



# Physical Activity Motivation And Benefits In People With Multiple Sclerosis

By: **Kimberly S. Fasczewski**, Diane L. Gill & Sara M. Rothberger

## Abstract

**Purpose:** Multiple sclerosis is a degenerative neurological disease that affects 2.1 million people worldwide. There is no cure, but an expanding body of research supports the positive impact of physical activity and suggests physical activity has benefits for the individual's psychological and physical well-being. **Material and methods:** Using Self-Determination Theory as a framework, mixed methods with a focus on qualitative interviews were used to explore physical activity motivation and benefits with a sample of highly active people with multiple sclerosis ( $n=15$ ). Disability level ranged from not disabled to wheelchair bound with the majority of participants reporting minimal impact from multiple sclerosis. Survey data were collected using a number of open-ended questions along with measures of self-efficacy, self-determined motivation, physical activity, and quality of life. Additionally, eight individuals participated in semistructured telephone interviews focused on (a) motivation and strategies used to maintain physical activity and (b) the benefits and impact of physical activity in their lives. **Results:** The main findings were consistent with Self-Determination Theory; participants described feelings of accomplishment and competence in both their physical activity and daily life, as well as a sense of independence and autonomy. Similarly, all participants cited benefits, and the main themes were enhanced satisfaction with life and an overall positive outlook on life. **Conclusion:** Results provide insight into the role of physical activity in a highly active sample and have implications for professionals working in physical activity settings with the multiple sclerosis population. Interventions aimed at increasing long-term physical activity adherence should focus on increasing autonomy and competence for physical activity in the individual and promoting potential increased quality of life outcomes from physical activity participation.

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# Physical activity motivation and benefits in people with multiple sclerosis

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## ABSTRACT

**Purpose:** Multiple sclerosis is a degenerative neurological disease that affects 2.1 million people worldwide. There is no cure, but an expanding body of research supports the positive impact of physical activity and suggests physical activity has benefits for the individual's psychological and physical well-being.

**Material and methods:** Using Self-Determination Theory as a framework, mixed methods with a focus on qualitative interviews were used to explore physical activity motivation and benefits with a sample of highly active people with multiple sclerosis ( $n=15$ ). Disability level ranged from not disabled to wheelchair bound with the majority of participants reporting minimal impact from multiple sclerosis. Survey data were collected using a number of open-ended questions along with measures of self-efficacy, self-determined motivation, physical activity, and quality of life. Additionally, eight individuals participated in semistructured telephone interviews focused on (a) motivation and strategies used to maintain physical activity and (b) the benefits and impact of physical activity in their lives.

**Results:** The main findings were consistent with Self-Determination Theory; participants described feelings of accomplishment and competence in both their physical activity and daily life, as well as a sense of independence and autonomy. Similarly, all participants cited benefits, and the main themes were enhanced satisfaction with life and an overall positive outlook on life.

**Conclusion:** Results provide insight into the role of physical activity in a highly active sample and have implications for professionals working in physical activity settings with the multiple sclerosis population. Interventions aimed at increasing long-term physical activity adherence should focus on increasing autonomy and competence for physical activity in the individual and promoting potential increased quality of life outcomes from physical activity participation.

## ► IMPLICATIONS FOR REHABILITATION

- Multiple sclerosis is a chronic degenerative neurological disease that the individual lives with for a majority of the lifespan.
- Physical activity is one means that has been shown to aid in the control of multiple sclerosis symptoms.
- Increasing patient understanding of the benefits of using physical activity as a means to control multiple sclerosis symptoms may result in long-term physical activity adherence.
- Physical activity interventions that develop feelings of competence and independent choice in the patient may be more successful for long-term participation.

Multiple sclerosis (MS) is a chronic degenerative neurological disease that attacks the central nervous system at varying rates resulting in damage to the myelin covering and underlying nerve cell fibers [1,2]. This results in reduced or lost physical and cognitive functions with the location of the neurological damage dictating the type of symptoms [3,4]. MS is a long-term disease; there is no cure and it is typically diagnosed when the individual is in their late teens or early 20's and are otherwise healthy [5]. The only treatments currently available are disease modifying drugs designed to control symptoms and/or slow progression, and behaviors designed to control symptoms and improve quality of life (QOL).

