A formative evaluation of customized pamphlets to promote physical activity and symptom self-management in women with multiple sclerosis

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Abstract

Inactivity is a prevalent problem in the population affected with multiple sclerosis (MS). Thus, there is a need to develop and test physical activity (PA) interventions that can be widely disseminated. We conducted a formative evaluation as part of a randomized controlled trial of a pamphlet-based PA intervention among 30 women with MS. Pamphlets were customized to sub-sets of participants who shared similar symptoms and barriers to PA. Mixed methods were used to examine the intervention’s influence on self-efficacy, social support, processes of change and stages of change placement, as well as explore participants’ perceived barriers, motivators and strategies for engaging in a PA program. Results indicated that the intervention group significantly improved stages of change placement ($F = 16.64, P < 0.01$) and social support ($F = 4.08, P = 0.05$) in comparison to the control group. Fatigue, pain and lack of time were the commonly cited barriers to engage in the PA program; whereas the pamphlets, phone calls and action planning were cited as motivators. Participants used fatigue management strategies, enlisted social support and modified their environment to routinely engage in the PA program. Strategies were identified to improve the PA intervention in future research.

Inactivity is a pervasive problem in populations with disabling conditions [1], and it can result in the development of secondary conditions that may accelerate declines in quality of life [2]. Adults with disabling conditions often face unique barriers to routine physical activity (PA) engagement and typically receive limited support to overcome these barriers. For example, physicians usually do not have the time to counsel their patients on how to overcome barriers to routinely engage in PA, and community-based PA programs are often inaccessible to adults with disabilities [3, 4]. Targeted PA interventions, which can be widely disseminated and address the diverse health problems that create PA barriers, need to be developed and tested. Such PA interventions could reduce the prevalence of preventable functional declines and improve quality of life in the population with disabling conditions.

The premise of targeted and tailored interventions is to create a customized educational content that is more relevant to a sub-set of individuals (targeted) and/or a specific individual (tailored) [5]. Customized educational content might be more likely to be thought about and therefore acted upon [6]. Research indicates that tailored interventions are effective, and in some cases, they are more effective than non-tailored interventions in promoting behavior change in the general population [7, 8]. There might be additional benefits in developing targeted and tailored interventions for adults with disabling conditions because of the heterogeneity
in how health problems interact with psychosocial cognitions. Furthermore, targeted and tailored interventions are conducive to distance learning delivery formats, which can help reduce common barriers (e.g. transportation and cost) associated with face-to-face interventions among adults with disabling conditions.

Marcus et al. developed a tailored distance learning intervention that is effective in promoting PA among sedentary healthy adults [9–11]. The intervention is based on Social Cognitive Theory [12] and Transtheoretical Model [13]. For example, the Social Cognitive Theory provided guidance on increasing self-efficacy, such as using verbal persuasion and addressing feelings associated with the physiological response of exercise, whereas the Transtheoretical Model provided guidance on customizing the intervention. The Transtheoretical Model delineates people into one of five stages of readiness to change behavior (i.e. pre-contemplation, contemplation, preparation, action and maintenance) so that messages can be customized to particular stages of change. For example, people in early stages received print material that targets self-efficacy and cognitive processes of change (e.g. increasing knowledge) to promote PA [14].

We hypothesized that showing people how to engage in a standardized home exercise program and following up with targeted print material adapted from Marcus et al. [9–11] would increase PA levels and subsequently improve health and function in adults with multiple sclerosis (MS). MS was selected as the disease model because it is the most common progressive neurological condition among young adults, yet life expectancy is similar to the general population [15]. Thus, it is important for people with MS to develop life-long habits to engage in PA to help prevent secondary conditions and functional declines. Furthermore, addressing the wide range of MS impairments (e.g. fatigue, cognitive deficits and mobility problems) that act as PA barriers could facilitate adaptation of intervention for different disabling conditions in future research.

