved in tailoring treatment plans for MS patients [18]. By presenting additional options for multimodal lifestyle-related interventions to plwMS, this information may enrich the overall approach to patient care.

1.1 Aims

This study sought to conduct a qualitative analysis of semi-structured interviews to explore participants' motivations, experiences, and outcomes from a subset of people living with MS from a larger randomized controlled trial (RCT) to test the effectiveness of a lifestyle intervention—the MS Online Course (MSOC) [19]. As a part of the broader analysis of participants’ experiences one month after completing the MSOC, the current study aimed to explore changes in mental health, including any perceived changes to illness perceptions. Where previous research has focused on evaluating the quantitative effects of lifestyle modification on health outcomes [e.g., 12-14], the current study adopts a qualitative methodology to take a closer look at the specific impact of lifestyle modification information on individuals’ illness perceptions, identified through inductive thematic analysis.

2.0 Methods

Transcripts were imported into NVivo (NVivo qualitative data analysis software, Version 12, 2018; QSR International Pty Ltd). In line with best-practice data management, document coding and theme development was maintained within Nvivo outputs. The RCT was pre-registered with the Australian New Zealand Clinical Registry (ACTRN12621001605886) and adhered to CONSORT reporting guidelines. This study conforms to the Consolidated Criteria for Reporting Qualitative Research (COREQ)[20] and the APA Style Journal Article Reporting Standards [21]. Ethics approval was received by The University of Melbourne Human Research Ethics subcommittee (ID: 22140).

2.1 Study design and procedure

2.1.1 Larger MSOC RCT

The MSOC Effectiveness RCT is a randomised, single-blinded trial of a six-week online lifestyle modification intervention that follows participants who completed the MSOC over a 2.5-year period. Please note that the RCT is currently ongoing, and data collection for the primary study outcomes at the 6-month follow-up is underway. Consequently, the short-term primary study outcomes were unavailable during the execution of this study.

Details of the MSOC have been previously and comprehensively described [19]. Participants were recruited internationally via invitations posted to MS society websites (e.g., MS Australia), research newsletters (e.g., Clinical Trials Australia), Instagram and public MS Facebook groups. Eligibility criteria were people aged 18 years or above, fluent in English, with a self-reported physician's diagnosis of MS. Exclusion criteria for this study included the presence of a significant comorbid neurological condition or chronic disease (such as stroke) and participation in another randomized controlled trial (RCT). At baseline (0-months), within the context of the first education module of the MSOC module, participants completed an online survey that included questions relating to socio-demographics, disease variables (e.g., MS subtype), lifestyle habits, and physical- and mental-health outcomes.

Two MSOCs (the intervention course [IC] and the standard-care course [SCC]) were developed by collaboratively by researchers and plwMS to provide information on modification of lifestyle-related risk factors. The objective is to compare the effectiveness of each course in a larger RCT for improving quality of life and health outcomes. The IC and SCC both provide knowledge in 7 modules: (1) Introduction; (2) Eat Well; (3) Sunlight and Vitamin D; (4) Exercise; (5) Meditation and Mind-body Connection; (6) Medication and Family Prevention; and (7) Conclusion. The SCC provided general lifestyle information obtained from reputable MS websites, whereas the IC offered information tailored to plwMS based on the Overcoming MS program, an evidence-based lifestyle modification program for plwMS [22]. Supplementary Table 1 contains further detail on the differences between course content.

2.2 Qualitative study

2.2.1 Recruitment

Participants of the RCT who completed all course modules, the pre-course baseline survey and post-course evaluation survey across both study arms (n=53), were invited by email to participate in a 45–60-minute semi-structured interview one month after completing the course (Figure 1). In total 38 participants accepted the invitation. Written informed consent was obtained from all participants in the baseline survey, within the first MSOC module of the RCT, and verbal consent was obtained prior to participating in semi-structured interviews purposed for qualitative analyses. Demographic and clinical quantitative data presented in the current study were obtained from the pre-course baseline survey. The Hospital and Anxiety Depression Scale (HADS)[23] was reported to characterise the severity of self-reported depressive and anxiety symptoms. The HADS, employed extensively in MS samples [e.g., 24-25], has demonstrated accurate sensitivity and specificity for major depressive disorder (90%, 87%) and generalized anxiety disorder (88%, 81%) within the MS population [26]. Ambulation levels were evaluated using the Patient-Determined Disease Steps scale (PDDS)[27], recognised as an indicator of overall disability in individuals with mild-to-moderate disabilities due to MS [28].

2.3 Interview Procedure

Participants were invited by email to participate in semi-structured interviews one month after completing the MSOC. Interviews occurred at a time convenient for participants between 14/10/2022 and 16/11/22 and were conducted by S.N (lead interviewer), R.D, J.R and P.J using Zoom software licensed by The University of Melbourne or WhatsApp. Interviewers had a research background, and either a) had substantial experience conducting qualitative research, or b) were highly trained health-care professionals routinely involved in the clinical management of MS and other chronic diseases. There were minor variations in the interview scripts for the intervention versus standard-care group.

Interview questions broadly covered the following domains:

1) Expectations, goals and knowledge seeking
2) Views of the content of the course
3) Initial changes to lifestyle
4) Initial changes to well-being, health and stress
5) Initial changes to self-efficacy
6) Engagement with the online community

To ensure consistency in the delivery of the interview schedule between interviewers, authors (R.D, J.R, P.J) observed one interview conducted by the lead interviewer (S.J). Minor changes to the structure of the interview schedule were made following the three initial interviews with the intention of ensuring the schedule followed a coherent, logical order (e.g., all questions probing mental-health variables were asked consecutively). With participant permission, interviews were audio-recorded and transcribed, verbatim, using voice-recognition software (www.temi.com). Transcripts were saved in a restricted folder and were accessed by interviewers. Transcript text was altered for the following purposes: upholding participant confidentiality by redacting sensitive disclosures as requested by participants and ensuring that text were a verbatim account participants' verbal response.

2.4 Statistical analysis

Inductive, reflexive thematic analysis (RTA) was used as a means of identifying, analysing and reporting patterns in the data [29]. RTA was selected as it allows for researcher autonomy in the processes of determining themes (latent or semantic) and establishing the most relevant analysis to use (inductive vs. theoretical). This study applied the six distinct phases of thematic analysis: 1) data familarisation; 2) generating codes; 3) constructing themes; 4) reviewing potential themes; 5) defining and naming themes; and 6) producing the report [29]. The data-set was divided into two, according to the IC and SCC arm, and both were analysed and coded independently by R.D and W.B, respectively.

Following data familiarisation and coding, the research team met to review potential themes to ensure alignment with the raw data and participants' perspectives. To enhance transparency, verbatim quotes have been included to illustrate themes, allowing readers to assess the validity of researchers' interpretations.