Physical activity (PA) has been shown to minimize physical MS symptoms and improve cognitive ability, but many individuals with MS avoid PA [6,7]. PA can be defined as activity that increases heart rate, requires large muscle group movement, and gets the body moving [8]. Currently, only a small proportion of

individuals with MS report meeting the minimum guidelines for PA for patients with MS [9,10]. The implementation of PA as a supplemental treatment for patients with MS who are sedentary is a growing research area [11]. A review of this research shows that numerous physical characteristics (muscular strength, aerobic capacity, walking performance, fatigue, balance, and gait) as well as QOL can be improved [12]. A recent meta-analysis indicated small but significant improvements in walking mobility in patients who participate in exercise programs [13]. Additionally, PA has been shown to reduce MS flare-ups [6,7] and disease progression in some patients who incorporated long-term PA into their lives [14].

In addition to physical benefits, PA participation has been shown to increase self-efficacy and optimism, which can have a positive effect on an individual with MS's motivation for PA [15,16]. Individuals with MS who report higher self-efficacy also report higher levels of PA, and PA interventions that have been designed around increasing self-efficacy increase PA [16].

Participants with MS in PA programs report higher levels of functioning and overall QOL than nonphysically active controls [17]. A recent meta-analysis confirms this positive impact of PA on QOL for those with MS [18]. It appears that PA positively influences overall QOL while aiding in physical MS symptom management [12]. Furthermore, for individuals with MS, when exercise improves physical performance, self-efficacy also improves [6], creating a PA – self-efficacy cycle that leads to improved QOL.

There is a subset of the MS population who are highly physically active. These individuals not only meet the recommended minimum for daily PA participation, they exceed it. A recent case study of a highly physically active elite amateur mountain bike racer with MS (Author) suggested that PA was linked to the participant's perceived ability to control her disease and that PA participation increased her overall QOL. The next logical step is to examine the role of PA in a larger sample of highly physically active individuals with MS.

The current research explored the motivation for and benefits of PA in a subset of the MS population who are highly physically active. Using Self-Determination Theory as a framework, motivation and benefits of PA were explored. Self-Determination Theory is a cognitive behavioral theory that relies on the basic needs of competency, autonomy, and relatedness as motivators of behavior [19,20]. The higher an individual is on these constructs, the more self-determined they are and the more likely they are to continue the behavior [21]. This research sought to answer two questions. First, what motivates individuals with MS to maintain high levels of physical activity? Second, what are the benefits and perceived impact of PA in their lives? It is expected that the benefits will include MS symptom control, increased feelings of competency, autonomy and relatedness for PA, and that those benefits will contribute to a perception of increased QOL. Understanding this motivation and the resulting perceived benefits is the first step towards developing effective interventions for increasing PA in all individuals with MS.

## Methods

This research uses mixed methods including surveys with a sample of highly active participants with MS, and semi-structured interviews with a subset of this sample. A phenomenological approach with a concurrent nested design was used; the majority of the analyses originated from the interview data [22,23]. Quantitative data were used for a clear, detailed description of the sample and to provide a numeric value to the Self-Determination Theory and quality of life measures, and qualitative data were then used to provide an in-depth picture of the ways individual participants exhibited these constructs in their lived experiences. Research was approved by the Institutional Review Board and informed consent was obtained from all participants.

### Participants

Participants were recruited using social media (Facebook link to a survey shared on personal Facebook pages) and word of mouth (participants encouraged others they knew to participate – primarily through sharing the Facebook link). Inclusion criteria were regular PA participation and a clinical diagnosis of MS at least 1 year prior. All participants reported being diagnosed with the Relapsing Remitting form of MS. For the purposes of this research, PA was defined as two times the score deemed “sufficiently active” by the Godin Leisure-Time Physical Activity Measure [24,25]. This was chosen because the Godin give recommended

level of PA for minimal health benefits and this project was interested in individuals that were highly physically active, meaning they exceeded the minimum necessary. From the original 21 respondents, 15 (4 men, 11 women) were determined to fit both the physical activity and disease diagnosis criteria for the study. The mean age of participants was 40.3 years (SD = 9.1), with a range of 21–50.