A previous report, which described a pilot randomized controlled trial (RCT) of 30 women with MS, indicated that the targeted print-based intervention can significantly improve PA and physical function compared to a delay treatment contact-control group [16]. This report describes a formative evaluation of the print-based intervention used in the pilot RCT. A formative evaluation focuses on ‘the internal dynamics and actual operations of a program in order to understand its strength and weaknesses’ [17]. Such an evaluation is consistent with recommendations to explore the black box of implementing a complex intervention [18, 19]. Specifically, we used mixed methods to (i) examine the potential of the intervention to improve psychosocial constructs and stages of change placement, (ii) describe participants’ perceived motivators, barriers and strategies for engaging in an exercise program and (iii) identify strategies to better target and tailor the print-based intervention in future research.

Methods

Research design
A mixed methods randomized controlled pilot study was conducted using a delayed treatment group as the control. Thirty women with a physician-confirmed diagnosis of relapsing-remitting MS were randomized to receive the intervention immediately \((n = 14)\) or after 12 weeks \((n = 16)\). Inclusion–exclusion criteria, sample characteristics and results are summarized in Tables I and II. Self-report questionnaires and a physical assessment were employed immediately before the intervention and at Weeks 12 and 24. Qualitative interviews were conducted at Week 24. Twenty-three participants completed questionnaires and the physical assessment were employed immediately before the intervention and at Weeks 12 and 24. Qualitative interviews were conducted at Week 24. Twenty-three participants completed questionnaires and the physical assessment at Week 24, with one additional participant completing only the qualitative interview over the phone due to transportation difficulties. The Consort diagram is published elsewhere [16]. The Cleveland Clinic Institutional Review Board approved this study.

Intervention

Standardized home exercise program

The intervention consisted of showing participants how to engage in a standardized home exercise
The home exercise program consisted of aerobic, balance and strength training exercises 3–5 days per week. Participants were given a mini-cycle and elastic resistance bands to engage in the program. The first author who is trained and experienced in working with people with MS showed participants how to perform the exercises during two in-person sessions (2 weeks apart). The first session focused on demonstrating the exercises, whereas the second session focused on ensuring that participants were correctly performing the exercises. The goal of the standardized home exercise program was to assist participants in maintaining function and improving fitness levels. The standardized home exercise program is in contrast to a tailored, therapeutic home exercise program that is typically prescribed by a physical therapist and focuses on having patients engage in particular exercises with the goal of improving underlying impairments.

Overview of targeted pamphlets
After the second session, targeted pamphlets were provided to participants. The pamphlets consisted of customized educational content based on participants’ stages of change for PA and barriers to engaging in PA. The pamphlets were distributed every 3 weeks, and alternated between stage-matched PA pamphlets, barrier-matched self-management pamphlets, and tip sheets (i.e. practical advice on how to exercise). The goal of the stage-matched PA pamphlets was to promote exercise adherence and increase overall PA levels, whereas the goal of barrier-matched self-management pamphlets was to help participants overcome their specified barriers for engaging in PA. A certified health and fitness instructor who is trained in exercise promotion for special populations called up the participants in the immediate and delayed group every 3 weeks. During these phone calls, participants were asked questions about their PA habits and barriers to

<table>
<thead>
<tr>
<th>Table I. Summary of research design and primary outcomes for health and function and physical activity levels</th>
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<tbody>
<tr>
<td>Research design</td>
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<tr>
<td>Recruitment efforts</td>
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</table>
| Inclusion criteria | 1. Physician-confirmed diagnosis of relapsing-remitting MS  
2. Aged 18–65 years  
3. Ability to walk 25 feet with or without a cane |
| Exclusion criteria | 1. Exercising ≥150 min per week  
2. Pregnancy  
3. Cardiopulmonary disease  
4. ≥4 falls in the past 6 months  
5. Severe cognitive deficits  
6. Unable to read at a 6th grade level  
7. Co-morbid condition leading to hospitalization in the past year |
| Participant numbers and retention | Assessed for eligibility (n = 78)  
Randomized (n = 30)  
Received pamphlet-based intervention (n = 28)  
Completed questionnaires and physical assessments at Week 24 (n = 23)  
Completed qualitative interviews at Week 24 (n = 24) |
| Main results | 1. Between groups: The intervention group significantly improved physical activity levels and symptom severity in comparison to participants in the delayed group.  
2. Maintenance: Participants in the immediate group who continued to receive phone calls and pamphlets maintained their physical activity levels and improvements in symptom severity 12 weeks after their post-test assessment. |
determine which pamphlets would be given and also ensure that participants in both the groups received the same number of contacts with research staff. Table III summarizes the behavior change strategies implemented in the intervention using the Coventry, Aberdeen & London - refined (CALO-RE) taxonomy [20].