Participants in the SCC arm reported some changes in mental-health; however, responses were varied, and participants attributed lifestyle changes to external factors. As such, only responses from participants within the IC arm were retained and presented for this study. Four superordinate themes were identified from the data corpus (see Figure 2). Four superordinate themes were discerned from the data corpus, as depicted in Figure 2. Given their distinct nature and relevance to diverse fields of inquiry, the research team opted to partition the data corpus based on these superordinate themes. Subsequently, separate analyses were conducted for each theme. This study focuses on the superordinate theme 'changes in mental-health aspects,' delving into psychological phenomena such as participants' experiences in modifying illness perceptions over the course. Another superordinate theme, namely 'information seeking,' which centers on online information-seeking behaviors for plwMS and was reported separately [30]. Examination of the remaining two themes required quantitative examination to derive their meaning. A quantitative approach aligns with the goals of the larger RCT, specifically aimed at measuring changes in MS symptoms and lifestyle following MSOC completion.

3.0 Results

3.1 Participant characteristics

Table 1 provides demographic and clinical characteristics. Among the 22 participants who completed the IC (mean age 48±12), most identified as female (86%) and self-reported a relapsing-remitting MS (RRMS) phenotype (82%). The majority of participants scored within the ‘normal’ (<8 HADS score) ranges for depression (86%), with just over half scoring ‘normal’ for anxiety (59%). Clinically significant fatigue was reported by a large proportion of participants (59%), and 68% of participants had no or mild disability.

[Table 1.]

3.2 Themes

Within *‘changes in mental-health aspects’,* three themes relating to illness perceptions were identified within the IC arm. The first theme, *“self-efficacy for disease management”* explored individuals' perceptions of increased confidence and motivation to manage MS, gained through engaging with and applying lifestyle modification information from the IC. Data relating to this theme reflected beliefs about one’s capacity to execute behaviours necessary for disease management, resembling the concept of self-efficacy assessed in the Multiple Sclerosis Self-Efficacy Scale (MSES)[31], the gold-standard assessment for self-efficacy in pwMS. Thus, the designation of this theme title was deemed appropriate.

The second theme, *“personal control”* explored individuals' perceptions of improved sense of personal control over MS, developed through engaging with and applying lifestyle modification information from the IC. Lastly, the third theme, *“illness coherence”* explored individuals' experience of an increased and more coherent cognitive representation of their MS. These two themes were named due to the high similarity to the factors ‘personal control’ and ‘illness coherence’, as described by the Illness Perceptions Questionnaire (IPQ)[32].

Quotations are reported to illustrate themes, identified by the study arm (IC) and participant number.

[Figure 2.]

3.2.1 Self-efficacy for disease management

The theme ‘*self-efficacy for disease management*’ explored individuals’ perceptions of increased confidence and motivation gained through undertaking the IC, and by commencing the recommended lifestyle changes provided in the IC. Increased self-efficacy had three effects, referred to as subthemes, including; *“taking responsibility over health”*; *“from contemplation to determination”*; and *“behaviour change in action”*.

Participants described improvements in their self-efficacy to manage their MS through learning about lifestyle modifications for diet, exercise, and mindfulness practice. Course information appeared to foster motivation to adopt a future-oriented focus and prioritise what changes may be important for improving health, based on evidence presented in the course. Equipped with this lifestyle modification information, participants described feeling an increased sense of confidence to take up responsibility over their own health and motivation to make recommended lifestyle changes.

“I felt confident (from the course) that I now have the data behind making changes. I can believe it” (IC18)

“It’s had a positive effect because I feel more confidence that I know what I need to do and that I’ll be able to do it” (IC6)

The lifestyle modification information provided in the IC also resulted in participants having increased responsibility and ownership of managing their health, as well as the confidence to adopt the recommendations of the course and explore further lifestyle-related information.

“The course gave me a launching pad of things I can look at myself” (IC14)

“Having a course like this has helped me know that I am on the right path. I’m doing the right things. I’ve got more information while I was doing the course that boosted me” (IC9)

Increased confidence and motivation, stemming from the IC, enabled many participants to move through stages of changes in lifestyle management, as delineated by Stages of Change Model [33]. Improvements in self-efficacy empowered a shift away from merely contemplating change and towards a more determined and committed approach. This was demonstrated through the development of action plans, with many describing plans to make life-overhauling changes.

“Now I know what I need to do, to achieve what I want to achieve. I know how to get there. I’ve got a plan” (IC6)

In contrast, others referred to more specific targets for change, such as supplementation with omega-3 fatty acids, and increasing their vitamin-D exposure, exercise, and re-engaging with mindfulness techniques including mindful breathing and awareness. For some, this involved introducing the first form of intentional exercise into their lives in recent years.

“It helped. I already knew some of the changes I needed to make but it pushed me into making them. So you know, in addition to just relying on vitamin D supplements, I need to actually get out in the sun” (IC22)

“I have a plan moving forward. I’m really gonna step that (exercise) up. I’ve got a stronger awareness of the boxes I need to tick. I’ve got a target” (IC6)

For some, plans had begun to take effect, actions were underway, and new patterns of behaviour were forming. Participants described improvements in mood and attributed this to the integration of lifestyle changes.

“I’m not as depressed as I used to be” (IC2)

“I’m happier now” (IC20)

“I feel more in control. Because when you feel that something is stressful if I go and meditate, afterwards I am more relaxed and those bad feelings are better” (IC20)

Participant’s responses also raised the possibility of a bidirectional relationship between self-efficacy and change; self-efficacy prompting lifestyle modifications, with these modifications providing the opportunity for positive, mastery experiences that further contribute to self-efficacy.

“When I started to do some changing, I started to feel more confident, and overall, it’s been better for my mental-health” (IC18)

“I definitely feel more confident. It helped me be free of confusion about how my immune system works on MS drugs and leave behind fear of the unknown. I’m remembering to breathe and reduce stress and that it’s important to fuel your body, make good choices, one at a time” (IC4)

3.2.2 Personal control

The theme, ‘*personal control*’ explored individuals' awareness of their improved personal control over their MS through engaging with lifestyle-related modification information. This theme included five subthemes relating to different forms of control, including: ‘*control in the face of realism’; ‘control, in parts’; ‘control through confidence’; ‘control over disease course’; ‘mending control lost through diagnosis’*.

Overwhelmingly, participants expressed an increased sense of control over their MS, although tempered by realism of the disease. They were able to find a balance between focusing on, and directing attention towards controllable elements of MS, whilst also accepting that their actions, alone, could not cure them of their MS.

