

Title: A concerns report survey of physical activity support needs of people with moderate-to-severe MS disability and family caregivers.

Running Head: Physical activity support needs of people with MS and family caregivers

Authors: Afolasade Fakolade¹, Amy Latimer-Cheung², Trisha Parsons¹, Marcia Finlayson¹.

Affiliations: ¹Queen's University, School of Rehabilitation Therapy, Louise D. Acton Building, 31 George Street, Kingston, ON, Canada K7L 3N6; ²Queen's University, School of Kinesiology and Health Studies, SKHS Building, 28 Division Street, Kingston, ON Canada K7L 3N6

Corresponding author: Afolasade Fakolade, Queen's University, School of Rehabilitation Therapy, Louise D. Acton Building, 31 George Street, Kingston, ON, Canada K7L 3N6. Tel: +1 613-533-3407
email: a.farotimi@queensu.ca.

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Abstract

Purpose: To identify the most pressing needs for community resources to support physical activity participation, determinants of perceived need, and barriers to co-participation in physical activity among people with multiple sclerosis who have moderate-to-severe disability and the family caregivers providing assistance to such individuals.

Methods: Seventy-eight people with multiple sclerosis and 46 family caregivers participated in this cross-sectional survey study, guided by the Concerns Report Methodology.

Results: The results show differences between groups in rankings for some need items. However, three need items were prioritized by both people with multiple sclerosis and the family caregivers: 1) information about available resources to support physical activity participation, with needs indexes of 76.6% and 52.3% respectively; 2) programs that support joint participation of people with multiple sclerosis together with their caregivers in physical activity, with needs indexes of 62.0% and 68.9% respectively; and 3) programs that have affordable total cost of participation, with needs indexes of 50.7% and 52.3% respectively. A broad range of factors (i.e., education, living situation, type of community, marital status, employment, and income, as well as comorbidity status) was significantly associated with one or more of these need items. Several modifiable impairment-related, personal and logistical factors were identified by both groups as barriers to co-participation in physical activity.

Conclusion: The findings highlight the complexity of developing community resources that target physical activity promotion in multiple sclerosis dyads. Importantly, our findings suggest that resources designed to influence dyadic physical activity participation need to include content that are responsive and tailored to both the needs of the person with multiple sclerosis and the unique needs of the family caregiver. The results also underscore the importance of reinforcing physical activity as a shared behavior and providing information about affordable options for exercising together to the benefit of each individual and the dyad (i.e. partnership). Overall, our findings provide a possible starting point to guide the identification of potential participants that might benefit the most from future intervention development work.

Keywords: Community resources, physical activity, multiple sclerosis, caregiver care-recipient dyads, moderate-to-severe disability

Introduction

Multiple sclerosis (MS) is a chronic progressive neurological condition with a prevalence of 291 per 100,000 people in Canada [1]. The prevalence rate is projected to rise to 430 cases per 100,000 people, corresponding to over 130,000 Canadians living with MS by 2031 [2]. Many people with MS, especially those individuals with moderate-to-severe disability, often cope with disease-related stressors including decline in functional status (e.g., poor mobility) and physiologic deconditioning [3]. As a result, these individuals require assistance to manage associated life roles in the home and community. The task of providing this ongoing assistance falls primarily on family caregivers such as relatives and close friends [4]. Family caregivers provide about 80% of the care people with MS need and may spend up to 12 hours/day in various caregiving activities [5–7]. Although there are positive aspects of providing care to people with MS [8], caregivers also experience considerable stress due to the physical and emotional dependency that develops among their care-recipients as the disease progresses and disability accumulates [4]. As a result, people with MS and their caregivers often need to work collaboratively to identify strategies to manage and cope with disease- and caregiving-related stressors [9].

The Developmental Contextual Coping Model [10] provides a theoretical framework for understanding dyadic coping in chronic diseases such as MS. The model describes four strategies that may be used to manage disease- and caregiving-related stressors. These strategies include: 1) uninvolved coping, where each partner is coping alone with their individual stressors; 2) supportive coping, which involves provision of physical, instrumental or emotional support from one partner to the other person; 3) collaborative coping, which extends beyond the provision of social support to a situation whereby both partners actively negotiate aspects of their shared experience and take equal responsibility for engaging in practical coping strategies (e.g., joint problem solving and goal setting for physical activity); and 4) control strategies where one partner, usually the caregiver, underestimates the abilities of and dominates the actions of the other partner by taking charge and telling the other person what to do.

According to the model, dyads who jointly appraise the disease as a shared disease, pull resources together and engage in collaborative coping strategies are better able to confront and overcome the challenges of living with and managing chronic diseases [11]. Thus, the model emphasizes the importance of considering the health of the person with a chronic disease and his/her caregiver as an interdependent unit rather than each in isolation. Research investigating this model has also shown that collaborative coping strategies contribute to beneficial health outcomes including reduction in self-reported heart failure symptoms [12], and improvement in metabolic control [13] and quality of life [14] among dyads affected by various chronic diseases. In particular, joint participation in physical activity may improve exercise adherence, muscle strength, physical function and psychological health for both partners, as well as caregiver coping skills [15–18].

Despite models such as the Developmental Contextual Coping Model [10], few researchers have included both people with moderate-to-severe MS disability and their caregivers together as *active participants* in physical activity studies [9,19]. Current literature is also lacking as to what factors influence co-participation (i.e., people with MS and their caregivers together) in physical activity. These issues limit our ability to identify strategies to enhance dyadic participation in physical activity to the benefit of each individual and the dyad (i.e. partnership). In addition, service providers and individuals working in public health systems need to be aware of the dyads' perceived need for community resources that might support their participation in physical activity, as well as the determinants of perceived need. Such knowledge is an important prerequisite to developing the necessary types and scopes of resources for reducing unmet needs. Identifying determinants of perceived need may also provide guidance for targeting efforts to ensure optimum utilization of such resources.

Research that attempts to examine perceived need is guided by a number of conceptual models, the most common of which is the Andersen-Newman model [20]. Originally developed to predict health service utilization, it has now become an extensively used model for needs assessment and analysis of factors that can influence perceived need [21,22]. In the original model, Andersen and Newman [23] describe individual and societal determinants of health service utilization. Within the individual factors,

three types of variables are considered: predisposing characteristics, enabling factors and health need factors. Predisposing characteristics (e.g., age, sex) are hypothesized to increase an individual's inclination or tendency to use services. Enabling factors (e.g. income and living situation) impede or facilitate individuals to use service. Health need factors (e.g., overall health status and disease conditions) trigger the use of services. The Andersen-Newman model is a flexible and robust conceptual framework that allows the selection of variables and suitable methods related to the researcher's area of interest or specific hypothesis. The model also provides a suitable framework when exploratory research is needed due to dearth of previous research in an area, as in this study.