Out of the group of 15 highly physically active participants, eight (men = 1, women = 7) participated in follow-up interviews consisting of a single 20- to 60-min phone conversation. The mean age of the participants in the follow-up interviews was 43.5 years (SD = 10.03), Godin PA level was 91.8 (SD = 71.98), and reported time with MS was 7 years (SD = 4.34). Participation in the follow-up interviews was determined on a volunteer basis with participants leaving contact information at the end of the survey if they wished to participate. Ten participants initially agreed to participate in interviews but due to scheduling conflicts, only eight were interviewed. Seven participants were interviewed via telephone and one individual was interviewed in person.

### Survey

The online survey was developed and distributed using Qualtrics. The survey included demographic information (age, gender, race/ethnicity, MS status), established measures of self-determined motivation and quality of life, as well as self-efficacy and PA participation, and open-ended items.

### Motivation measures

The *Self Determination Scale* (SDS; [19], is a 10-item scale with two 5-item subscales (awareness of self, perceived choice) that can be combined. According to Self-Determination Theory, the more an individual is self-determined and intrinsically motivated, the more likely they will participate [20].

The *Behavioral Regulation in Exercise Questionnaire – 2* (BREQ-2; [26] is a multidimensional scale based on the motivation continuum in Self-Determination Theory that includes amotivation (not motivated at all), external motivation (motivated by rewards and punishments), introjected motivation (motivated by feelings of guilt or self-worth), identified motivation (motivated by the importance of the activity to personal goals), and intrinsic motivation (motivated by the inherent enjoyment of the activity). Each subscale is calculated individually and scores can also be combined on a weighted basis to calculate an overall relative autonomy index (RAI). Neither of these measures has been previously used to examine individuals with MS. To our knowledge, this is the first study that has examined PA in this population using Self-Determination Theory. The selection of the Self-Determination Theory and BREQ-2 measures was based on their previous validation and use with a wide variety of populations [27,28].

### Outcome measures

Three outcome measures were used. The *Quality of Life Survey* [29] has seven subscales (social, spiritual, emotional, cognitive, physical, ADL/functional, and integrated) that assess an individual's perceived quality of life. In addition to the Quality of Life survey, related constructs of life satisfaction and optimism were measured. The *Life Orientation Test-R* [30] measures optimism and pessimism. The *Satisfaction with Life Scale*, assesses overall satisfaction with life [31]. All three of these measures have good

psychometric properties and have been used with research on PA [30,32–35].

**Physical Activity.** PA levels were measured using the Godin Leisure Time Physical Activity Scale [25], which asks how often individuals engage in PA at light, moderate, or strenuous levels. A formula is used to calculate a MET score for weekly activity (9 × strenuous, 5 × moderate, and 3 × light). MET scores can be used to classify PA participation into “sufficiently active” (24 and higher), “moderately active” (14–23), and “insufficiently active” (less than 14). Based on their responses, all participants were well above the PA classification of “active” ( $M = 75.7$ ,  $SD = 55.7$ ; range 34–264). The Godin has been used frequently as a measure of PA in MS research [6,36,37].

### Self-efficacy

Self-efficacy for PA was measured with two items using a 10-point scale: How confident are you that you can participate in PA at least 2.5 h per week, and how confident are you that you can participate in PA at least 5 h per week? An added question asked: How confident are you in your ability to live a normal life? The intentionally vague term “normal life” was used to allow the participants to introduce their individual perceptions of what they view as a normal life.

### Open-ended items

The following open-ended questions were also asked: Describe your overall well-being, What motivates you to be physically active, How does MS impact your life, How does PA specifically relate to your MS, and How does PA add to your overall well-being?