“I believe it [lifestyle modification] won’t necessarily get rid of the MS, but it will improve my day to day, symptom-wise” (IC1)

“I’m trying to cover all bases. Trying to take some control of a condition that I don’t really have much control of” (IC19)

Having accepted that MS is a chronic disease, some participants began to focus on the possibility that lifestyle modifications may help to control the progression of symptoms.

“So it (the course), made me realise I can actually, through diet and lifestyle change, I potentially hold off anything getting worse” (IC14)

“I’m interested in all the factors I can change that are in my hands, to change the course of the disease” (IC12)

Many expressed a conservative view of lifestyle modification, stating that even if modifications may not control the disease or symptoms directly, lifestyle modification provided the opportunity to experience a sense of control.

“I cannot control it (the disease), but at least I have a feeling I’m controlling it. Which is also very important. It motivated me more to do it (make lifestyle modifications)” (IC17)

“When I was diagnosed I asked my neurologist about the diet changes and she said, ‘as a doctor, I cannot tell you that diet change will help you, but I think you should change your diet because it will make you feel like you’re in control.’ Even if it's just that this course gave me information on flax-seed oil. It’s something new that gives me an idea that I am at least a bit more in control than I was” (IC17)

IC information prompted participants to evaluate the utility of all-or-nothing thinking in relation to personal control, that is, the polarity of being *‘in control’* of their MS versus being *‘out of control’* of their MS. Through learning about controllable aspects of health (e.g., diet, exercise), participants were able to re-conceptualise control as a feeling which varies along a continuum between these two possibilities. That is, self-management lifestyle modification offers individuals the opportunity to gain more control over their MS.

“I don’t feel like I can control whether or not I’m going to get new lesions…but I’m doing as much as I can within my control, which is to exercise more, continue to eat a health diet, meditation, yoga” (IC4)

“It (the course) gave me the push to take more control over my life, with my knowledge about lifestyle modification. I think it helped more than I realised at the time” (IC13)

The IC made participants feel they could extend their sense of control over their MS and explore other avenues to gain further control of their MS in the future.

“It (the course) just made me think ‘...well, wait a minute, I know I can manage this. I know I can control this, or control elements of it.’ The course gave me a bit more motivation to consider, what else can I do here?” (IC13)

For some, confidence was highly interrelated with control, such that increases in confidence coincided with increases in perceptions of personal control.

“I think it helped me. I was sort of 80% there, but after the course, I’m at 100%. It comes hand in hand with more confidence, you feel like you do have more control. I know now what I need to do and it’s only up to me to do it” (IC6)

“I am not at the stage where I can defend and justify following the diet, but I’m trying my best to get to that stage… confidence for me comes from having a better understanding of the oils and that. I’m not there yet, but I am more confident, and my confidence comes from feeling a little bit of control” (IC19)

For one newly diagnosed participant there was distance between their current reality and a state of perceived control over their MS. However, there were indications the IC and possibly other education courses may have contributed to them feeling more in control.

“I completely panicked after I was diagnosed and I was planning things in advance, and I was like, no, I can’t do that because maybe I won’t be able to walk by then…I felt completely out of control the entire time…Once your realise you can’t actually live like that, then that (personal control) slowly comes back and it’s still coming back and this course has helped” (IC15)

3.2.3 Illness coherence

The theme of ‘*illness coherence*’ encompassed individuals’ beliefs in a more coherent understanding of MS through exposure to the IC. This theme included two subthemes, including: *‘seeking out uncomplicated information’* and *‘small parts make a whole’.*

Participants emphasised the challenges associated with complex health information, complicated by medical terminology, and the barrier this information imposes for constructing a coherent representation of MS. In contrast, the IC was regarded as a helpful source of information; scaffolding participants' understanding of health information.

“Medical information is difficult to understand, but the more I read about it, the easier it becomes” (IC1)

One participant described the protective effects of uncomplicated communication within the acute adjustment period following diagnosis.

“It (the course) has been helpful. Normalising MS, especially for people in their twenties or thirties who are unexpectedly catapulted into a chronic situation. It’s a lot to take in because we’re at a point in our lives where everything feels like it's starting. Then it feels like you’re figuring out a whole new identity. So, simple communication on health information is helpful. This is a lifestyle change, and also the way we view it, or the way we can support others in understanding it is helpful” (IC5)

The opportunity to understand and piece together complex health information enabled participants to develop a more coherent mental representation of their disease, which they viewed as important for their general wellbeing.

“Overall I think it (doing the IC) was good for my wellbeing…more information makes me more informed and then the changes that I’m implementing should be positive on my overall wellbeing” (IC1)

This allowed some to begin translating health information into everyday wellbeing practices, such as mediation, with beneficial results.

“I think things have gotten better since the course, I can say that. And the course helped me to put things together, especially for me, meditation, I’m doing a bit more meditation, which I find really does help” (IC9)

4.0 Discussion

The present study assessed participants’ responses one month after completing the intervention arm (IC) of an online education lifestyle intervention program designed specifically for plwMS. To the best of our knowledge, this study represents one of the first qualitative explorations into the effects of lifestyle modification on illness perceptions within the MS population. Specifically, the study aimed to understand the sequelae of the IC on individuals' cognitive representations of their MS. Within the superordinate theme of '*changes in mental-health aspects'*, three subthemes were identified: '*self-efficacy for disease management*', '*personal control'* perceptions, and '*illness coherence*' perceptions. Findings contribute to the expanding evidence-base for the significance of illness perceptions in understanding the lived experiences of plwMS. Moreover, findings provide preliminary support for the pathway theorised in the Common-Sense Model of Self-regulation theory (CSM) between exposure to new and valid information and self-reported changes in the nature and valence of control perceptions, illness coherence, and self-efficacy beliefs [16].

The positive effects of self-managed lifestyle modification on mental-health outcomes in the MS population, such as depression and anxiety, are well established [14]. However, the current study provides evidence to suggest that lifestyle modification, even the mere exposure to lifestyle-related information, may yield benefits for individuals in how they perceive their disease. Illness perceptions have been proposed as cognitive mechanisms underlying changes in depression and anxiety [5], and may be helpful in linking lifestyle modification to positive mental-health outcomes. Positioned as a valuable adjunct to clinician-administered therapies, lifestyle modification has the potential to empower individuals to assume greater responsibility over their disease management, thereby enhancing the comprehensiveness of the treatment approach.

4.1 Principal results

4.1.1 Deciphering the connection: Lifestyle modification and personal control

Gaining a sense of control, which is often reduced following MS diagnosis [34], was a primary motivating factor for engaging with the MSOC, as identified in an earlier qualitative study nested within a pilot study to examine the feasibility of the MSOC [35]. Moreover, evidence substantiates the importance of personal control perceptions for mental-health outcomes in plwMS [e.g., 36-37]. While the current analysis confirms the importance of personal control perceptions and highlights the impact of the IC on this aspect, it also provides novel insights into the multidimensional nature of personal control perceptions in the context of MS. Findings illustrate how personal control may be formed, the extent of control gained, and its relevance across MS-related experiences.