This study incorporated the theoretical framework of the Developmental Contextual Coping Model [10] and the conceptual model of Andersen-Newman [20] to examine the most pressing needs for community resources to support physical activity participation in people with moderate-to-severe MS disability and family caregivers. We were also interested in identifying determinants of perceived need and the barriers to co-participation in physical activity in these groups. For the purposes of this study, we defined community resources as follows: *the people, places, programs/interventions and services that members of a given community (i.e., people with MS and family caregivers) can turn to for tools to help them initiate and/or maintain a physically active lifestyle.*

We focused on three research questions:

1. What are the most pressing needs for community resources to support physical activity participation for people with moderate-to-severe MS disability and family caregivers?
2. What are the predisposing characteristics, enabling and health need factors that are associated with these needs?
3. What are the barriers to co-participation in physical activity for people with moderate-to-severe MS disability and family caregivers?

Methods

Study design

We conducted a cross-sectional survey study using the Concerns Report Methodology [24]. This methodology involves a systematic participatory approach to needs assessment with agenda setting, capacity building and empowerment for change among individuals who share a common issue. It is a particularly useful way of getting the community members and needs assessment team to prioritize the needs and concerns within a community. The prioritized list can then inform the development or planning of appropriate resources to address the needs. There are five basic phases of the Concerns Report Methodology, which include: 1) focus groups with representatives of the target groups; 2) development of a structured survey by a working group of key informants; 3) survey dissemination and analysis; 4) public meetings and setting up action committees; and 5) monitoring of the committee and dissemination of the final report. It is important to note that phases one through three identify and prioritize needs and concerns, while phases four and five focus on planning actions and solutions, which can take several years. This study focuses on the survey development (phase 2) and survey dissemination and analysis (phase 3) of the Concerns Report Methodology. The findings from the focus groups (phase 1) have been published previously [9].

Survey design

Two separate surveys were developed based on the findings from the focus group study [9] – one for people with MS and the other for family caregivers. The process of developing the surveys was iterative and involved four researchers (AF, AL-C, TP and MF), three people with MS and two family caregivers (hereafter referred to as the team). The people with MS and family caregivers were identified from the focus group participants. The survey development process began with the lead researcher (AF) generating a preliminary list of survey items from concepts embedded within the focus group data. Then, she sent draft copies of the surveys via email to the team for review and feedback. The next step involved a face-to-face meeting, during which the team discussed the feedback and also identified additional items to be included in the surveys. Subsequently, the lead researcher revised the surveys and resent to the team for

final comments. No additional changes to the content of the surveys were suggested at this time. A pilot involving two people with MS and two family caregivers was conducted from May 5-12, 2016. Individuals who participated in the pilot were different from the team and the pilot data were not included in the final analysis.

Survey content and dissemination

Each of the surveys consisted of five sections. The first section gathered information on routine physical activity including the types of and time spent engaging in activities over the previous one week [25]. The second section asked respondents to rate the importance of and satisfaction with 13 community resources that might support their participation in physical activity on a scale of 1 (completely unimportant/completely unsatisfied) to 5 (very important/very satisfied). These items were used to generate a Needs Index, which was calculated as proportion of important/very important – proportion of satisfied/very satisfied [26]. There are no published cut-off points for decisions based on the Needs Index. Herein, we focus on items identified by both the people with MS and the family caregivers with Needs Index $\geq 50\%$. We chose this cut-off point because it indicates that the majority of the respondents identified the item as a need.

The third section gathered information on barriers to co-participation in physical activity. No existing measures were available, so the team selected and adapted items from instruments used in previous studies involving the general population and people with chronic health conditions including MS [27–30]. Participants were asked to consider when participating in physical activity together with the person with MS or caregiver (depending on the primary respondent) and rate the extent to which each barrier might impede co-participation on a scale of 1 (very small barrier) to 5 (very big barrier) [27]. The fourth section gathered information on general health. For the people with MS, the questions inquired about type of MS, diagnosis year, disease severity [31], self-rated health [32] and comorbidity status [33]. For the family caregivers, we gathered information about self-rated health and comorbidity status. The final section gathered information on basic socio-demographic characteristics (age, sex, education, and living situation, as well as type of community, and marital, employment and income status). For the

caregivers, we added additional questions about relationship with and number of years of providing assistance to a person with MS. The surveys were disseminated using Fluidsurvey, an online survey system. We chose to use online surveys because of the high use of the internet by people with MS [34] and family caregivers [35], as well as the ease of access, simplicity and minimal budgetary and time commitment associated with this method of dissemination [36].

Participant recruitment

To limit the possibility of losing interested individuals and for ease of participation, we recruited in two distinct streams – one stream for people with MS and the other for family caregivers. This method ensured that, if desired, people with MS could participate independent of their caregivers and vice-versa. It is important to note that a random sample could not be selected because we did not have access to a comprehensive list with adequate numbers of people with MS and family caregivers with email addresses. Therefore, we used different channels to invite people with MS and family caregivers to answer the online survey. Personal e-mails containing a link to the appropriate surveys were sent to individuals who had participated in previous studies conducted by our research team and who had consented to being contacted for additional MS research projects. In addition, each MS Society chapter across Canada was contacted by email to request that a link to each of the surveys be distributed to their members. An advertisement was also placed on the MS Society of Canada Research Portal. Finally, snowball sampling was used to identify potential participants by including an item at the end of each survey asking respondents to forward a link to either the person with MS or family caregiver (depending on the primary respondent). Given these recruitment strategies, the total number of people with MS and caregivers who received the survey link was not known; therefore, we were unable to determine a response rate.

Eligibility criteria

We included screening questions for eligibility as part of the surveys. When potential respondents activated the survey link, they were guided to the survey website where they were presented with detailed information about the purpose of the study. Individuals were then invited, via the website, to consent and undergo an online screening process to confirm that they met the inclusion criteria for the study. The

inclusion criteria for people with MS were: a) ≥ 18 years old; b) diagnosis of MS; c) a score of 3-6 on the Patient Determined Disease Steps; and d) ability to complete the survey in English. The inclusion criteria for the family caregivers were: a) ≥ 18 years old; b) providing ≥ 45 mins/day of support to a person with MS with moderate-to-severe disability; and c) ability to complete the survey in English. The Research Ethics Board at the authors' institution approved all study procedures.

Participants

A total of 196 individuals (121 people with MS and 75 family caregivers) consented to the survey. However, 30 people with MS and 24 family caregivers decided not to be screened and discontinued the survey after providing consent. After completing the screening process, eight people with MS and one family caregiver were deemed ineligible (due to disease severity or age). Another five people with MS and four family caregivers were eligible but chose to discontinue the survey after completing the screening process (i.e., they did not proceed to answering any of the survey questions). Therefore, the final sample consisted of 124 respondents (78 people with MS and 46 family caregivers). A flowchart of the study recruitment process is presented in figure 1

<Insert figure 1 here>

Data analysis

The data were downloaded from Fluidsurvey and imported into IBM SPSS Statistics for Windows, version 24 (IBM Corp, Armonk, NY) for analysis. We summarized sample characteristics and described the proportion of participants reporting barriers to co-participation in physical activity using mean (SD) and frequency distributions (n [%]) as appropriate. Factors associated with perceived need items were examined using logistic regression. Because of a small sample size for some response options, several variables had to be collapsed to create dichotomous variables including education (<college, \geq college), marital status (single, married), living situation (live alone, live with someone else), personal annual income (<\$50,000CAD, \geq \$50,000CAD), type of community (small town/rural, medium/large urban center), and health status (poor-to-fair, good-to-excellent). Multicollinearity among the variables was assessed using the Variance Inflation Factor [37] while model fit was assessed by the Hosmer and

Lemeshow goodness-of-fit test [38]. Importantly, two sets of analyses were carried out to examine significant factors associated with perceived need. The first set of analyses combined both people with MS and family caregivers together in the model, while the second set of analyses was done on each group separately.