### Interviews

Participants were given an extensive list of interview questions in advance so they had time to think about their responses. These questions were as follows: How would you describe your overall well-being? Are you physically active? What are your typical activities? What motivates you to be physically active? How does physical activity relate to your overall well-being? What does physical activity mean to you? When were you diagnosed with MS? What is a typical day like? How does MS relate to your overall well-being? How does physical activity relate to your MS? What does being physically active mean to you? Have you always been physically active? When you were diagnosed with MS, did it affect your activity level? How did things change? How do you deal with the bad days? Do you continue with exercise on the bad days? Is there anything else you would like to share? Providing the extended list of questions in advance was intended to elicit thought so participants could provide more in-depth responses [38]. The goal during the interview was not to objectively get a direct answer to each question, but instead to create a dialog that would describe the individual’s experience as completely as possible.

The principal investigator (first author) began the interview by asking the participant to simply tell his or her story. If the participant did not address the questions while telling their story, the PI prompted them with the research questions. Interviews lasted between 20 minutes and 1 hour. All interviews were audiorecorded and later transcribed verbatim. The transcribed interviews were coded into clusters of meaning based on the constructs of Self-Determination Theory and quality of life by two independent researchers (the PI and a research assistant) [39,40]. Researchers then met to come to consensus on the data in these clusters and

Table 1. Descriptive information for all measures.

Measure <sup>a</sup> (possible range)	Mean (sd)
Self-efficacy PA (1–10)	8.63 (2.50)
Self-efficacy to live a normal life (1–10)	8.27 (2.60)
Godin PA level (METS) (34–264) <sup>b</sup>	75.7 (55.73)
Motivational measures	
SDS Self-awareness (1–5)	3.89 (0.67)
SDS choice in life (1–5)	4.13 (0.48)
SDS All (1–5)	4.01 (0.40)
BREQ-2 amotivation (1–5)	1.08 (0.26)
BREQ-2 external (1–5)	1.63 (0.74)
BREQ-2 introjected (1–5)	2.71 (0.99)
BREQ-2 identified (1–5)	4.57 (0.60)
BREQ-2 intrinsic (1–5)	4.50 (0.63)
Outcome measures	
SWLS (5–35)	28.6 (2.92)
LOTR optimism (5–15)	12.47 (1.64)
LOTR pessimism (5–15)	9.33 (1.76)
QOL social (5–25)	21.0 (3.87)
QOL spiritual (5–25)	17.34 (5.94)
QOL emotional (5–25)	19.56 (3.24)
QOL cognitive (5–25)	16.33 (4.42)
QOL physical (5–25)	20.34 (3.52)
QOL ADL/functional (3–15)	13.93 (1.34)
QOL integrated (4–20)	17.33 (1.71)

<sup>a</sup>For all measures, a higher score indicates higher levels of that construct.

<sup>b</sup>Observed range, actual possible range is 0 and above.

to develop consensus themes [40]. The coded data from these clusters produced two main themes: (a) motivational strategies used to maintain physical activity, and (b) benefits and impact of physical activity (PA), which were then discussed and interpreted jointly by the two researchers. Data were explored in terms of these two themes. The quantitative data were used to contextualize the results of these analyzes and highlight trends.

## Results

### Survey results

Twenty-one individuals responded to the online survey. Of those, four were removed because they did not complete the entire survey and two were removed because they did not meet the PA requirements. Participants were primarily female (11 women, 4 men), all were Caucasian, had been diagnosed with MS between 1 and 37 years ago, and reported being highly physically active; all but 2 reported being employed. As Table 1 shows, participants had high self-efficacy, self-determined motivation, and quality of life. Participants reported high scores on all measures associated with self-determined motivation, including Self Determination Scale scores, the more self-determined scores on the Behavioral Regulation in Exercise Questionnaire (intrinsic, integrated, identified), and lower scores on the less self-determined scales (amotivation, external, introjected). Participants also had high scores on the outcome measures of optimism, life satisfaction, and all Quality of Life Scale domain scores.