Participants' reports suggested that control may be linked to levels of confidence, and vice versa. Gaining more information about lifestyle modification, through the IC, helped to bolster individuals' confidence and enabled them to feel more in control of MS. Importantly, this was tendered by a pragmatic, continuum-based view of control over MS. While some participants described retrospective feelings of helplessness and a lack of control at the time of diagnosis, they now acknowledged the possibility of exerting partial control over MS, aided through their engagement with the IC. This is unexpected as most study participants were within the first five years of diagnosis, a period marked by increased distress and tendencies toward all-or-nothing cognitive patterns [38]. Notably, the majority of participants in this analysis scored within the normal ranges for depression and anxiety, contrasting findings from previous observational research [2].

As such, study participants may represent a subsample of plwMS who exhibit more positive mental-health than the general MS population and may therefore face fewer barriers in undertaking lifestyle modification. Motivation difficulties and fatigue, which are also hallmark symptoms of depression in plwMS [39-40], are common barriers to lifestyle modification [41]. Future research is encouraged to examine how mental-health influences engagement with lifestyle modification information, initiating lifestyle changes, and the extent to which mental-health may impact the effectiveness of self-management interventions on personal control perceptions.

4.1.2 Building illness coherence: When information becomes clear

Participants' responses in the current study highlighted the changing nature of illness coherence, triggered by an MS diagnosis, and shaped through their interaction with the IC. One participant described their experience of diagnosis as a sudden shift, ‘catapulting’ them into a situation that required them to reconstruct their identity in mid-life. Notably, given that MS is frequently misunderstood and concealed, the period following diagnosis often requires individuals to assert their understanding of MS, and how MS uniquely manifests within them [42]. Therefore, sourcing health information represents a high priority for plwMS [42].

The concept of illness coherence represents a relatively new idea, distinct from the construct of ‘sense of coherence’, which enables individuals to cope with adverse experiences and is regarded as a dispositional trait (i.e., a characteristic embedded within the personality) [43]. Sense of coherence has demonstrated predictive power across a spectrum of physical and mental-health outcomes in plwMS [44-45], however; given its supposed trait-like structure, its susceptibility to forms of intervention is likely limited. In contrast, illness coherence perceptions have been shown to exhibit temporal variability [46], and their connections to mental-health outcomes, encompassing depression and anxiety, have been documented in a handful of MS studies [e.g., 47-48] and are firmly established within the context of other chronic disease populations [49]. Hence, while sense of coherence may prove difficult to influence, illness perceptions may potentially be modified.

The CSM posits that exposure to new and expert information may alter illness perceptions, including psychological adjustment outcomes [16]. The present study extends this concept, suggesting a precondition for such change: health information must be presented in a way that can be easily understood by individuals without specialised medical knowledge. Participant responses suggested that their engagement with uncomplicated health information within the IC facilitated a process of reintegration, helping them to “put things together” again, toward a coherent mental representation of MS. Consequently, participants described improvements in wellbeing and the practical application of information provided in the IC into daily life, including mindfulness.

4.1.3 The role of self-efficacy in advancing through stages of change

Individuals reported increased self-efficacy for disease management following engagement with the IC. The effects of improved self-efficacy on lifestyle modification manifested in diverse ways. The stages of change model [33] is a highly influential framework for understanding health-related behaviour, and its application can lend meaning to the present findings. Through this lens, participant responses can be allocated to two different stages of readiness. The first set of responses suggested that the IC helped them overcome ambivalence toward change, progressing from Prochaska et al.’s c*ontemplation* stage to *preparation/determination* [33]. At this stage, individuals had established the belief that lifestyle modification may lead to a healthier life and described planning steps toward change, with some already experiencing positive effects.

The second set of responses suggested a more advanced stage of change, narrating experiences consistent with a transition from *preparation/determination* into *action*. By incorporating recommended adjustments, including increasing exercise, mindfulness practices, and making dietary modifications, participants noted improvements in their wellbeing, within a mere month, further enhancing their self-efficacy. These responses raise the possibility of a bidirectional relationship between self-efficacy and lifestyle modification changes, whereby changes in one factor feed into changes in the other. The pathway from self-efficacy to behaviour change has been tested and substantiated in prior research [50], although operating under the assumption that changes in self-efficacy precede behavioural changes.

It should be noted that an individual’s baseline stage of change (i.e., where individuals are at in terms of contemplating/actioning change) may predict the likelihood of behaviour change [51], and the act of enrolling in and completing a self-guided lifestyle modification course likely signifies contemplation of change. Future research may consider assessing individuals’ baseline self-efficacy for disease management as one index of readiness for change. Tailoring lifestyle modification educational programs according to the individual’s stage of readiness may help to optimise lifestyle modification change. This approach may help cater to those who are less inclined to engage with lifestyle modification, specifically those in the precontemplation stage, and those who are working to maintain changes and prevent regression to earlier stages.

4.2 Limitations and future research

A one-month time lag between completion of the MSOC and the interviews yielded insights into the immediate impacts of engagement and implementation of lifestyle modifications. Nonetheless, the long-term effects of the MSOC, specifically the IC, could not be determined due to the scope of the present study. Future research should examine changes in illness perceptions to determine if changes are maintained or bolstered through longer-term implementation of lifestyle changes, as individuals witness the benefits of modifications. Of equal importance, researchers should seek to assess cases where individuals initially implemented learned information but experienced a subsequent decline in their efforts over time.

Despite the strengths in the study's international scope and voluntary sampling, certain participant characteristics were underrepresented. In alignment with the study's objective to evaluate the course's impact, a deliberate selection process was necessary wherein only a small percentage of participants who had completed the larger RCT were eligible for qualitative interviews. However, this targeted approach introduces constraints on the generalizability of findings, warranting caution in extending these results to the broader MS population. These underrepresented characteristics encompass males, individuals from non-WEIRD countries, those identifying outside the binary categories of male or female, individuals with progressive MS phenotypes, and those exhibiting moderate-to-higher levels of depressive and anxiety symptoms.

4.3 Conclusions

The current study provides evidence for the therapeutic impact of engagement with educational information on lifestyle modification factors (e.g., diet, exercise, mindfulness, vitamin D exposure). Whilst illness perceptions have been quantitatively studied in the MS population, the present study marks one of the first qualitative examinations and provides deeper insights into the formation and modification of illness perceptions commonly linked to mental and physical-health outcomes. Findings suggest that the IC – a self-guided lifestyle modification program – may serve as a valuable adjunct to clinician-administered therapies, improving sense of personal control over MS, disease coherence and self-efficacy for improved self-management.