**PA pamphlets**

The stage-matched PA pamphlets were adapted from Marcus *et al.* [9–11] with guidance from clinicians, researchers and people with MS. Pamphlets were made more relevant, for example, by including additional information on the possible benefits of PA specific to MS and by providing examples of using problem-solving strategies to overcome MS-related PA barriers. The Stages of Change questionnaire was employed to determine which PA pamphlets were provided [9]. Participants responded to four yes/no questions that were used in a scoring algorithm to delineate participants into one of five stages of change for PA behavior. Depending on the participants’ stages of change, one of five PA pamphlets was provided to them.

**Self-management pamphlets**

Participants were also given pamphlets on how to self-manage symptoms and other barriers not necessarily specific to their MS (e.g. time management skills). Most of these pamphlets were publically available from the National MS Society. A modified version of the validated Symptoms of Multiple Sclerosis Scale [21] was used to determine which pamphlets were given to the participants. The original version of the questionnaire measured the extent to which individuals experienced common MS symptoms, such as fatigue and pain. We modified questions to ask the extent to which individuals experienced each symptom as a barrier to PA. We also asked participants to list and rate the extent of any other barriers they were experiencing. Participants’ rating of their most problematic barrier was used to determine the topic of the pamphlet (e.g. fatigue, pain or time management) that was provided. Participants were then asked to select a self-management strategy from their pamphlet and to complete an action plan worksheet (i.e. setting realistic goals, assessing confidence and anticipating barriers) [22]. The modified Symptoms of Multiple Sclerosis Scale guided the selection of pamphlets and was used for descriptive purposes (i.e. it was not used as an outcome measure in the quantitative analysis described further).

**Outcome measures**

*Stages of change*

In addition to using the Stages of Change questionnaire [23, 24] to determine which PA pamphlets participants received, this questionnaire was also used to examine the influence of the intervention on advancing stages of change placement. A score ranging from 1 to 5, with 1 indicating the pre-contemplation stage and 5 indicating the maintenance stage, was used in the analysis. In a previous sample of 165 adults with MS, test–retest reliability ($\hat{K} = 0.61$, $P < 0.001$; Spearman’s $\rho = 0.72$, $P < 0.001$), concurrent validity with the Godin...
Leisure-Time Exercise Questionnaire (Spearman’s rho = 0.71, P < 0.001) and predictive validity with Transtheoretical model constructs (e.g. process of change and self-efficacy) were deemed to be adequate [25].

**Self-efficacy**

Self-efficacy was evaluated using a scale developed by Marcus et al. [24, 26]. Participants rated how confident they were on a scale of 1 (‘not at all confident’) to 5 (‘extremely confident’) that they could engage in PA when experiencing five common PA barriers (e.g. bad weather). To increase the scale’s relevance for MS, we asked an additional question concerning how confident they were in their ability to engage in PA without making their MS symptoms worse. Responses to the six questions were averaged (score range 1–5). A higher score indicates increased confidence to overcome barriers to engage in PA. Internal consistency (α = 0.84) and predictive validity with stages of change placement were established in a previous sample of 165 adults with MS [25]. Test–retest reliability over a 12-week period for participants in the delayed group was adequate (t[14] = 0.12, P = 0.92; r = 0.76, P < 0.001).

**Processes of change**

Behavioral and cognitive processes of change were evaluated using a 40-item scale [23]. The scale was divided into two subscales: behavioral processes (e.g. enlisting social support and using reminders) and cognitive processes (e.g. increasing knowledge and comprehending benefits). Participants responded to the questions on a scale of 1 (never) to 5 (repeatedly). Responses that corresponded to each of the two subscales were averaged. A higher score indicates more frequent use of processes of change to engage in PA (score range 1–5). Internal consistency (α = 0.92), test–retest reliability (Behavior: t[164] = −0.75, P = 0.46; r = 0.79, P < 0.001; Cognitive: t[164] = −0.11, P = 0.91; r = 0.77, P < 0.001) and predictive validity with stages of change placement were deemed adequate in a previous sample of 165 adults with MS [25].