Pearson correlations of PA (Godin METS) with the main motivation and outcome measures were calculated, but given the small sample ( $n = 15$ ), few correlations were statistically significant. PA level was highly correlated with self-efficacy for PA participation ( $r = 0.728$ ,  $p < 0.01$ ), demonstrating that individuals who believed they had the ability to be active were more likely to be active. Interestingly, PA was also highly correlated with self-efficacy for the ability to live a normal life ( $r = 0.734$ ,  $p < 0.01$ ). Although correlations of PA with the main motivation and outcome measures were not statistically significant, PA was correlated at low–moderate levels with Satisfaction with Life Scale ( $r = 0.207$ , n.s.) and at higher moderate levels with integrated QOL ( $r = 0.488$ , n.s.).



**Table 2.** Demographics for interview participants.

Participant (Alias)	Gender	Age	Godin PA Level	Years with MS	Activities	Employment
Carrie	F	50	55.5	13	Mountain biking	Registered nurse
Kelly	F	44	50	5	Yoga, Zumba, Tennis, Cycling	Respiratory therapist
Becky	F	35	88	12	Cycling, Yoga, Bowling, Hiking	Data analyst
Heather	F	29	63	1	Running, Cycling	Teacher
Deb	F	61	95	9	Swimming, Cycling, Running	Unemployed
Christopher	M	37	77	8	Swimming, Cycling, Running	Surveyor
Michelle	F	49	42	6	Swimming, Walking	Registered Dietician
Abby	F	43	264	2	Running, Swimming, Weights, Core, Yoga, Boxing	Curator of art museum
Mean (SD)		Age 43.5 (10.03)	PA Level 91.8 (71.98)		Years MS 7 (4.34)	

### Open-ended survey responses

Although the five open-ended questions at the end of the survey were optional, all 15 participants responded. The responses were anonymous. Common themes are presented for each research question in the following section.

*Describe your overall well-being.* All participants reported high levels of satisfaction with their well-being. Participants were happy with their lives and the future. "Great! I live each day as if it were my last and in doing that I believe everyday was better than the previous." "Excellent," "Overall well-being is good to excellent most days."

*What motivates you to be physically active?* Participants reported three main themes: health ("I want to stay healthy"), stress relief ("The desire to release stress, enjoy, and escape"), and MS symptom control ("I know that MS is going to take over some day ... I'm pushing that out as far as I can by exercising and eating right," "Being active is my way of controlling my disease"). All three themes were strong motivators and nine of the participants reported more than one reason for PA participation. Twelve of the 15 individuals cited MS symptom control as the biggest motivator in remaining physically active.

*How does PA add to your overall well-being?* Two main themes emerged, physical fitness/strength, and QOL/mental wellness/happiness. Overall fitness and strength was cited by 12 of the 15 participants. Individuals liked the feeling of being strong and capable of physical movement; six participants cited physical activity as the primary reason they were able to move the way they could. "It's crucial that I stay physically active. I know others who have not and have never been able to regain that mobility," "It is therapeutic," "it keeps me fit and strong," and "I feel better overall." Physical activity was also cited as a catalyst for maintaining a happy life by six of the participants. "It makes me happier," "better mood," and "once I have set an athletic goal and accomplish that goal ... I am rewarded with an amazing sense of self-worth." Five participants cited both themes as ways that PA aided their overall well-being. "It is my entire being of physical, mental, and spiritual well-being."

*How does PA specifically relate to your MS?* All participants reported using PA as a means to control MS and an important factor in their battle with the disease. "I feel it keeps me from suffering the effects of MS," "Taking care of myself through PA gives me the strength to fight my MS when I am dealing with an exacerbation," "I feel better when I stay active."

*How does MS impact your life?* Two themes were apparent: MS is just part of life, and physical limitations due to MS. Eleven of the 15 participants felt that MS was just part of life and who they were; they learned to live with it. "It is part of me, I am MS. But I also have a life so they have to intertwine," "I honestly forget I have it," and "MS is just a hurdle on the road of life." Additionally, three participants looked at MS as a positive instead of a negative, suggesting that it has taught them to live a more meaningful, full life. "I treat it as the best thing that has ever happened to

me ... when I was diagnosed I realized how much worse my life could be." Seven participants also spoke of the limitations that they lived with due to their MS. "It has slowed me down. When I am tired I feel really wiped out," "It affects my sleep patterns," "Mostly just cognitive fatigue," and "some days barely at all and others a disorienting obstacle course."