Acknowledgements: The authors gratefully acknowledge the generous contribution of those who participated in the MSOC feasibility trial, those who participated in qualitative interviews, and the individuals currently participating in the MSOC effectiveness RCT, and specifically the participants interviewed in the present study.

Conflicts of interest: GAJ is the author of “Overcoming Multiple Sclerosis”. GAJ and SN are co-editors of “Overcoming Multiple Sclerosis Handbook. Roadmap to Good Health”, and facilitators of past residential lifestyle modification workshops. PJ is a contributor to “Overcoming Multiple Sclerosis Handbook. Roadmap to Good Health”. The other authors report there are no competing interests to declare.

Abbreviations:
MS: Multiple sclerosis
PlwMS: Persons living with multiple sclerosis
RRMS: Relapsing-remitting multiple sclerosis
PPMS: Primary progressive multiple sclerosis
SPMS: Secondary progressive multiple sclerosis
MSOC: Multiple Sclerosis Online Course
IC: Intervention course
SCC: Standard care course
RCT: Randomised controlled trial
QoL: Quality of life
CSM: Common-Sense Model of Self-Regulation Theory
HADS: Hospital Anxiety Depression Scale
PDSS: Patient-determined disease steps
FSS: Fatigue severity scale
RTA: Reflexive thematic analysis

Data availability statement: The raw demographic data and full code book supporting the conclusions of this article will be made available by the authors upon reasonable request, without undue reservation.

Funding: We thank our industry partners, JMA Creative, who created the web-platform and developed content. The technical development of the MSOC via JMA creative was funded by the Overcoming MS Charity (UK). This work was supported by the Neuroepidemiology Unit at The University of Melbourne which is funded by anonymous philanthropic donors.

Ethics statement: The study involving humans was conducted according to the guidelines of the Declaration of Helsinki and approved by The University of Melbourne Human Research Ethics subcommittee (ID: 22140). The trial was pre-registered with the Australian New Zealand Clinical Registry (ACTRN12621001605886; Date of registration: 25 November 2021) and adhered to CONSORT reporting guidelines. All participants gave an informed consent to be enrolled in the research. Additionally, participants provided written and verbal consent to undertake semi-structured qualitative interviews for the purposes of this research.

CRediT authorship contribution statement: Rebekah Allison Davenport: Conceptualisation, Project Administration, Validation, Investigation, Methodology, Data-analysis, Visualisation, Writing. **William Bevens:** Conceptualisation, Validation, Methodology, Data-analysis, Writing – Review and Editing. **Sandra Neate:** Conceptualisation, Validation, Investigation, Methodology, Visualisation, Writing – Review and Editing, Supervision. **Pia Jelinek:** Validation, Investigation, Methodology, Writing – Review and Editing. **Maggie Yu:** Conceptualisation, Investigation, Methodology, Data-analysis, Writing – Review and Editing. **George Jelinek:** Conceptualisation, Methodology, Writing – Review and Editing, Funding Acquisition. **Jeanette Reece:** Conceptualisation, Project Administration, Validation, Investigation, Methodology, Writing – Review and Editing, Supervision.

Positionality statement: Recognizing that our identities can shape our scientific perspectives (Roberts et al., 2020), we aim to offer readers insight into our backgrounds as authors. When the manuscript was submitted, five authors self-identified as women and two authors as men. Regarding race, six self-identified as white, and one as East Asian/Chinese.

Multimedia Appendix

Multimedia Figure 1. Participant flow diagram.

Figure 2. Schematic of the qualitative analysis process stages 1-3.

Table 1. Self-reported demographic and clinical characteristics of MSOC interventional arm interviewees (n= 22) at baseline.

Interview schedule of questions for participants.

Supplementary Table 1. Outline of intervention and standard-care course format

18

References

[1]. Ackroyd, K., Fortune, D.G., Price, S., Howell, S., Sharrack, B. and Isaac, C.L., (2011). Adversarial growth in patients with multiple sclerosis and their partners: Relationships with illness perceptions, disability and distress. *Journal of Clinical Psychology in Medical*

Settings, *18*, pp.372-379. https://doi.org/10.1007/s10880-011-9265-0

[2]. Boeschoten, R. E., Braamse, A. M., Beekman, A. T., Cuijpers, P., van Oppen, P., Dekker, J., & Uitdehaag, B. M. (2017). Prevalence of depression and anxiety in multiple sclerosis: a systematic review and meta-analysis. *Journal of the Neurological Sciences*, 372, 331-341.https://doi.org/10.1016/j.jns.2016.11.067

[3]. Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. Springer publishing company.

[4]. Lazarus, R. S., & Opton Jr, E. M. (1966). The study of psychological stress: A summary of theoretical formulations and experimental findings. *Anxiety and Behavior*, 1, 225-262.

[5]. Bassi, M., Cilia, S., Falautano, M., Grobberio, M., Niccolai, C., ...& Delle Fave, A. (2020). Illness perceptions and psychological adjustment among persons with multiple sclerosis: the mediating role of coping strategies and social support. *Disability and Rehabilitation*, *42*(26), 3780-3792. https://doi.org/10.1080/09638288.2019.1610511

[6]. Lester, K., Stepleman, L., & Hughes, M. (2007). The association of illness severity, self-reported cognitive impairment, and perceived illness management with depression and anxiety in a multiple sclerosis clinic population. *Journal of Behavioral Medicine*, *30*, 177-186. https://doi.org/10.1007/s10865-007-9095-6

[7]. Miller, J. R., Altaras, C., Vissicchio, N. A., Zemon, V., Portnoy, J. G., Gromisch, E. S., Sloan, J., Tyry, T., & Foley, F. W. (2020). The influence of trait mindfulness on depression in multiple sclerosis: potential implications for treatment. *Quality of Life Research*, *29*, 3243-3250. https://doi.org/10.1007/s11136-020-02567-6

[8]. Tingey, J. L., Valentine, T. R., Kratz, A. L., Bentley, J. A., Ehde, D. M., & Alschuler, K. N. (2023). Self-efficacy trajectories of individuals newly diagnosed with multiple sclerosis. *Rehabilitation Psychology*. https://doi.org/10.1037/rep0000487

[9]. Dehghan, M., Sharifi, P., Hasani, J., Young, C. A., & Langdon, D. (2023). Healthier living with MS: The key role of self-efficacy and emotion regulation. *Multiple Sclerosis and Related Disorders*, 73, 104608. https://doi.org/10.1016/j.msard.2023.104608

[10]. Hazhir, F., Ahadi, H., Pourshahbaz, A., & Rezaei, M. (2012). The effectiveness of cognitive-behavior therapy on illness representations of multiple-sclerosis and improving their emotional states. *Journal of Kermanshah University of Medical Sciences*, 15(6).