**Social support**

The Social Support for Physical Activity Scale was also administered [27]. This questionnaire generates two subscales that measure the amount of social support offered from family and friends to exercise. Questions included how often family or friends...
made positive comments about physical appearance and took over chores to enable exercise. Two mean scores were calculated: one for friends and another for family. A higher score indicates greater social support to engage in PA (score range 0–5). Internal consistency ($\alpha = 0.94$), test–retest reliability for family ($r = 0.67$, $P < 0.01$) and friends ($r = 0.86$, $P < 0.01$) and predictive validity with PA levels were deemed adequate in a previous sample of 38 adults with MS [28].

**Self-management self-efficacy**

The Self-Efficacy for Managing Chronic Disease [29] was used to measure confidence in self-managing symptoms and emotions to engage in activities as desired. A 10-point scale ranging from ‘not confident at all’ to ‘completely confident’ is used to rate questions. A higher score indicates increased confidence to self-manage stress and symptoms to engage in activities as desired. Internal consistency ($\alpha = 0.87$) and test–retest reliability were deemed adequate in a previous sample of 165 adults with MS ($t[163] = -0.12$, $P = 0.91$; $r = 0.78$, $P < 0.01$).

**Qualitative interviews**

During the follow-up assessment, we conducted semi-structured interviews to examine attitudes toward the pamphlets and home exercise program. Interviews were conducted by trained research assistants who were not involved in delivering the intervention. All interviews were tape-recorded and transcribed verbatim. We first asked participants to discuss their experience in the study and their attitudes toward the intervention. For example, we asked what they liked and disliked about the pamphlets and what they would do to improve them. We also asked about their experience with home exercise program, specifically the facilitators and barriers for engaging in it.

**Quantitative analysis**

We first calculated descriptive statistics and summary scores for each questionnaire. We then determined whether there were any significant differences between groups at pre-test. To examine the influence of the interventions on psychosocial constructs and stages of change placement, we conducted an intent-to-treat analysis. The last observation carried forward was used to impute missing data. To determine whether there were significant differences between groups at post-test, we used a one-way MANOVA subtracting week 1 scores from week 12 scores (between groups: immediate, $n = 14$ versus delayed, $n = 16$). To determine whether there were significant improvements across time, we employed repeated-measures MANOVA using weeks 1 and 12 data for the immediate group and using weeks 12 and 24 data for the delayed group ($n = 30$; within groups: baseline versus 12-week post-intervention).

**Qualitative analysis**

We used an issue-focused analysis approach, which is a method for analyzing data pertaining to a specific topic [30]. Specifically, we wanted to identify strategies to tailor the intervention and determine perceived exercise barriers and facilitators. Data were first organized by each question in the interview guide. We then reviewed responses for each question to identify overarching data categories and sub-categories. To help ensure the trustworthiness of the qualitative analysis, categories were identified through discussion and consensus. The first and third authors coded data independently into categories. Disagreements were discussed until consensus was reached. Categories and sub-categories were revised as necessary to help facilitate a coherent and accurate description of the qualitative data.

**Results**

**Quantitative results**

Table IV describes participants’ barriers for engaging in the prescribed exercise program and self-management goals for overcoming barriers. There were no significant differences between the groups at pre-test. The one-way MANOVA indicated significant differences in change scores between the immediate group and the delayed group (Wilks’ $\lambda = 0.49$, $F_{7,22} = 3.33$, $P = 0.014$). Between-subject
Contrasts (immediate: \( n = 14 \) versus delayed: \( n = 16 \)) indicated that participants who received the intervention significantly improved their stages of change placement \( (F = 16.64, P < 0.001) \) and social support received from family members \( (F = 4.08, P = 0.053) \) in comparison to participants in the delayed group. Similar results were obtained when data were not imputed, i.e. significant improvements in stages of change placement \( (t = 4.03, P < 0.001) \) and social support from family \( (t = 2.12, P = 0.04) \). The repeated-measures MANOVA \( (n = 30) \) indicated significant differences across time \( (\text{Wilks’ } \lambda = 0.37, F_{7,23} = 5.54, P = 0.001) \). Within-subject contrasts indicated that participants significantly improved stages of change \( (F = 20.16, P < 0.001) \) and behavioral processes of change \( (F = 9.07, P = 0.005) \) from immediately before the intervention compared to 12 weeks after receiving the intervention (Table V).