### Semistructured interviews

Eight of the participants from the original sample agreed to do in-depth, semistructured interviews. These participants were involved in PA that ranged from endurance sport participation (triathlon, competitive cycling, running races) to recreational physical activity (yoga, walking) to activities for individuals with limited mobility (pool therapy, assisted weight exercises). A brief description of their demographics can be found in [Table 2](#).

The semistructured interview questions explored the individual's PA participation, MS symptoms, and the relationship of both of these to overall QOL. The researchers coded these responses first into categories and then into two main themes: (a) the benefits and impact of PA and (b) strategies they used to maintain physical activity. These themes were related and responses often led from one theme to the next during the conversation, and several subthemes emerged.

### Benefits and impact of PA

All participants reported experiencing benefits of PA related to *controlling MS symptoms* and improving QOL. They reported a direct link between PA and their ability to live the life they were living, and credited PA with physical and psychological benefits. Some participants spoke directly about the relationship between PA and their MS: "I had an MRI a couple of months ago. I don't have any new lesions, I'm basically stable ... I really think it was because of the exercise ... I think it has helped a lot. I feel a lot better now." (Kelly). "For 4 years I was not able to do any real exercise or training as I was very ill. But with my (PA) plan in place and dedication to getting better, I have been able to stop the progression of the MS and also reverse the damage" (Christopher). Some extended this to the ability to control other aspects of their life: "(PA) helps my well-being so much because it is that space ... whether it's the disease itself that's frustrating you or something silly in your life or something big in your life. That's where it helps my mental well-being and I haven't ever found something that fully does that as well" (Abby), and "It's (PA is) part of my life and helps me greatly to cope with life's pressures and stresses" (Christopher). For some, an active lifestyle was used as a coping mechanism. For others, this physical symptom control resulted in other psychological changes. Abby talked about taking boxing classes that benefited her physically, but also greatly increased her self-efficacy for physical movement. "My latest thing is boxing because it's helped me with balance ... I can even jump rope ... I didn't think I'd be able to jump rope again ... Exactly why do I

want to jump rope; it was just because I felt like I should be able to do that again ... So that's been one of my coolest discoveries." (Abby) For her, this return of physical functioning is a positive change on its own but the confidence she has gained, although not explicitly stated, impacts her overall QOL in arguably greater ways.

Being fit and active was important to these individuals, and was reflected in their concern about *fitness and overall health*. One participant, Deb, was a breast cancer survivor who had not been diagnosed with MS until after she had lived through the cancer. She used PA to deal with her cancer recovery and was using it the same way with her MS: "I always have stayed active. I think as I got older I got more active. With the breast cancer, and now with the MS, I want to stay in shape. I want to look good in my clothes. I want to stay healthy and I want to be strong enough to fight and to just be." Abby spoke about being fit and active and how being diagnosed had forced her to find different means of PA. Prior to diagnosis, she was a distance runner. "I realized that I still can't really run and definitely not competitively or the distances but then I realized that I needed that and that that was who I was ... I switched doctors and my new doctor was, 'Oh yeah, we can totally find a way for you to exercise' ... slowly started to add things back until I found a balance."

For some of the participants, PA was part of their identity. Heather spoke about how PA had always been part of her. "I have always just felt like there was no other option but to be an active person. I feel like it's a natural part of my life and always has been ... I just feel like I just need it to be happy." Participants talked about how they could not imagine what life would hold if they were not able to be fit and active.

Many mentioned that if they became physically limited and could not continue in their current PA of choice, they would have to find a different activity to remain active. "If for some reason I couldn't ride the bike, I would have to find something else, because it's just ... I don't know ... It makes everything better" (Becky). Michelle, who was more disabled, spoke of other ways that she had already adapted her routine in order to remain physically active. "I went from a solo bike to riding with my husband." She also spoke of switching to water aerobics because it helped her maintain activity in spite of physical limitations. Carrie spoke about what happened when others with MS were not active. "I have several friends with MS and they're not as active and they have a lot more symptoms, a lot more complaints. They're having exacerbations a lot more often and I credit the cycling and being active and always trying to be as fit as possible because I'm finding in the winter when I'm not doing as much, that's when my symptoms bother me the most."