Results

Participants Characteristics

Table 1 summarizes the characteristics of the study sample. Importantly, the information presented in the table does not reflect which respondents were matched care-recipient caregiver dyads, as this information was not collected as part of this study. The mean age was 54.5 years (standard deviation (SD) = 10.6) for people with MS and 51.6 years (SD = 8.7) for family caregivers. The majority of the people with MS were female (76.9%) diagnosed with relapsing-remitting MS (51.2%). The mean Patient Determined Disease Step score was 5.0 (SD = 1.4), indicating disability severe enough to require use of a cane or bilateral support for ambulation. The majority of the family caregivers were male (63.0%), spouses (73.9%) who had been providing assistance to a person with MS for an average of 9.4 years (SD = 7.1). Across the sample, the majority of the respondents had \geq college degree (59.7%) and lived in medium/large urban population centers (68.5%).

<Insert table 1 here>

Routine physical activity

People with MS engaged in physical activity for an average of 3.0 days/week (SD = 2.1) and spent 58.4 minutes/week (SD = 46.0) in various activities over the course of the week. On the other hand, family caregivers engaged in physical activity for an average of 3.7 days/week (SD = 2.6) and spent 94.4 minutes/week (SD = 58.6) in various activities over the course of the week. Figure 2 presents the activities in which participants routinely engage. As shown in the figure, the top three commonly identified activities among people with MS were brisk walking (n = 55, 70%), gardening (n = 27, 35%) and strength training exercises (n = 25, 32%). Among the family caregivers, household chores (n = 32, 70%), brisk walking (n = 24, 52%) and gardening (n = 29, 41%) were the three most commonly reported activities.

<Insert figure 2 here>

The Needs Index for people with MS and family caregivers

Table 2 presents the Needs Index for people with MS and family caregivers. As shown in the table, three items were perceived as top priorities by both groups. These items were the need for: 1) information about available resources to support physical activity participation (Need Index for people with MS = 76.6; Need Index for family caregivers = 52.3); 2) programs that support joint participation of people with MS and their family caregivers in physical activity (Need Index for people with MS = 62.0, Need Index for family caregivers = 68.9); and 3) programs that have affordable total cost of participation (Need Index for people with MS = 50.7, Need Index for family caregivers = 52.3).

Factors associated with each of the three prioritized and shared need items

The results of the logistic regression models for each of the shared need items are shown in table 3. Variance Inflation Factor values were below 10 indicating that the variables had independent effects within each model. Each of the models fit the data well as shown by Hosmer and Lemeshow Goodness-of-fit test, which produced p-values of 1.0, 1.0 and 0.3 respectively.

Information about available resources to support physical activity participation

The model with people with MS and the family caregivers together included two enabling factors (i.e., living situation and type of community). There were no significant predisposing or need factors in this model. As shown in table 3, individuals who were living alone were more likely to report the need for information about available resources to support physical activity participation (odds ratio = 3.7 [1.3-10.4]) than individuals who were living with someone else. Compared with individuals who lived in medium/large urban areas, those who resided in rural areas/small towns were more likely to report perceived need for information about available resources to support physical activity participation (odds ratio =7.0 [2.2-22.3]). The results of the model with only people with MS were generally consistent with the results of the model with people with MS and the family caregivers together. However, in the model that included only the family caregivers, no enabling, predisposing or need factors emerged as significant factors.

Programs that support joint participation of people with MS and caregivers in physical activity

The model with people with MS and the family caregivers together included one predisposing characteristic (i.e., education), one enabling factor (i.e., marital status), and one health need factor (i.e., comorbidity status). As shown in table 3 individuals who reported ≥ 1 comorbid condition were more likely to report a perceived need than those with no comorbidity (odds ratio = 2.9 [1.2–6.8]). In addition, individuals who were married were more likely to report a perceived need than their single counterparts (odds ratio = 3.3 [1.3–8.5]). Finally, individuals with \leq college degree were more likely to report a perceived need than those with more than college degree (odds ratio = 4.0 [1.6–9.8]). The results of the model with people with MS alone showed that being married and having less than college degree were significantly associated with perceived need (odds ratio = 5.1 [1.5-17.3] and 7.1 [2.1-23.8] respectively. Comorbidity was not significantly associated with perceived need in this model. On the other hand, the model with the family caregivers alone showed that only comorbidity was associated with perceived need (odds ratio = 6.8 [1.8-25.0]). Education and marital status were not significantly associated with perceived need in this model.

Programs that have affordable total cost of participation

The model with people with MS and the family caregivers together included four enabling factors (i.e., type of community, living situation employment and income) and one need factor one health need factor (i.e., comorbidity status). No predisposing factors were significant. As shown in table 3 individuals who reported ≥ 1 comorbid condition were more likely to report a need than those with no comorbidity (odds ratio = 8.1 [3.1-20.9]). In addition, individuals living in rural areas and small towns were more likely to report a perceived need than individuals who resided in medium/large population centers (odds ratio = 5.3 [1.8–15.8]). Compared with individuals who lived with someone else, those who lived alone were more likely to report perceived need (odds ratio = 3.4 [1.1–10.6]). Individuals who earned $< \$50,000$ CAD were more likely to report perceived need than those who earned $\geq \$50,000$ CAD (odds ratio = 3.9 [1.4–11.1]). The results of the model with only people with MS showed that having a comorbidity, living alone and earning $< \$50,000$ CAD were significantly associated with perceived need (odds ratio = 8.8 [2.0-38.7], 4.3

[1.3-18.1] and 22.3 [3.5-143.5] respectively). Type of community was not significantly associated with perceived need in this model. On the other hand, the model with the family caregivers alone showed that living in rural areas/small towns and having ≥ 1 comorbid condition were associated with perceived need with odds ratios of 3.4 [2.7-20.9] and 4.2 [2.8-13.5] respectively. Living situation and income were not significantly associated with perceived need in this model.