**Qualitative results**

**Cognitive motivators**

Table VI summarizes the categories and sub-categories generated through the qualitative data. Learning about the benefits of exercise, learning and planning how to exercise with MS symptoms, and re-framing thoughts about exercise were frequently described as motivational to engage in PA. Several participants noted that learning how to exercise while coping with MS symptoms was a necessary step to regular engagement. Participant 4 said, “My problem is the fatigue. That’s what was holding me back before. […] So I overdo it. This is showing me, teaching me to slow it down and increase it just a little.”

Planning ahead, setting goals and thinking about when and how to engage in exercise were described as helpful strategies as well. Participants would reflect on the relevance of the information and how to incorporate it into their personal situation. Participants noticed that they thought about exercise and PA differently after reading the pamphlets. Participant 2 described re-framing their thoughts on what constituted PA, “[the pamphlets] gave you ideas on other things that you could do around the house, [such as] walking, and gardening […] it would really help if I think of these as an exercise, an activity that’s helping me in another way. Then I’d be more inclined to do it and more often.”

**Behavioral motivators**

When participants were asked what helped motivate them to engage in the program, many recalled specific behavioral strategies they learned about in the pamphlets. Participants described using reminders, self-monitoring and committing themselves to following guidelines. Participants used many different types of reminders (e.g. receiving the print material, Post-its, and exercise equipment) and self-monitoring methods (e.g. calendar on the refrigerator, cell phone applications and study diary).

Following recommended exercise guidelines (e.g. starting off slowly and trying to exercise for 5 min even when fatigued) facilitated regular exercise
engagement. Participant 5 said, “I didn’t know this, after 18 years I didn’t know this, that with the exercises you try it for five minutes and then if it doesn’t work you’re done, but a lot of times it works and I continued to exercise instead of give up.” Participant 6 discussed how following the recommendation to start off slowly helped, “Um, but because this program started out really slow like just putting a, a bike on my floor at home and just pedaling [it] got me thinking, okay, I can do this.” Participant 3 described how the specific exercise instructions were helpful, “Cause when you’re just setting it up doing it on your own you’re like, hm, am I doing enough? Should I be doing more? [...] And so your pamphlets give the basics and then, you know, how to go next and so I like that.”

**Cognitive–behavioral motivators**

Several participants described using a trial-and-error process to engage in exercise. Participants reflected on their past successes and failures to engage in exercise and then described how they re-adjusted their action plan. Participant 8 said, “Even when it got harder, then I had to make a different plan because I, I was like okay, this isn’t working because if I wait to do this at this time of day when I don’t walk really well, this doesn’t work for me.” Participant 13 said, “So it was kind of a work in progress and I think [...] well I’m going to try this, didn’t seem to work. Try something else until you get to something that does work.”

**Social motivators**

Social motivators involved creating accountability through phone calls, encouraging communication and social support, and comparing themselves to others in similar situations. Participants stated that sharing their action plan over the phone helped. Participant 11 said, “I would say the accountability came from having an action plan and having someone I needed to report it to.” Some noted that the only reason they read the pamphlets was because they knew they would be receiving a phone call.

Encouraging communication and social support from friends, family and physicians were described as a motivator. Participant 10 described using a trial-and-error process to develop an effective action plan that utilized the support of family members:

I had tried a few of them. The first one I did was to try to schedule like on my calendar to exercise and again it was like, you know, life happens. [...] The next one was to try to have a partner to just sort of check in with and say hey this is what I’m doing [...] And the last action plan that was the most successful was engaging my family in it.