[11]. Bebo, B., Cintina, I., LaRocca, N., Ritter, L., Talente, B., Hartung, D., ... & Yang, G. (2022). The economic burden of multiple sclerosis in the United States: estimate of direct and indirect costs. *Neurology*, 98(18), e1810-e1817. https://doi.org/10.1212/WNL.0000000000200150

[12]. Simpson-Yap, N., Probst, Y., Reece, J.C., Jelinek, G.A., & Neate, S. (2022). Prospective associations of better quality of the diet with improved quality of life over 7.5 years in people with multiple sclerosis. *Multiple Sclerosis and Related Disorders, 60,* 103710. https://doi.org/10.1016/j.msard.2022.103710

[13]. Wills, O. C., & Probst, Y. C. (2022). Understanding lifestyle self-management regimens that improve the life quality of people living with multiple sclerosis: a systematic review and meta-analysis. *Health and Quality of Life Outcomes*, 20(1), 1-28. https://doi.org/10.1186/s12955-022-02046-1

[14]. Kidd, T., Carey, N., Mold, F., Westwood, S., Miklaucich, M., Konstantara, E., ... & Cooke, D. (2017). A systematic review of the effectiveness of self-management interventions in people with multiple sclerosis at improving depression, anxiety and quality of life. *PloS One*, 12(10), e0185931. https://doi.org/10.1371/journal.pone.0185931

[15]. Leventhal, H. (1980). Toward a comprehensive theory of emotion. In *Advances in experimental social psychology* (Vol. 13, pp. 139-207). Academic Press. https://doi.org/10.1016/S0065-2601(08)60132-X

[16]. Leventhal, H., Phillips, L. A., & Burns, E. (2016). The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management. *Journal of Behavioral Medicine*, *39*, 935-946. https://doi.org/10.1007/s10865-016-9782-2

[17]. Lynd, L. D., Henrich, N. J., Hategeka, C., Marra, C. A., Mittmann, N., Evans, C., & Traboulsee, A. L. (2018). Perspectives of patients with multiple sclerosis on drug treatment: a qualitative study. *International Journal of MS Care,* 20(6), 269-277. https://doi.org/10.7224/1537-2073.2017-109

[18]. Henschke, A., Desborough, J., Parkinson, A., Brunoro, C., Fanning, V., Lueck, C., ... & Cook, M. (2021). Personalizing medicine and technologies to address the experiences and needs of people with multiple sclerosis. *Journal of Personalized Medicine*, *11*(8), 791. https://doi.org/10.3390/jpm11080791

[19]. Reece, J. C., Yu, M., Bevens, W., Simpson-Yap, S., Jelinek, G., Jelinek, P., ... & Neate, S. (2023). Study protocol for an online lifestyle modification education course for people living with multiple sclerosis: the multiple sclerosis online course (MSOC). *BMC Neurology*, 23(1), 1-15. https://doi.org/10.1186/s12883-023-03298-0

[20]. Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care,* *19*(6), 349-357.

https://doi.org/10.1093/intqhc/mzm042

[21]. Kazak, A. E. (2018). Editorial: Journal article reporting standards. American Psychologist, 73(1), 1–2. https://doi.org/10.1037/amp0000263

[22]. Jelinek, G., Neate, S., & O'donoghue, M. (2022). *Overcoming Multiple Sclerosis Handbook: Roadmap to Good Health*. Atlantic Books.

[23]. Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, *67*(6), 361-370. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x

[24]. Dahl, O. P., Stordal, E., Lydersen, S., & Midgard, R. (2009). Anxiety and depression in multiple sclerosis. A comparative population-based study in Nord-Trøndelag County, Norway. *Multiple Sclerosis Journal*, *15*(12), 1495-1501. https://doi.org/10.1177/1352458509351542

[25]. Janssens, A. C., Buljevac, D., van Doorn, P. V., van der Meché, F. G., Polman, C. H., Passchier, J., & Hintzen, R. Q. (2006). Prediction of anxiety and distress following diagnosis of multiple sclerosis: a two-year longitudinal study. *Multiple Sclerosis Journal*, *12*(6), 794-801. https://doi.org/10.1177/1352458506070935

[26]. Honarmand, K., & Feinstein, A. (2009). Validation of the Hospital Anxiety and Depression Scale for use with multiple sclerosis patients. *Multiple Sclerosis Journal*, *15*(12), 1518-1524. https://doi.org/10.1177/1352458509347150

[27]. Hohol, M. J., Orav, E. J., & Weiner, H. L. (1995). Disease steps in multiple sclerosis: a simple approach to evaluate disease progression. *Neurology*, *45*(2), 251-255. https://doi.org/10.1212/WNL.45.2.251

[28]. Marrie, R., McFadyen, C., Yaeger, L., & Salter, A. (2023). A systematic review of the validity and reliability of the patient-determined disease steps scale. *International Journal of MS Care*, *25*(1), 20-25. https://doi.org/10.7224/1537-2073.2021-102

[29]. Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. https://doi.org/10.1191/1478088706qp063oa

[30]. Bevens, W., Davenport, R., Neate, S., Yu, M., Jelinek, P., Jelinek, G. A., & Reece, J. (2024). Web-Based Health Information Seeking by People Living With Multiple Sclerosis: Qualitative Investigation of the Multiple Sclerosis Online Course. *Journal of Medical Internet Research*, *26*, e53372. https://doi.org/10.2196/53372

[31]. Rigby, S. A., Domenech, C., Thornton, E. W., Tedman, S., & Young, C. A. (2003). Development and validation of a self-efficacy measure for people with multiple sclerosis: the Multiple Sclerosis Self-efficacy Scale. *Multiple Sclerosis Journal*, 9(1), 73-81. https://

doi.org/10.1191/1352458503ms870oa

[32]. Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: a new method for assessing the cognitive representation of illness. *Psychology and Health*, 11(3), 431-445. https://doi.org/10.1080/08870449608400270

[33]. Prochaska, J. O., & Velicer, W. F. (1997). The transtheoretical model of health behavior change. *American journal of health promotion*, *12*(1), 38-48. https://doi.org/10.4278/0890-1171-12.1.38

[34]. Garabedian, M., Perrone, E., Pileggi, C., & Zimmerman, V. (2020). Support group participation: effect on perceptions of patients with newly diagnosed multiple sclerosis. *International Journal of MS Care,* 22(3), 115-121. https://doi.org/10.1371/journal.pone.0185931