<Insert table 3 here>

Barriers to co-participation in physical activity

Among the family caregivers, the most frequently cited barriers to co-participation in physical activity together with their care-recipients with MS were *variability or unpredictability associated with MS* with 80.4% (n = 37) of the sample citing this as a big barrier (Table 4). Next was *lack of choice and control over physical activity and level of participation* (n = 37, 80.4%) and *total cost of participating in a physical activity program is high* (n = 37, 80.4%). This was followed by lack of *accessible locations* (n = 32, 69.6%) and *lack of time* (n = 23, 50%). The less prominent barriers included *lack of confidence to be physically active* with only 10.9% (n = 5) of the sample registering this as a big barrier. Next was *embarrassment about personal appearance when participating in physical activity* (n = 7, 15.2%) and *lack of enjoyment* (n = 10, 21.7%). In contrast, people with MS rated more items as small barriers rather than big barriers when considering participating together with their caregivers in physical activity. Specifically, the most frequently ranked barriers were *safety issues within the community* with 56.4% (n = 44) of the sample ranking this as a small barrier. Next was *lack of confidence* (n = 43, 55.1%) and *lack of time* (n = 42, 53.8%).

<Insert table 4 here>

Discussion

MS has life-altering consequences for both people with the disease and the family caregivers who support these individuals. The benefits of physical activity for all people underscore a unique opportunity to develop resources that can support physical activity participation for people with MS and their caregivers. Our study is unique because it uses the Concerns Report Methodology to identify the most pressing

community resources needed to support physical activity participation from the perspective of both people with moderate-to-severe MS disability and family caregivers, identifying these needs in these groups has never been done before.

Perceived need for community resources

As there has been limited research to date examining the perceived need for community resources in relation to physical activity support, comparing our findings to the extant literature is difficult. Therefore, we reviewed this research in the context of the broader needs assessment literature to understand how our findings might align with this body of evidence.

First, it was interesting to note the differences between the people with MS and family caregivers in their need rankings for some items. Specifically, while people with MS identified the need for programs with facilitators who have adequate MS knowledge and training as a top priority, it was a much lower need for the family caregivers. In addition, the family caregivers identified programs that provide opportunities to learn about options for incorporating physical activity into daily life as a top priority while it was a lower priority for people with MS. This finding is important to highlight because it suggests that certain resources may be more or less salient to individual partners in a dyad depending on their role (i.e. person with MS versus caregiver), consistent with previous research incorporating dyadic models to study health and wellbeing [39,40]. Importantly, it adds a layer of complexity to developing dyadic physical activity interventions, and underscores the importance of including a combination of strategies targeted at ensuring balanced opportunities for both members of the dyad to optimize their physical activity participation. The need for different intervention strategies for addressing specific caregiver care-recipient priorities have also been highlighted in studies from different disciplines, and with other forms of interventions apart from physical activity [16,17].

The results show three shared items ranked as top priorities by the majority of participants in both groups: 1) information about available resources to support physical activity participation (e.g., publicity and advertisement of programs, information on fee assistance opportunities etc.); 2) programs that support joint participation of people with MS and their caregivers in physical activity (i.e., programs that include

components that both groups can benefit from and enjoy); and 3) programs that have affordable total cost of participation (e.g., parking, membership fees etc.). These findings also have important implications for future program development. First, they underscore the critical role that program developers, service providers and individuals working in public health systems have to play in ensuring that people with MS and their caregivers have the necessary infrastructure and resources to be physically active in the home and community. Previous researchers have documented the role of healthcare providers in supporting people with MS as they transition from a physically inactive lifestyle to an active one, and our findings reaffirm these studies [41–43]. In addition, this finding also reiterates the need to direct health promotion efforts towards developing dyadic models of care that target the health and wellbeing of both people with moderate-to-severe MS disability and their caregivers; a group that has been consistently excluded in previous research. Indeed, emerging evidence from populations with other neurological diseases including stroke, Parkinson’s and Alzheimer’s disease [44–47] has demonstrated that dyadic physical activity programs are beneficial to the physical and mental health of both partners. Together with our findings, this body of knowledge highlights the potential for dyadic physical activity programs to be an important component of support required by those affected by MS.

Factors associated with perceived need

Although different combinations of factors emerged as drivers of each of the three prioritized need items, overall, we found that income, education, living situation, marital status, and type of community were independently associated with one or more of the need items. Previous research has demonstrated the association between sociodemographic profiles and perceived unmet need for social and health care-related services [48–51]. Specifically, these studies have shown that people with chronic diseases including dementia and MS who live alone, in rural areas, have lower educational status or report inadequate income are more likely to have significantly more unmet needs including those related to healthcare services. Our results were generally consistent with these findings, except in the need for programs that support joint participation of people with MS and their caregivers in physical activity, where those participants who were married were more likely to report perceived need. This is an interesting finding to highlight given

that the presence of social relationships has been reported as a critical resource for promoting physical activity [52]. Other researchers have suggested that the presence of a support partner might not necessarily translate to the provision and receipt of social support for health promoting behaviors [53]. Of significance to our study, family caregivers may be present but unavailable to support the physical activity efforts of their care-recipients and vice versa for several reasons including disease symptoms and stress associated with both caregiving and non-caregiving responsibilities [9,54]. It is possible that this situation is more of a reality for married rather than single participants. Thus, these individuals may be more acutely aware of the lack of resources that consider inputs and outcomes for both partners and support physical activity in the context of close relationships. This finding highlights an opportunity for clinicians and individuals working in public health systems to reinforce physical activity as a shared behavior with synergistic benefits to each partner and the dyad (i.e., partnership).

It was interesting to note that in the separate analysis for each of the groups, the factors that emerged as significant drivers of perceived need varied somewhat between people with MS and the family caregivers. For instance, while living arrangement, type of community and income were significantly associated with perceived need for information about available resources to support physical activity participation among people with MS, no significant factors emerged among the family caregivers. In addition, the model for people with MS alone identified comorbidity, living arrangement and income as important drivers of perceived need for programs that have affordable total costs of participation, while only comorbidity emerged as a significant factor among the family caregivers. Overall, the model for the family caregivers alone yielded less information in terms of significant drivers of perceived need. It is possible that other factors that were not included in the analysis may be driving perceived need particularly among the family caregivers. For instance, we did not collect information related to caregiving burden. Previous research suggests that greater burden of care and distress are associated with increased likelihood of reporting unmet need for general health services among family caregivers [55]. Future larger studies may need to explore in more detail the complexity of factors beyond sociodemographic profiles driving perceived need and the reasons for the differences between people with MS and the family caregivers.

Our results show that comorbidity was particularly important for both people with MS and the family caregivers. Specifically comorbidity was associated with one of the three prioritized need items for people with MS (i.e., programs that have affordable total costs of participation). In addition, comorbidity emerged as a significant factor associated with two of the three need items among the family caregivers (i.e., programs that support joint participation in physical activity and programs that have affordable total cost of participation). This finding resonates with previous research in populations with other chronic diseases [56,57]. For instance, Thorsen et al. [56] demonstrated that comorbidity is associated with a high level of unmet rehabilitation needs among people with cancer. This finding is important given the high prevalence of comorbidity in MS and the role that physical activity plays in effecting comorbidities among people with the disease [58]. Although we are unaware of any studies that have assessed the prevalence of comorbidity in family caregivers assisting people with MS, Gupta and colleagues [59] showed that family caregivers of people with MS had higher Charlson Comorbidity Index scores than non-caregivers. Research in other chronic diseases (e.g., dementia) has shown that up to 81.5% of caregivers have one or more comorbid health conditions [60]. Given that individuals with comorbidity are typically excluded from physical activity studies in MS [61], our findings further underscore the importance of providing affordable opportunities for both people with MS and their caregivers who have comorbidities to improve their participation in physical activity.