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**Table V. Means and standard deviations of psychosocial construct measures between (immediate versus delayed) and within groups (pre-test versus post-test across groups over a 12-week period)**

<table>
<thead>
<tr>
<th>Psychosocial measure</th>
<th>Between-subject effects</th>
<th>Within-subject effects</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>Immediate group (n = 14)</td>
<td>Delayed group (n = 16)</td>
</tr>
<tr>
<td></td>
<td>ΔM (SD)</td>
<td>ΔM (SD)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stages of change</td>
<td>1.00 (0.88)*</td>
<td>−0.38 (0.96)</td>
</tr>
<tr>
<td>Self-management self-efficacy</td>
<td>−0.27 (1.59)</td>
<td>−0.18 (1.34)</td>
</tr>
<tr>
<td>Physical activity self-efficacy</td>
<td>−0.10 (0.45)</td>
<td>−0.02 (0.79)</td>
</tr>
<tr>
<td>Cognitive processes of change</td>
<td>−0.08 (0.38)</td>
<td>0.02 (0.38)</td>
</tr>
<tr>
<td>Behavioral processes of change</td>
<td>0.14 (0.52)</td>
<td>−0.05 (0.53)</td>
</tr>
<tr>
<td>Social support from friends</td>
<td>−0.07 (0.67)</td>
<td>−0.43 (1.15)</td>
</tr>
<tr>
<td>Social support for family</td>
<td>0.03 (0.55)*</td>
<td>−0.48 (0.80)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2.30 (0.79)</td>
<td>3.07 (0.98)**</td>
</tr>
<tr>
<td></td>
<td>7.55 (1.65)</td>
<td>7.18 (1.85)</td>
</tr>
<tr>
<td></td>
<td>2.80 (0.70)</td>
<td>2.87 (0.77)</td>
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<td></td>
<td>3.28 (0.66)</td>
<td>3.30 (0.65)</td>
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<tr>
<td></td>
<td>2.91 (0.68)</td>
<td>3.22 (0.66)**</td>
</tr>
<tr>
<td></td>
<td>1.54 (0.95)</td>
<td>1.89 (1.17)</td>
</tr>
<tr>
<td></td>
<td>1.27 (0.98)</td>
<td>1.42 (0.95)</td>
</tr>
</tbody>
</table>

For all psychosocial measures, higher scores indicate greater improvement; ΔM = mean change scores (Week 12 minus Week 1); *Between-subjects test: significantly different from delayed group (P < 0.05); **Within-subjects test: significantly different from pre-test (P < 0.05).
One participant described how encouraging communication with their neurologist helped facilitate exercising:

It’s only been 18 months. So I probably would have thought, well, this is my life. No exercise for me ever again. So having him to call and suggest to call my neurologist helped me a lot, too. And I know that sounds weird, like why wouldn’t you have just called your neurologist to begin with? I didn’t want them to be like, oh, it’s just spasticity, deal with it.

Participants discussed how they compared themselves to other people, which sometimes motivated them to engage in exercise. Some said they related to the people in the pamphlet who were experiencing similar barriers. Participants compared themselves...
to individuals who used a wheelchair and hoped that exercise would help delay having to use a wheelchair, while others were inspired by the fact that the person who used a wheelchair led an active lifestyle.

**Qualitative results: barriers**

**Social environmental barriers**

Social obligations and comparisons, not enough time in the day, and being unable to prioritize exercise were cited as barriers to exercising. Having to take care of a loved one, working all day and not having the energy to exercise in the evening, or not being able to get into a routine were commonly cited barriers. Participant 18 stated, “The biggest one I think for me is, is finding the time.” Participant 20 said, “Just, uh, putting it off [exercise] and then getting out of a routine that’s sometimes difficult to get back into.” Two participants noted that they knew other people with MS who had been very physically active yet experienced exacerbations and increased symptoms. Thus, they questioned whether it was worth the extra effort to prioritize engagement in exercise.

**Health problems and impairment barriers**

Fatigue, pain, bladder problems and mobility impairments were all cited as barriers to exercising. Fatigue was cited as the most common barrier to the exercise program. Some participants exercised in the morning because they had the most energy then, whereas other participants did not exercise in the morning because they were then fatigued for the remainder of the day. Participant 17 said, “A lot of fatigue and finding time to do stuff. Because I have a physically demanding job, it’s hard to – I don’t want to exercise before I go to work because then I’m tired and exhausted by the time I get to work.”