The benefits these individuals report from PA participation are directly related to their abilities to control MS, and consequently improve overall QOL. These perceived benefits were a driving motivator behind the reason for PA participation. The common theme for all participants, regardless of what the activity was or how limited their physical abilities, was the importance of PA for controlling their MS, reducing overall stress levels, and consequently increasing overall QOL. PA was seen as a necessary part of life with MS and was part of who these individuals were.

#### *Strategies for maintaining PA*

*Social connections* in the form of family and friends were cited by all participants as motivators to remain physically active. "I am very conscious of my MS challenge so my motivation is to continue to work on my health so I can lead an active normal life and enjoy my family" (Christopher). Participants described

strategies to maintain PA, including incorporating friends into workouts and having a workout plan. Michelle was fairly limited by her MS and she spoke of a solution that involved her friends. "I have friends come once or twice a week and help me through exercise, and I find that it really feels good physically, but it's also I think, emotionally, really good, because it's a way to stay connected." In this way, PA is not only a way for Michelle to control her disease symptoms, it is a way to maintain the friendships and social connections that add to overall QOL. Others spoke of training partners or groups that were an important part of their PA routine. Remaining socially connected seemed to add to motivation for PA for all participants. This subtheme was very strong and appeared in every interview.

Strategies to remain physically active were also *focused on what the individual could do*, instead of dwelling on past abilities or current limitations. Abby explained: "It's what I can do today and I celebrate that and don't look back and think, 'you should be able to do this or you used to run a mile in this'." This type of sentiment was expressed by a number of the participants. Even Michelle, who was the most physically limited, spoke of the ways she focused on the things she could still do as motivators for continued participation. "I've always been very active looking for alternative stuff too, so I'm always rolling over every possible stone, and trying everything under the sun just to try to stay on top of things, and to try to stay positive."

Participants described a delicate *balance between the desire to use PA to control MS and the need to listen to their bodies* when it was time for recovery. "You have to be your own advocate. You know your body. If something's wrong with your body, then slow it down" (Kelly). She then went on to explain: "I know a lot of people push themselves too hard and I think that can cause them to go into relapse. I just have to be careful." Similar responses were reported by others. MS itself was motivation to remain active, so this balance was sometimes difficult. "If I'm tired one day, I will not do it (PA) I'm not obsessive about it at all. If I miss a couple days ... I miss it and I feel guilty that I'm not doing something." (Deb)

## **Discussion**

This project examined a subset of the MS population that was highly physically active in order to understand what advantages PA provided to these individuals. Participants clearly saw benefits to PA participation and these benefits were directly related to their overall QOL and motivation to continue participating in PA. The survey data showed high scores on motives and benefits were interconnected, and it was often difficult to distinguish whether a statement was referring to a motivator or a benefit. Participants were motivated by the benefits they perceived, and those benefits drove continued participation. Although the small sample size limited the meaningful statistical analysis of the survey data, high scores on the more self-determined subscales on the BREQ-2 (identified, intrinsic) in conjunction with the high SDS scores, reinforce the high levels of self-determined motivation for PA participation that was reported by participants in the interviews. This same trend was seen in the QOL scales, with high scores on the SWLS and on the QOL measures that directly related to both PA (physical, functional) and overall QOL (integrated).

Participants associated PA with an overall healthy lifestyle and this equated to high overall QOL. For these individuals PA equaled a high QOL in spite of MS symptoms. The survey data showed suggestive trends in the relationships between PA and QOL (integrated), and PA and satisfaction with life (SWLS), even in this small sample; and there is some evidence in recent research that

supports this type of PA/QOL relationship in individuals with MS [41]. The open-ended responses clarified the role of physical activity in participants' quality of life. For example, Abby spoke about taking up boxing and that she was able to physically do something that she could not do before – jump rope. She never explicitly stated that boxing improved her QOL or alleviated stress, but it was clear that her participation in boxing did both of these things. Although jumping rope was not a skill necessary for her to function in her daily life, she clearly associated this skill with being physically capable, and being physically capable with higher QOL. The act of jumping rope was representative of overall physical capabilities (balance), which translated into higher QOL. PA was associated with controlling MS symptoms and thus motivation for PA remained high when symptoms were controlled. This is an example of identified regulation – the individual is motivated to participate in PA because of the direct results (MS symptom control) they are gaining from that participation [21]. The highest score reported on the BREQ-2 subscales was that of identified regulation, suggesting that participants are driven to be physically active because of the perceived benefits gained from this PA.