We did not observe associations between other predisposing characteristics (i.e., age, sex) and any of the need items in any of the models. Other studies have demonstrated strong age and sex differences in the experience of need, where younger adults and women are more likely to have unmet needs for health-related care and services [49,62,63]. A possible reason for the difference between this study and others may be due to different study designs, populations and data collection methods. For instance, previous studies have included equal or near-equal sex and gender representations whereas our sample comprised majorly of female middle-aged adults.

Barriers to co-participation in physical activity

To the authors' knowledge, this is the first quantitative survey to explore barriers to co-participation together in physical activity from the perspective of both people with MS and family caregivers. Previous cross-sectional surveys have been restricted in scope to exploring barriers that limit an individual's own physical activity and do not provide insights into the barriers to dyadic physical activity participation. Barriers that emerged from the present study include impairment-related issues, self-efficacy, neighbourhood safety, program/facility affordability and accessibility and other logistical factors. These are commonly reported barriers to participation in physical activity across diverse populations with and without chronic diseases [29,64–67] and it is not surprising that they limit dyadic physical activity opportunities as well as individual opportunities for activity. However, it is reassuring that the majority of these barriers are potentially modifiable through the design of appropriate interventions. The differences between groups regarding the extent to which these factors might impede co-participation in physical activity suggest that a “one-size-fits-all” approach is not appropriate. Given the numerous benefits of regular participation in physical activity, increased flexibility in designing strategies to enhance dyadic participation in the presence of unique caregiver and care-recipients barriers is an important consideration.

Physical activity behavior

Our results also show that the majority of the family caregivers (70%) identified household chores as routine physical activity. We are unaware of any studies identifying the frequency and types of physical activity self-selected by family caregivers assisting people with MS. Previous research has indicated that about 66% of adults in the general population engage in one or more 10min bouts of domestic physical activity daily [68]. The high proportion of family caregivers in our study reporting household chores as routine physical activity has significant clinical implications. In an effort to encourage sedentary individuals to engage in at least some physical activity, emphasis has shifted from promoting structured forms of physical activity to lifestyle activities, which can form part of a normal daily routine. It is possible that the family caregivers in our study may assume that housework is moderate intensity physical activity, and therefore counts towards the recommended 150min/week of moderate-to-vigorous physical activity.

However, researchers have shown that household chores alone may not be sufficient to provide the health benefits normally associated with regular participation in physical activity [69]. Together, these findings suggest the need to provide family caregivers assisting people with MS with information on the benefits of reallocating housework time to alternate light or moderate-to vigorous physical activity and the tools to appropriately quantify intensity of physical activity in order to ensure that they are indeed engaging at the level that is associated with health benefits.

Limitations

Findings of the current study should be treated as exploratory and must be viewed in light of several limitations. First, we recruited people with MS and family caregivers separately rather than together as dyads, and our Research Ethics Board's confidentiality requirements prevented keeping IP addresses or collecting information that would enable us establish which participants were matched caregiver care-recipient dyads. While this recruitment strategy limited the possibility of losing interested individuals by giving people with MS the choice to participate independent of their caregivers and vice-versa, it influenced our ability to study possible interdependent processes within dyads. For instance, it would be interesting to explore how the perceived need of people with MS influences the need perception of their own caregivers and vice versa. Second, our sample was primarily made up of middle-aged women, thus our results may not be generalizable to individuals of other age groups or to men. Some of the confidence limits are wide suggesting that the results may not be a true representation of the population. Future studies should include a larger sample with equal sex and age group representation. Another limitation relates to the use of online survey methods. Although high Internet usage have been documented among people with MS and MS caregivers previously, it is possible that this data collection method may introduce a sample bias, where only those individuals with access and skills to complete this survey online were interested in our study. A further limitation is the use of snowball sampling and the inability to ascertain that the survey was actually completed by someone who has MS/caregiver, and that it was not completed numerous times by the same participant on different machines. These issues pose a threat to the validity of the survey

findings. Finally, the cross-sectional study design precludes the ability to comment on the consistency of the identified needs and barriers over time.

Conclusion

This study identified community resources that might support people with MS and family caregivers assisting such individuals to participate in physical activity. The results of the study highlight the need for a dyadic intervention that targets people with MS and their caregivers together as *active participants*. Such an intervention will likely include a combination of different components (multicomponent intervention) such as integrating content on increasing physical activity with attention to the barriers that might impede such an increase. The findings further highlight the complexity of developing community resources that target physical activity promotion in MS dyads and underscore the importance of reinforcing physical activity as a shared behavior and providing information about options for exercising together to the benefit of each individual and the dyad (i.e. partnership). Overall, our findings provide a possible starting point to guide the identification of potential participants that might benefit the most from future intervention development work.

Declaration of Interest Statement

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References

1. Multiple Sclerosis International Federation. Atlas of MS 2013: Mapping multiple sclerosis around the world. 2013.
2. Amankwah N, Marrie RA, Bancej C, Garner R, Manuel DG, Wall R, Finès P, Bernier J, Tu K, Reimer K. Multiple sclerosis in Canada 2011 to 2031: results of a microsimulation modelling study of epidemiological and economic impacts. *Chronic Dis Inj Can.* 2017;37:37–48.
3. Sandroff BM, Klaren RE, Motl RW. Relationships among physical inactivity, deconditioning, and walking impairment in persons with multiple sclerosis. *J Neurol Phys Ther.* 2015;39:103–110.
4. McKeown LP, Porter-Armstrong AP, Baxter GD. The needs and experiences of caregivers of individuals with multiple sclerosis: a systematic review. *Clin Rehabil.* 2003;17:234–248.
5. Finlayson M, Cho C. A descriptive profile of caregivers of older adults with MS and the assistance they provide. *Disabil Rehabil.* 2008;30:1848–1857.
6. Carton H, Loos R, Pacolet J, Versieck K, Vlietinck R. A quantitative study of unpaid caregiving in multiple sclerosis. *Mult Scler.* 2000;6:274–279.
7. Rivera-Navarro J, Manuel Morales-González J, Benito-León J. Informal caregiving in multiple sclerosis patients: data from the Madrid Demyelinating Disease Group study. *Disabil Rehabil.* 2003;25:1057–1064.
8. Pakenham KI. Benefit finding in multiple sclerosis and associations with positive and negative outcomes. *Health Psychol.* 2005;24:123.
9. Fakolade A, Lamarre J, Latimer-Cheung A, Parsons T, Morrow SA, Finlayson M. Understanding leisure-time physical activity: Voices of people with MS who have moderate-to-severe disability and their family caregivers. *Health Expect.* 2017;00:1–11.
10. Berg CA, Upchurch R. A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychol Bull.* 2007;133:920.
11. Berg CA, Wiebe DJ, Butner J, Bloor L, Bradstreet C, Upchurch R, Hayes J, Stephenson R, Nail L, Patton G. Collaborative coping and daily mood in couples dealing with prostate cancer. *Psychol Aging.* 2008;23:505–516.
12. Rohrbaugh MJ, Mehl MR, Shoham V, Reilly ES, Ewy GA. Prognostic significance of spouse we talk in couples coping with heart failure. *J Consult Clin Psychol.* 2008;76:781–789.
13. Körner A, Würz J, Brosseau DC, Brähler E, Kapellen T, Kiess W. Parental dyadic coping in families of children and adolescents with type 1 diabetes. *J Pediatr Endocrinol Metab.* 2013;26:867–875.
14. Meier C, Bodenmann G, Mörgeli H, Jenewein J. Dyadic coping, quality of life, and psychological distress among chronic obstructive pulmonary disease patients and their partners. *Int J Chron Obstruct Pulmon Dis.* 2011;6:583–596.
15. Winters-Stone KM, Lyons KS, Dobek J, Dieckmann NF, Bennett JA, Nail L, Beer TM. Benefits of partnered strength training for prostate cancer survivors and spouses: results from a randomized controlled trial of the Exercising Together project. *J Cancer Surviv.* 2015:1–12.