[35]. Neate, S. L., Bevens, W., Jelinek, P. L., Gray, K. M., Weiland, T. J., Nag, N., ... & Reece, J. C. (2022). A multiple sclerosis lifestyle behavior online course: Qualitative analysis of participants' motivations, expectations and experiences. *Frontiers in Public Health*, 10, 1022185. https://doi.org/10.3389/fpubh.2022.1022185

[36]. Brown, R. F., Valpiani, E. M., Tennant, C. C., Dunn, S. M., Sharrock, M., Hodgkinson, S., & Pollard, J. D. (2009). Longitudinal assessment of anxiety, depression, and fatigue in people with multiple sclerosis. *Psychology and Psychotherapy: Theory, Research and Practice*, *82*(1), 41-56. https://doi.org/10.1348/147608308X345614

[37]. Jopson, N. M., & Moss-Morris, R. (2003). The role of illness severity and illness representations in adjusting to multiple sclerosis. *Journal of psychosomatic research*, *54*(6), 503-511

[38]. Dennison, L., Moss-Morris, R., Silber, E., Galea, I., & Chalder, T. (2010). Cognitive and behavioural correlates of different domains of psychological adjustment in early-stage multiple sclerosis. *Journal of Psychosomatic Research*, 69(4), 353-361. https://doi.org/10.1016/j.jpsychores.2010.04.009

[39]. Schreurs, K. M., de Ridder, D. T., & Bensing, J. M. (2002). Fatigue in multiple sclerosis: reciprocal relationships with physical disabilities and depression. *Journal of Psychosomatic Research*, 53(3), 775-781. https://doi.org/10.1016/S0022-3999(02)00326-4

[40]. Solaro, C., Gamberini, G., & Masuccio, F. G. (2018). Depression in multiple sclerosis: epidemiology, aetiology, diagnosis and treatment. *CNS Drugs*, 32(2), 117-133. https://doi.org/10.1007/s40263-018-0489-5

[41]. Neate, S. L., Donald, A., Jelinek, G. A., & Nag, N. (2022). Experiences of and attitudes to

lifestyle modification for the management of multiple sclerosis: A qualitative analysis of free-text survey data. *Health Expectations*, 25(1), 214-222. https://doi.org/10.1111/hex.13364

[42]. Desborough, J., Brunoro, C., Parkinson, A., Chisholm, K., Elisha, M., Drew, J., ... & Phillips, C. (2020). ‘It struck at the heart of who I thought I was’: A meta-synthesis of the qualitative literature examining the experiences of people with multiple sclerosis. *Health Expectations*, *23*(5), 1007-1027. https://doi.org/10.1111/hex.13093

[43]. Antonovsky, A., 1987. Unraveling the mystery of health: How people manage stress and stay well. *San Francisco*, *175*.

[44]. Broersma, F., Oeseburg, B., Dijkstra, J., & Wynia, K. (2018). The impact of self-perceived limitations, stigma and sense of coherence on quality of life in multiple sclerosis patients: results of a cross-sectional study. *Clinical Rehabilitation*, *32*(4), 536-545. https://doi.org/10.1177/0269215517730670

[45]. Calandri, E., Graziano, F., Borghi, M., & Bonino, S. (2017). Coping strategies and adjustment to multiple sclerosis among recently diagnosed patients: the mediating role of sense of coherence. *Clinical Rehabilitation*, *31*(10), 1386-1395. https://doi.org/10.1177/0269215517695374

[46]. Bonsaksen, T., Lerdal, A., & Fagermoen, M. S. (2015). Trajectories of illness perceptions in persons with chronic illness: An explorative longitudinal study. *Journal of Health Psychology*, *20*(7), 942-953. https://doi.org/10.1177/1359105313504235

[47]. Kroencke, D. C., Denney, D. R., & Lynch, S. G. (2001). Depression during exacerbations in multiple sclerosis: the importance of uncertainty. *Multiple Sclerosis Journal*, *7*(4), 237-242. https://doi.org/10.1177/135245850100700405

[48]. Lynch, S. G., Kroencke, D. C., & Denney, D. R. (2001). The relationship between disability and depression in multiple sclerosis: the role of uncertainty, coping, and hope. *Multiple Sclerosis Journal*, *7*(6), 411-416.

[49]. Dempster, M., Howell, D., & McCorry, N. K. (2015). Illness perceptions and coping in physical health conditions: A meta-analysis. *Journal of Psychosomatic Research*, *79*(6), 506-513. https://doi.org/10.1016/j.jpsychores.2015.10.006

[50]. Schwarzer, R., Lippke, S., & Luszczynska, A. (2011). Mechanisms of health behavior change in persons with chronic illness or disability: the Health Action Process Approach (HAPA). *Rehabilitation Psychology*, *56*(3), 161. https://doi.org/10.1037/a0024509

[51]. Engels, E. S., Nigg, C. R., & Reimers, A. K. (2022). Predictors of physical activity behavior change based on the current stage of change—an analysis of young people from

24

Hawai’i. *Journal of Behavioral Medicine*, 45(1), 38-49. https://doi.org/10.1371/journal.pone.0185931

Table 1. *Self-reported demographic and clinical characteristics of MSOC interventional arm interviewees (n= 22) at baseline.*

Demographics	**n(%)/M(SD)**
Age	48.14 (12.25)
Gender	
Male	3(36.60%)
Female	19(86.40%)
Other	0(0.00%)
Country of residence	
Australia/NZ	5(22.73%)
USA/Canada	5(22.73%)
UK	3(13.64%)
Other	9(40.91%)
Highest educational level	
Post-graduate degree	7(31.82%)
University degree	7(31.82%)
Secondary education	2(9.09%)
Higher education qualification (e.g., certificate, diploma)	6(27.27%)
Employment status	
Currently employed	13(59.09%)
Unemployed	8(36.36%)
Missing	1(4.6%)
Currently in a relationship	
Yes	14(63.60%)
No	8(36.36%)

2

Clinical characteristics	
MS phenotype	
RRMS	18(81.82%)
PPMS	2(9.09%)
SPMS	1(4.55%)
Unsure/other	1(4.54%)
Years since MS diagnosis	5.36(4.30)
Disability level	1.55 (1.82)
Normal/mild (PDDS ≤2)	15(68.18%)
Moderate (PDDS ≥3-5)	6(27.27%)
Severe (PDDS ≥6)	1(4.55%)
DMT use	
Yes	13(59.09%)
No	9(40.91%)
Comorbidities	
Yes	16(72.73%)
No	4(18.18%)
Missing	2 (9.09%)
Anaemia/blood disease	1(4.55%)
Anxiety	4(18.18%)
Back pain	4(18.18%)
Lung disease	2(9.09%)
Other (e.g., high cholesterol)	11(50.00%)
Fatigue levels	4.81 (1.59)
Normal/mild	9 (40.91%)
Clinically-significant (FSS>5)	13(59.09%)