Participants expressed some uncertainty regarding what they would do in the future as their physical abilities declined. This could be a reason that PA was so important. MS disease progression cannot be completely controlled, but PA, which is a means to help control the MS symptoms, can be controlled. Participants looked to others with MS who were not active and saw a version of where they might be in the future, which motivated their continued PA. For example, Carrie spoke about seeing others who were inactive and (therefore) disabled, and how she did not want to end up that way. In her view, MS symptoms were controlled by her PA participation, so she must continue to participate in PA. Michelle, who was already dealing with these physical limitations, had found ways to remain physically active. She still felt in control of her disease even though she had been forced to give up or alter many of her physical activities. These findings suggest that when individuals feel they are controlling their destiny, they will continue to participate in PA even as MS symptoms increase and physical abilities are limited. The motivation for this behavior is self-determined, the individual feels competent and in control of the behavior (PA) so it is likely to continue [20].

Participants viewed periods where they were inactive as times where MS symptoms bothered them more. Whether the relationship was coincidental, or the increased MS symptoms were a result of the inactivity, was irrelevant to these individuals. They perceived that PA controlled their symptoms and improved their QOL. Whether causation existed, participants perceived PA as necessary and a means for control over an uncontrollable situation.

All participants seemed to thoroughly enjoy PA. Regardless of PA type or the motivation, the activity itself brought enjoyment. No individuals participated in any PA modalities that were dictated by someone else. They all chose what and how they participated. This may have been one of the reasons for the enjoyment, PA was self-determined. According to Self-Determination Theory, autonomy is a critical element for long term adherence [20]. The individual freely chooses and controls the behavior (PA). No one is telling them that they need to do these specific activities. They are doing something they enjoy and experiencing benefits – all within their own control.

Interventions designed to increase PA in the MS population might focus on developing a sense of competence or efficacy for PA, while also giving choices to foster autonomy. This can be accomplished with education about PA and its benefits while aiding individuals in choosing activities they enjoy and

feel they can do. These strategies should increase self-determined motivation for PA, increase actual participation, and ultimately enhance overall quality of life in the individual. There is evidence that PA interventions based in Self-Determination Theory are effective in increasing PA participation in overweight individuals [42] and increased introjected motivation has been shown to predict long-term PA adherence in previously inactive women [43]. Given the findings in the current research, it is reasonable to explore this approach further as a means to increase PA in the inactive population of individuals with MS.

This research was limited in its scope and generalizability. This was a small, selective sample of highly active individuals who were recruited using one specific method (Facebook). The next logical step in this research is a larger study examining individuals with a wider range of MS symptoms. In the current study we are unable to determine whether the motivation and benefits for PA are specific to individuals with MS or unrelated to disease status. Future research with a wider range of MS patients may address the current limitations.

## Conclusions

Participants had high levels of motivation for PA and all had strategies that aided them in maintaining this participation. They also connected PA with MS symptom control and enhanced QOL. These individuals were very confident that they could remain physically active and were motivated to do so. All individuals directly related PA to improved MS symptoms, and this appeared to be the strongest motivating factor for continued participation. Even those individuals who were limited in mobility were very confident that they were able to do some type of activity and that the activity made a difference. Participants expressed high self-determined motivation for PA; they chose their activities and were confident they would stay active. These findings suggest that motivation for PA behavior can be explained by Self-Determination Theory. Individuals with high self-determined motivation for PA appear to participate in PA long term and this participation reportedly increases QOL. To this end, future interventions focused on increasing PA participation in individuals with MS should focus on increasing self-determined motivation for PA.

## Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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