**Qualitative results: attitudes toward the intervention**

**Pamphlet likes**

Most participants thought the pamphlets were informative, easy to understand, aesthetically pleasing and motivating. Participant 19 said, “Yes, I would read that and then be like okay time to go and make sure I do my 30 minutes on the treadmill.” Participant 23 said, “I thought the little character was cute. It was nice to, to have […] extra visual stimuli on each page so you knew basically when you’re looking at something. When I was reading something I could, since I’m a very visual person, I could kind of keep track of what page I was on.” Participant 22 said, “A lot of times with MS you don’t feel like it […] So, I think, like, the pamphlets made me realize that even though I couldn’t do it, I wasn’t a failure. I just needed to find a different way to do it.”

**Pamphlet dislikes**

However, some participants disagreed with the utility of the pamphlets. Some felt the reading material was not all that helpful and felt the reading material was too long. Participant 17 said, “Reading about it is not going to jump-start me.” Participant 20 said, “I didn’t really like the length of them because I have a lot of problems with concentration and memory.” Participant 5 said, “Some of them were good and some of them were pretty basic, but I’ve had MS for 18 years.”

Others found the lay-out to be distracting or wanted the pamphlets to be more customized to their specific situation. Participant 9 said, “I just got one that was a picture in the middle and then a whole bunch of text boxes around […] and for me that’s really, um, hard to focus on because my brain wants to see everything and I’m really easily distracted by things.” Participant 24 said, “I’m not in a wheelchair nor do I use a cane or a walker. So I don’t even, I never read those parts because to me that wasn’t applicable.”

**Delivery format**

Participants had mixed feelings on the print-based format and the frequency of contact. Some participants looked forward to receiving the pamphlets in the mail and found it acted as useful reminders. However, Participant 3 said, “I would be inclined to read something online or um, a tweet about something, or something on my iPhone where that’s more
my speed.” Participant 11 said, “I disliked [...] the fact that you all didn’t have us coming in as often, um, that the visits weren’t as close together.”

*Exercise program*

The prescribed exercise program also presented barriers for participants. Some felt the exercise program was too long, too difficult or just plain boring. Some wanted to exercise in a group, whereas others did not like the elastic bands and/or mini-cycle. A few participants noted that they could not do a particular exercise, which in turn led to frustration. Participant 16 noted that ‘the leg exercises’ were especially hard, as she had ‘a lot of trouble with [her] hips’. She further stated that “I found myself not wanting to do it [the exercise program] at all because I didn’t want to do the leg part. Like I felt like I had to do it all or nothing.”

**Discussion**

Our study focused on conducting a formative evaluation to identify strengths and weaknesses of a print-based PA intervention in women with MS. Overall, most participants perceived that the targeted print-based intervention motivated them to exercise. Results suggest that the intervention might be efficacious in advancing participants’ stage of change placement, encouraging social support and increasing the use of behavioral strategies to engage in exercise. However, results also suggest that the intervention could be better tailored to participants’ preferences and specific level of function. The study raises questions about the extent to which participants’ preferences can be accommodated while balancing benefits, costs and study rigor (e.g. treatment fidelity).

**Facilitators**

Participants cited a combination of receiving pamphlets and phone calls, setting goals, and creating an action plan as motivation to engaging in exercise. An unintended facilitator of the intervention was the phone calls. The purpose of these phone calls was to monitor for adverse events and assess PA levels, barriers and action plan goals to determine which pamphlets to mail. However, according to the participants, the phone calls also created accountability to read the pamphlets and engage in exercises. Future research should compare the cost-effectiveness and long-term utility of combining print mailings with phone calls.

Participants described using strategies that are consistent with the Transtheoretical Model [13]. They noted that learning about the benefits of exercise, enlisting social support and committing themselves to the exercise guidelines helped them to engage in exercise, which is consistent with Processes of Change defined in the Transtheoretical Model [14]. Our quantitative results reiterated that participants advanced in their stages of change placement, enlisted social support and increased their use of behavioral processes of change. Nonetheless, our quantitative findings also indicated that participants did not improve exercise self-efficacy. Marcus et al.’s [31] print-based tailored intervention significantly improved exercise self-efficacy in sedentary healthy adults. However, inactive people with MS might overestimate their exercise self-efficacy, which can result in no changes or even declines in self-efficacy once they gain experience with exercising [28, 32].