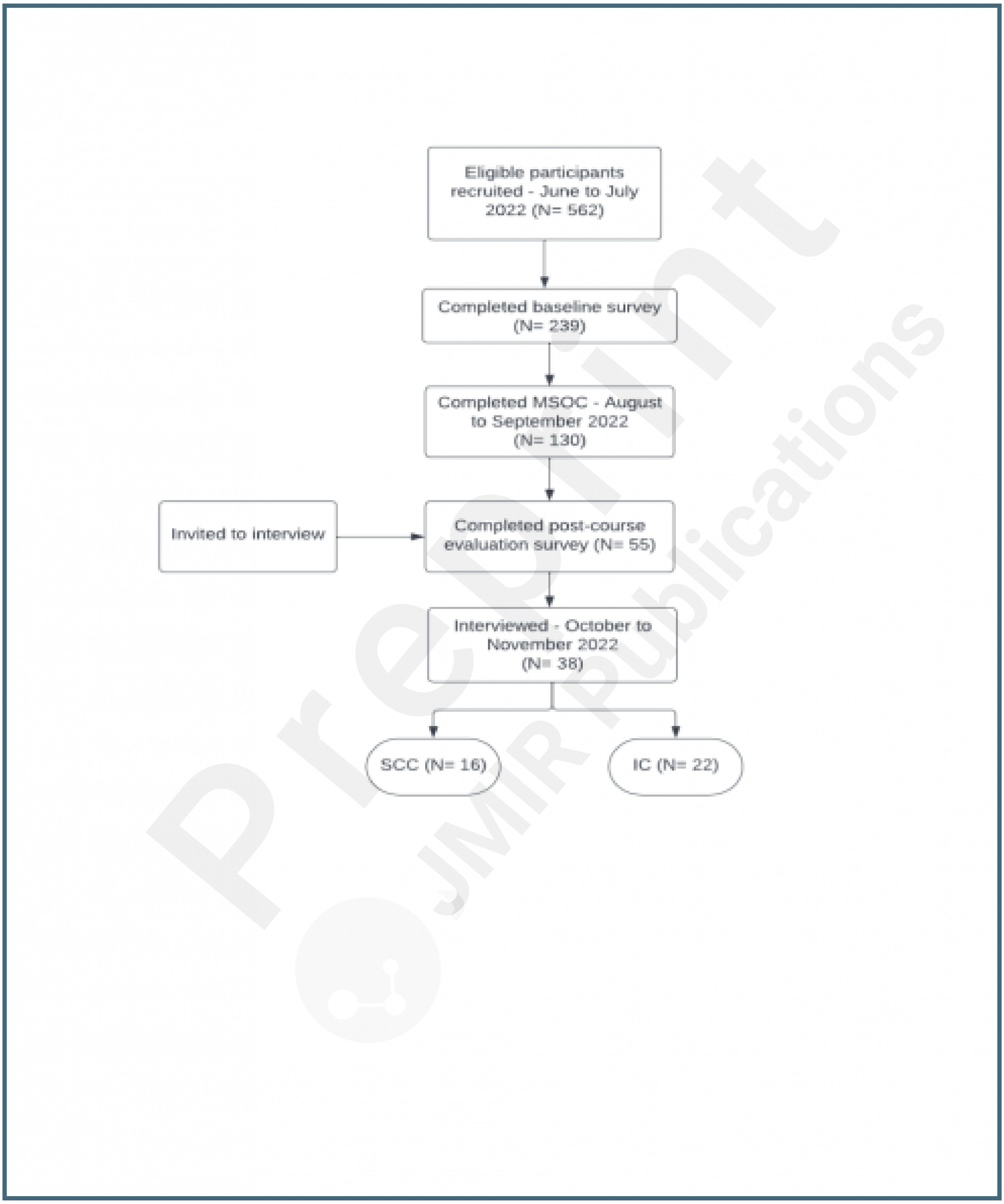
Depressive symptoms	4.91(3.07)
Normal (HADS <8)	19(86.36%)
Mild-moderate (HADS ≥8-10)	1(4.55%)
Clinically significant (HADS ≥11)	2(9.09%)
Anxiety symptoms	7.14(4.61)
Normal (HADS <8)	13(59.09%)
Mild-moderate (HADS ≥8-10)	5(22.73%)
Clinically significant (HADS ≥11)	4(18.18%)

Note. Abbreviations: MS= multiple sclerosis; FSS= fatigue severity scale; HADS= Hospital Anxiety and Depression Scale; MS= multiple sclerosis; RRMS= relapsing-remitting MS; PPMS= primary progressive MS; PDDS= patient-determined disease steps; SPMS= secondary progressive MS; DMT= disease-modifying treatments.

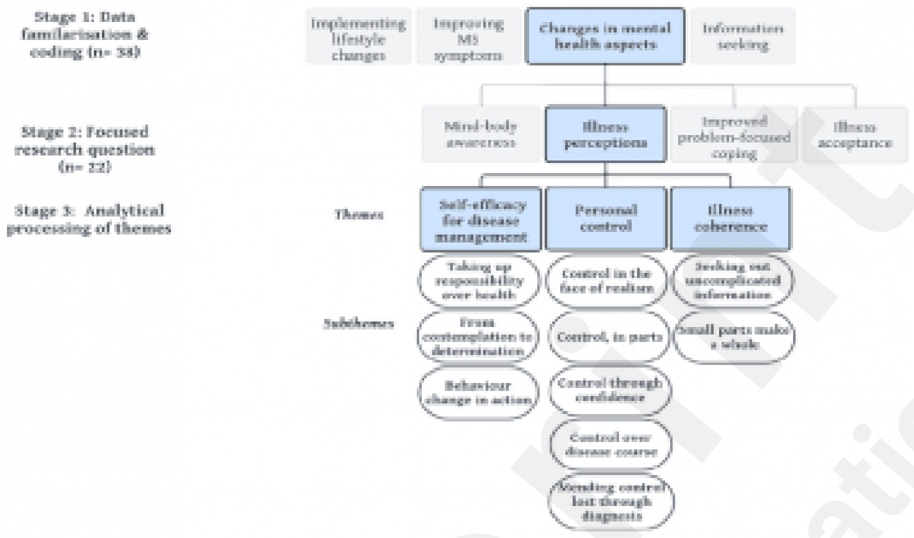
Supplementary Files

Figures

Participant flow diagram. Note. Abbreviations: MSOC= Multiple Sclerosis Online Course; SCC= Standard Care Course; IC= Intervention Course.



Schematic of the qualitative analysis process stages 1-3.



Multimedia Appendixes

Outline of intervention and standard-care course format.
URL: http://asset.jmir.pub/assets/339df20a4a91a2c63104e07e735b9024.docx