16. Prick A-E, de Lange J, Scherder E, Twisk J, Pot AM. The effects of a multicomponent dyadic intervention on the mood, behavior, and physical health of people with dementia: a randomized controlled trial. *Clin Interv Aging*. 2016;11:383.
17. Prick A-E, de Lange J, Twisk J, Pot AM. The effects of a multi-component dyadic intervention on the psychological distress of family caregivers providing care to people with dementia: a randomized controlled trial. *Int Psychogeriatr*. 2015;27:2031–2044.
18. Johnson MD, Anderson JR, Walker A, Wilcox A, Lewis VL, Robbins DC. Common dyadic coping is indirectly related to dietary and exercise adherence via patient and partner diabetes efficacy. *J Fam Psychol*. 2013;27:722–730.
19. Fakolade A, Latimer-Cheung A, Parsons T, Finlayson M. Correlating physical activity patterns of people with moderate-to-severe multiple sclerosis-disability and their family caregivers. Press. 2017.
20. Andersen RM. Revisiting the behavioral model and access to medical care: does it matter? *J Health Soc Behav*. 1995:1–10.
21. Calsyn RJ, Winter JP. Predicting four types of service needs in older adults. *Eval Program Plann*. 2001;24:157–166.
22. Black BS, Johnston D, Rabins PV, Morrison A, Lyketsos C, Samus QM. Unmet needs of community-residing persons with dementia and their informal caregivers: Findings from the Maximizing Independence at Home study. *J Am Geriatr Soc*. 2013;61:2087–2095.
23. Andersen R, Newman JF. Societal and individual determinants of medical care utilization in the United States. *Milbank Mem Fund Q Health Soc*. 1973:95–124.
24. Fawcett SB, Suarez de Balcazar Y, Whang-Ramos P, Seekins T, Bradford B, Mathews R. The concerns report: Involving consumers in planning for rehabilitation and independent living services. *Am Rehabil*. 1988;14:17–19.
25. Craig CL, Marshall AL, Sjoerstrom M, Bauman AE, Booth ML, Ainsworth BE, Pratt M, Ekelund U, Yngve A, Sallis JF. International physical activity questionnaire: 12-country reliability and validity. *Med Sci Sports Exerc*. 2003;35:1381–1395.
26. Finlayson M. Assessing Need for Services. In: Kielhofner G, editor. *Methods of Inquiry for Enhancing Practice*. Philadelphia, PA; 2006. pp 591–629.
27. Vasudevan V, Rimmer JH, Kviz F. Development of the barriers to physical activity questionnaire for people with mobility impairments. *Disabil Health J*. 2015;8:547–556.
28. Becker H, Stuijbergen A. What makes it so hard? Barriers to health promotion experienced by people with multiple sclerosis and polio. *Fam Community Health*. 2004;27:75–85.
29. Vanner EA, Block P, Christodoulou CC, Horowitz BP, Krupp LB. Pilot study exploring quality of life and barriers to leisure-time physical activity in persons with moderate to severe multiple sclerosis. *Disabil Health J*. 2008;1:58–65.
30. Clark AF, Scott DM. Barriers to walking: an investigation of adults in Hamilton (Ontario, Canada). *Int J Environ Res Public Health*. 2016;13:179.

31. Learmonth YC, Motl RW, Sandroff BM, Pula JH, Cadavid D. Validation of patient determined disease steps (PDDS) scale scores in persons with multiple sclerosis. *BMC Neurol.* 2013;13:37–37.
32. Idler EL, Kasl S. Health perceptions and survival: do global evaluations of health status really predict mortality? *J Gerontol.* 1991;46:S55–S65.
33. Marrie RA, Cohen J, Stuve O, Trojano M, Sorensen PS, Reingold S, Cutter G, Reider N. A systematic review of the incidence and prevalence of comorbidity in multiple sclerosis: Overview. *Mult Scler Houndmills Basingstoke Engl.* 2015;21:263–281.
34. Lejbkowitz I, Paperna T, Stein N, Dishon S, Miller A. Internet usage by patients with multiple sclerosis: implications to participatory medicine and personalized healthcare. *Mult Scler Int.* 2010;2010.
35. Buchanan RJ, Huang C, Crudden A. Use of the internet by informal caregivers assisting people with multiple sclerosis. *J Technol Hum Serv.* 2012;30:72–93.
36. Bethlehem J, Biffignandi S. *Handbook of web surveys.* John Wiley & Sons; 2011.
37. Midi H, Sarkar S, Rana S. Collinearity diagnostics of binary logistic regression model. *J Interdiscip Math.* 2010;13:253–267.
38. Hosmer DW, Hosmer T, Le Cessie S, Lemeshow S. A comparison of goodness-of-fit tests for the logistic regression model. *Stat Med.* 1997;16:965–980.
39. Reed RG, Butler EA, Kenny DA. Dyadic models for the study of health. *Soc Personal Psychol Compass.* 2013;7:228–245.
40. Quinn C, Dunbar SB, Clark PC, Strickland OL. Challenges and strategies of dyad research: cardiovascular examples. *Appl Nurs Res.* 2010;23:e15–e20.
41. Learmonth YC, Adamson BC, Balto JM, Chiu CY, Molina-Guzman I, Finlayson M, Riskin BJ, Motl RW. Multiple sclerosis patients need and want information on exercise promotion from healthcare providers: a qualitative study. *Health Expect [Internet].* 2016 July 20. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/27436592>
42. Learmonth YC, Adamson BC, Balto JM, Chiu C-Y, Molina-Guzman IM, Finlayson M, Barstow EA, Motl RW. Investigating the needs and wants of healthcare providers for promoting exercise in persons with multiple sclerosis: a qualitative study. *Disabil Rehabil.* 2017:1–9.
43. Sweet SN, Perrier M-J, Podzyhun C, Latimer-Cheung AE. Identifying physical activity information needs and preferred methods of delivery of people with multiple sclerosis. *Disabil Rehabil.* 2013;35:2056–2063.
44. Marsden D, Quinn R, Pond N, Golledge R, Neilson C, White J, McElduff P, Pollack M. A multidisciplinary group programme in rural settings for community-dwelling chronic stroke survivors and their carers: a pilot randomized controlled trial. *Clin Rehabil.* 2010;24:328–341.
45. Dal Bello-Haas V, O’Connell M, Morgan D, Crossley M. Lessons learned: feasibility and acceptability of a telehealth-delivered exercise intervention for rural-dwelling individuals with dementia and their caregivers. *Rural Remote Health.* 2014;14:2715.
46. Hackney ME, Earhart GM. Effects of dance on gait and balance in Parkinson’s disease: a comparison of partnered and nonpartnered dance movement. *Neurorehabil Neural Repair.* 2010;24:384–392.