**Barriers**

Consistent with the literature, we found that MS symptoms and one’s social environment often created many barriers to exercising [33–36]. MS fatigue and not enough time in the day were frequently cited barriers. MS fatigue decreased the ability to engage in exercise and increased concerns that exercise would result in lack of energy for other important activities. However, not having enough time in the day could indicate poor time management skills or that exercise is a low priority. Given the frequency of these two cited barriers, the print-based intervention might need to dedicate more time and resources to address these issues. Fortunately, fatigue management strategies and time management strategies might be complementary to each other. For example, encouraging shorter bouts of exercise.
PA throughout the day and re-evaluating priorities and standards could be both a fatigue and time management strategy [37].

Unfortunately, the intervention also created unintended barriers. In particular, the prescribed exercise program and the amount and type of social support provided were noted as barriers. Some participants wanted more flexibility in the prescribed exercises and some did not like using the mini-cycle and/or elastic resistance bands. Being unable to engage in even one of the exercises would sometimes be used as a rationale to not to engage in any of the exercises. Others wanted to exercise in a group with their peers or wanted more frequent contact with the interventionist. Encouraging interactions between study participants, using web-based technology and/or providing access to role models might help facilitate positive social comparisons that could increase motivation to exercise [38].

**Improving the intervention**

Results indicate three possible areas to improve the print-based PA intervention: (i) tailoring the exercise prescription, (ii) accounting for additional psychosocial constructs to better tailor the print material and (iii) varying the number and type of intervention contacts. According to participants, the exercise program could be better tailored to specific levels of function and preferences. Future implementations of the print-based intervention should explore the utility of having a physical therapist prescribe the exercise program. The therapist will have the expertise to prescribe exercises that improve the underlying impairments and could prescribe the program based on preferences (e.g. walking versus bicycling or a lifestyle-based PA program versus specific exercise regime). Furthermore, the print-based material could be further tailored to psychosocial constructs beyond the stage of change placement, such as self-efficacy and decisional balance, so information is perceived as being more relevant (e.g. adapting the Expert System from Marcus *et al.* [9, 10]).

Future implementation of print-based interventions should also explore whether accommodating preferences in the delivery of information and type and frequency of social support improves adherence. The print-based information could be delivered in a format that the participant most prefers (e.g. mail versus electronic). Options could be available to create peer social support groups for those who desire extra contact and support. The number of intervention contacts could be customized based on a participant’s engagement with the exercise program. For example, if someone is having difficulty engaging in the exercise program, they could receive more frequent intervention contacts.

Indeed, there are numerous possibilities regarding how to better target and tailor the intervention. However, it is unclear from the existing literature the extent to which accommodating differences in patients’ preferences and characteristics results in better exercise adherence. Clinical trials of tailored interventions that prescribe exercises based on preferences and level of function and offer varying levels of social support based on adherence levels are scarce in adults with disabling conditions [39]. Perhaps, this is because of the unknown differential benefits of exercise programs and issues around treatment fidelity. Adaptive clinical trial designs, such as a sequential multiple assignment randomization trial [40], could be used to evaluate tailored interventions with variations in dose, delivery format and timing of contacts.

**Study limitations**

This study was limited by its small sample size and generalizability. The small sample size, the limited inclusion of adults with gait disability and our research sample of only women with relapsing-remitting MS decrease generalizability. Although we felt that we reached data saturation with the qualitative study, such methodology also has limitations in its generalizability. Future studies will need to include a larger and more diverse research sample in terms of gender and functional status. Self-selection bias is also a limitation; specifically, individuals involved in the study might have been more motivated to engage in PA.
Conclusions

Implementing a print-based intervention might be beneficial in promoting exercise adherence and symptom self-management in people living with MS. Given the escalating costs of healthcare, the substantial costs in treating preventable diseases associated with inactivity [41, 42], and the pressures to improve the ‘value’ (i.e. quality and cost) of healthcare interventions, designing low-cost, distance learning PA interventions are areas that require research. Low-cost distance learning interventions that can be implemented within clinical care could be a useful complement to expensive disease-modifying therapies and other skilled services. There is mounting evidence for the benefits of rehabilitation services in patients with MS. However, the carryover of the benefits is usually short lived once rehabilitation services end [43]. Using distance-learning strategies to promote long-term exercise adherence might help prolong the effects of more skilled and expensive rehabilitation interventions.

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Conflict of interest statement

None declared.

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