47. Vreugdenhil A, Cannell J, Davies A, Razay G. A community-based exercise programme to improve functional ability in people with Alzheimer's disease: a randomized controlled trial. *Scand J Caring Sci.* 2012;26:12–19.
48. Miranda-Castillo C, Woods B, Orrell M. People with dementia living alone: what are their needs and what kind of support are they receiving? *Int Psychogeriatr.* 2010;22:607–617.
49. Plow M, Cho C, Finlayson M. Utilization of health promotion and wellness services among middle-aged and older adults with multiple sclerosis in the mid-west US. *Health Promot Int.* 2010;25:318–330.
50. Luutonen S, Vahlberg T, Eloranta S, Hyväri H, Salminen E. Breast cancer patients receiving postoperative radiotherapy: distress, depressive symptoms and unmet needs of psychosocial support. *Radiother Oncol.* 2011;100:299–303.
51. Lonergan R, Kinsella K, Fitzpatrick P, Duggan M, Jordan S, Bradley D, Hutchinson M, Tubridy N. Unmet needs of multiple sclerosis patients in the community. *Mult Scler Relat Disord.* 2015;4:144–150.
52. Gellert P, Ziegelmann JP, Warner LM, Schwarzer R. Physical activity intervention in older adults: does a participating partner make a difference? *Eur J Ageing.* 2011;8:211.
53. Umberson D, Liu H, Reczek C. Stress and health behaviour over the life course. *Adv Life Course Res.* 2008;13:19–44.
54. Horton S, MacDonald DJ, Erickson K, Dionigi RA. A qualitative investigation of exercising with MS and the impact on the spousal relationship. *Eur Rev Aging Phys Act.* 2015 October 7;12:3.
55. Van der Roest HG, Meiland FJ, Comijs HC, Derksen E, Jansen AP, van Hout HP, Jonker C, Dröes R-M. What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. *Int Psychogeriatr.* 2009;21:949–965.
56. Thorsen L, Gjerset GM, Loge JH, Kiserud CE, Skovlund E, Fløtten T, Fosså SD. Cancer patients' needs for rehabilitation services. *Acta Oncol.* 2011;50:212–222.
57. Urbanoski KA, Cairney J, Bassani DG, Rush BR. Perceived unmet need for mental health care for Canadians with co-occurring mental and substance use disorders. *Psychiatr Serv.* 2008;59:283–289.
58. Marrie RA, Hanwell H. General health issues in multiple sclerosis: comorbidities, secondary conditions, and health behaviors. *Contin Minneap Minn.* 2013;19:1046–1057.
59. Gupta S, Goren A, Phillips AL, Stewart M. Self-reported burden among caregivers of patients with multiple sclerosis. *Int J MS Care.* 2012;14:179–187.
60. Wang XR, Robinson KM, Carter-Harris L. Prevalence of chronic illnesses and characteristics of chronically ill informal caregivers of persons with dementia. *Age Ageing.* 2014;43:137–141.
61. Bisson EJ, Fakolade A, Pétrin J, Lamarre J, Finlayson M. Exercise interventions in multiple sclerosis rehabilitation need better reporting on comorbidities: a systematic scoping review. *Clin Rehabil.* 2017:0269215517698734.
62. Holm LV, Hansen DG, Johansen C, Vedsted P, Larsen PV, Kragstrup J, Søndergaard J. Participation in cancer rehabilitation and unmet needs: a population-based cohort study. *Support Care Cancer.* 2012;20:2913–2924.

63. Wessels H, de Graeff A, Wynia K, de Heus M, Kruitwagen CL, Woltjer GT, Teunissen SC, Voest EE. Gender-related needs and preferences in cancer care indicate the need for an individualized approach to cancer patients. *The Oncologist*. 2010;15:648–655.
64. Rimmer JH, Riley B, Wang E, Rauworth A, Jurkowski J. Physical activity participation among persons with disabilities: barriers and facilitators. *Am J Prev Med*. 2004;26:419–425.
65. Scelza WM, Kalpakjian CZ, Zemper ED, Tate DG. Perceived barriers to exercise in people with spinal cord injury. *Am J Phys Med Rehabil*. 2005;84:576–583.
66. Salmon J, Owen N, Crawford D, Bauman A, Sallis JF. Physical activity and sedentary behavior: a population-based study of barriers, enjoyment, and preference. *Health Psychol*. 2003;22:178.
67. Reichert FF, Barros AJ, Domingues MR, Hallal PC. The role of perceived personal barriers to engagement in leisure-time physical activity. *Am J Public Health*. 2007;97:515–519.
68. Murphy MH, Donnelly P, Breslin G, Shibli S, Nevill AM. Does doing housework keep you healthy? The contribution of domestic physical activity to meeting current recommendations for health. *BMC Public Health*. 2013;13:966.
69. Stamatakis E, Hamer M, Lawlor DA. Physical activity, mortality, and cardiovascular disease: is domestic physical activity beneficial? The Scottish Health Survey—1995, 1998, and 2003. *Am J Epidemiol*. 2009;169:1191–1200.

Table 1. Characteristics of the participants

Variable	People with MS (n= 78)	Family Caregivers (n= 46)	χ^2/t-test	p-value
Age (years)	54.5 (10.6)	51.6 (8.7)	1.6	0.11
Sex			19.6	<0.001
Male	18.0 (23.1)	29.0 (63.0)		
Female	60.0 (76.9)	17.0 (37.0)		
Education			4.4	0.035
< college	37.0 (47.4)	13.0 (28.3)		
≥ college	41.0 (52.6)	33.0 (71.7)		
Living situation			4.2	0.040
Living alone	27.0 (34.6)	8.0 (17.4)		
Living with someone else	51.0 (65.4)	38.0 (82.6)		
Type of community			1.9	0.17
Small town/rural area	28.0 (35.9)	11.0 (23.9)		
Medium/large urban center	50.0 (64.1)	35.0 (76.1)		
Employment			14.9	<0.001
Currently working	28.0 (35.9)	33.0 (71.7)		
Not working	50.0 (64.1)	13.0 (28.3)		
Income			1.4	0.23
<50,000	54.0 (69.2)	27.0 (58.7)		
≥50,000	24.0 (30.8)	19.0 (41.3)		
Comorbidity			0.7	0.41
No comorbid condition	45.0 (57.7)	23.0 (50.0)		
≥ 1 comorbid condition	33.0 (42.3)	23.0 (50.0)		
Meeting PA Guidelines			6.5	0.01
Yes	7.0 (9.0)	12.0 (26.1)		
No	71.0 (91.0)	34.0 (73.9)		
Health status			1.5	0.22
Poor to fair	27.0 (34.6)	21.0 (45.7)		
Good to excellent	51.0 (65.4)	25.0 (54.3)		
Type of MS				
Relapsing Remitting MS	40.0 (51.2)	-		
Primary Progressive MS	8.0 (10.3)	-		
Secondary Progressive MS	21.0 (26.9)	-		
Progressive Relapsing MS	3.0 (3.8)	-		
Mean Patient Determined Disease Steps (SD)	5.0 (1.4)	-		
Mean Disease duration years (SD)	14.7 (10.2)	-		
Relationship to person with MS				
Spouse	-	34.0 (73.9)		
Non-spouse	-	12.0 (26.1)		
Years since caregiving	-	9.4 (7.1)		

Note: values are presented as frequency count and percent unless otherwise stated

Table 2. Comparison of Need Index between People with MS and Family Caregivers

Community Resources	People with MS (n = 78)		Family Caregivers (n= 46)	
	Rank	Need Index	Rank	Need Index
Information about available resources to support physical activity participation (e.g. publicity and advertisement of programs, information on fee assistance opportunities etc.)	1	76.6	3	52.3
Programs that support joint participation of people with MS and their caregivers in physical activity (i.e., both groups can benefit from and enjoy the program)	2	62.0	1	68.9
Programs that have facilitators who have adequate MS specific knowledge and training	3	52.0	8	27.3
Programs that have affordable total cost of participation (e.g., parking, membership fees etc.)	4	50.7	3	52.3
Programs that are held in accessible locations (e.g., accessible parking, equipment, bathrooms, lockers etc.)	5	34.6	5	42.2
Programs that provide opportunities to learn about options for incorporating physical activity into daily life	6	23.7	2	60.0
Programs that increase confidence (self-efficacy) to deal with disease-related problems among people with MS and their caregivers	7	23.4	6	40.9
Programs that target the mind and the body	8	22.1	9	25.0
Programs that provide people with MS and caregivers with the necessary skills to deal with disease-related problems	9	19.5	4	43.2
Programs that are customized and flexible in presentation and delivery (e.g., face-to-face or over the internet, individual or group settings)	10	15.6	7	40.0
Programs that include a wide variety of relevant options for physical activity participation in the same location	11	12.8	12	-4.6
Accessible, reliable and safe bus routes to important places such as community recreation centers, shopping areas etc.	12	10.4	10	13.6
Walking and biking trails that form a viable transportation option to and from activities.	13	5.1	11	2.3

Table 3. Results from final logistic regression modelling for each of the prioritized needs

	df	Estimate (β)	SE	OR	95% CI		P
					Lower	Upper	
Information about available resources (n = 89)							
Constant	1	0.139	0.272	1.149			0.609
Living situation	1	1.315	0.525	3.726	1.333	10.415	0.012
Type of community	1	1.946	0.591	7.000	2.198	22.295	0.001
Programs that support joint participation of people with MS and caregivers (n = 67)							
Constant	1	-1.036	0.369	0.355			0.005
Comorbidity	1	1.046	0.442	2.845	1.196	6.771	0.018
Marital status	1	1.186	0.484	3.273	1.269	8.446	0.014
Education	1	1.378	0.459	3.965	1.613	9.748	0.003
Programs that have affordable total cost of participation (n = 53)							
Constant	1	-4.397	0.867	0.012			<0.001
Comorbidity	1	2.056	0.499	7.813	2.939	20.769	<0.001
Living situation	1	1.279	0.601	3.583	1.104	11.629	0.034
Type of community	1	1.716	0.568	5.561	1.827	16.925	0.003
Employment status	1	1.251	0.558	3.493	1.169	10.437	0.025
Individual income	1	1.911	0.615	6.762	2.026	22.565	0.002

Note: the numbers in parenthesis indicate the number of participants included in each of the models

Table 4: Barriers to co-participation in physical activity

How much of a barrier to co-participation in physical activity is?	People with MS (n=78)	Family Caregivers (n= 46)
	n (%)	
Lack of motivation		
small barrier	38 (48.7)	29 (63.0)
big barrier	17 (1.6)	13 (28.3)
Lack of confidence		
small barrier	43 (55.1)	38 (82.6)
big barrier	17 (21.8)	5 (10.9)
Lack of enjoyment		
small barrier	29 (37.2)	35 (76.1)
big barrier	29 (37.2)	10 (21.7)
Lack of time		
small barrier	42 (53.8)	19 (41.3)
big barrier	19 (24.4)	23 (50.0)
Lack of childcare/elder care support		
small barrier	25 (32.1)	9 (19.6)
big barrier	10 (12.8)	13 (28.3)
Lack of choice and control over physical activity and level of engagement		
small barrier	26 (33.3)	8 (17.4)
big barrier	32 (41.0)	37 (80.4)
Lack of accessible locations for physical activity		
small barrier	31 (39.7)	11 (23.9)
big barrier	30 (38.5)	32 (69.6)
Fitness level		
small barrier	27 (34.6)	23 (50.0)
big barrier	19 (24.4)	11 (23.9)
Embarrassment about personal appearance when participating in physical activity		
small barrier	37 (47.4)	25 (54.3)
big barrier	16 (20.5)	7 (15.2)
Variability or unpredictability associated with MS		
small barrier	30 (38.5)	7 (15.2)
big barrier	24 (30.8)	39 (84.8)
Energy requirement for physical activity is too high		
small barrier	26 (33.3)	22 (47.8)
big barrier	23 (29.5)	20 (43.5)
Total cost of participating in a physical activity program is high		
small barrier	21 (26.9)	7 (15.2)

big barrier	37 (47.4)	37 (80.4)
Safety issues within the community		
small barrier	44 (56.4)	23 (50.0)
big barrier	4 (5.1)	16 (34.8)
Bad weather		
small barrier	22 (28.2)	21 (45.7)
big barrier	26 (33.3)	21 (45.7)

Note: the percentages do not add up to 100% because we included only small and big barrier response options in the table for ease of presentation.

Figure Captions

Figure 1. Flowchart showing study recruitment process

Figure 2. Activities in which the participants routinely engage. Dark grey bars represent the activities in which people with MS routinely engage. Light grey bars represent the activities in which family caregivers routinely engage.