Exercise and Quality of Life in Women With Multiple Sclerosis

Peter R. Giacobbi, Jr.
University of Arizona, USA

Frederick Dietrich
Florida State University, USA

Rebecca Larson and Lesley J. White
University of Georgia, USA

The purpose of this study was to evaluate perceptions of quality of life after a 4-month progressive resistance training program for individuals with multiple sclerosis (MS). A second purpose was to examine participants’ views about factors that facilitated or impeded exercise behavior. Qualitative interviews were conducted with eight females (Mage = 49.86, SD = 6.94) with relapsing remitting MS. Audio-tape recorded interviews were transcribed verbatim and coded. Walking performance improved (M = 13.08%, SD = 7.11). All participants perceived improvements in muscular strength and endurance while six indicated improvements in walking endurance and performance in tasks of daily living. Social benefits of participation were discussed by seven participants including interactions in the exercise environment. We concluded that supervised resistance training may promote improvements in QOL for women with relapsing remitting MS.

Keywords: exercise, multiple sclerosis, quality of life

Multiple sclerosis (MS) is a chronic degenerative disease of the central nervous system that impacts an estimated 350,000 people in the United States and 2.5 million worldwide (Zivadinov et al., 2003). People with the disease experience a variety of symptoms that influence physical function along with a cycle of declining fitness, compromised performance in activities of daily living such as walking and standing, and reduced quality of life (Ragonese, 2008; Schapiro, 2003). Since there is no known cure for MS, strategies that are effective in attenuating quality of life (QOL) decrements are important from clinical and theoretical perspectives. One
strategy that is emerging as a potential tool to increase QOL for individuals with MS is exercise behavior. An emerging body of literature reveals improvements in QOL and overall functioning as a result of participation in exercise (McAuley et al., 2007). Reported here are results of a mixed-method study that evaluated the impact of a fitness intervention on QOL for women with MS. Of particular interest was the perceived impact of the intervention on participants’ fitness, functional activities of daily living, and psychosocial responses.

Quality of life (QOL) reflects physical functioning, social relationships, psychological, emotional, and spiritual domains (Dijkers, 2005; Fuhrer, 2000; Hays, Hahn, & Marshall, 2002; Kahneman, Diener, & Schwartz, 1999; Lankhorst et al., 1996; Lobentanz et al., 2004). As noted by Dijkers, there are three distinct QOL research traditions with unique operational and conceptual approaches: QOL as subjective well-being (SWB), achievements, and utility. QOL as subjective well-being is characteristic of psychological approaches that focus on individuals’ internal subjective viewpoint, affective responses and evaluations of whether their goals, values, and life accomplishments are consistent with expectations. From this standpoint, the relative balance between individuals’ life expectations and priorities based on their own appraisals of reality is a major determinant of QOL. This QOL definition is closely aligned with open-ended qualitative interviews since this research approach allows individuals to describe and judge their own life experiences and QOL.

A second approach to the conceptualization of QOL focuses on people’s achievements and may include social relationships, accomplishments, material possessions, and overall health (Dijkers, 2005). Health-related QOL is a major subcategory of this medically-oriented definition with a focus on the presence versus absence of various symptoms. The use of a standardized symptom assessment, such as the SF-36, is the most common representation of evaluating QOL from this perspective (Ware, 2000).

The third QOL definition discussed by Dijkers is the utility approach, which encompasses domains that society deems important (Dijkers, 2005). This may include assessments of behavioral functioning in the areas of mobility, physical activity or fitness capabilities, sensory acuity, and social activities (Kaplan & Bush, 1982). The utility approach to defining and measuring QOL is considered to be more “objective” by Dijkers and involves assessments of disability-adjusted life years, which are measures of disease or disability burden expressed as the number of years lost because of poor health or disability (Menken, Munsat, & Tool, 2000).

Consistent with recent findings and recommendations in the adapted physical activity (PA) and rehabilitation sciences literature (Giacobbi, Stancil, Hardin, & Bryant, 2008; Tate, Kaplakjian, & Forcheimer, 2002), we adopted a mixed-methods conceptual and operational approach toward evaluating QOL by assessing one functional activity of daily living, walking, along with qualitative interviews to understand if and how a fitness intervention may impact eight women with MS. This area of inquiry is important because individuals with MS report lower QOL than those without (Murphy et al., 1998). Theoretically and empirically grounded physical activity interventions that promote favorable QOL outcomes may play an important role as part of a broader comprehensive approach to disease management for those with MS.

Despite evidence that appropriately prescribed physical activity and exercise can have important fitness, functional, and health benefits for those with MS,
individuals with this disease are less active than their matched non-MS counterparts (USDHHS, 2000). Evidence also suggests that participation in structured exercise programs yield improvements in muscle strength and fatigue resistance (White et al., 2004), cardiorespiratory fitness (Petajan, Gappmaier, & White, 1996), reduced cardiovascular disease risk (White et al., 2006), and improved QOL (McAuley et al., 2007; Motl, McAuley, & Snook, 2007; Motl & Snook, 2008). Thus, exercise may be an effective way to attenuate the loss or improve function of daily life tasks, overall health, and well-being.

A difficult question left unanswered from previously published exercise studies concerns individual and environmental factors that facilitate or impede participation in PA behavior over time. Therefore, a secondary purpose of this study was to explore barriers and facilitators to participation in PA behavior immediately after completion of the intervention and at 8 months follow-up. To inform this secondary purpose, we used the PA for people with disability model (PAD) as a framework to explore PA for individuals with MS (van der Ploeg, van der Beek, Luc, van der Woude, & van Mechelen, 2004). This theoretical model is concerned with the determinants of PA behavior for individuals with disabilities. It represents an integration of the International Classification of Functioning and Health model developed by the World Health Organization (World Health Organization, 2001) with social-psychological constructs that include behavioral intention, facilitators and barriers to physical activity, and self-efficacy. The PAD predicts that individuals’ body functions and structures, activities of daily living, and participation in social, recreational, and physical activity are determined by environmental (i.e., transportation, accessibility) and personal (i.e., health condition, facilitators, and barriers) factors linked to PA behavior. For instance, individuals with supportive friends and colleagues who live in communities that provide access to recreational facilities for individuals with disabilities would view these facilitating environmental conditions favorably and have intentions to engage in physical activity. The combined effect of favorable environmental conditions, personal factors, and behavioral intentions are predicted to lead to participation in various activities conducive to an active lifestyle. The PAD model is based on the rationale that important outcomes result from physical activity behavior including improved QOL.

A final rationale for this study is that much of the available research on QOL in people with MS is based on observations from forced choice questionnaires and experimental methodologies that limit the number of outcomes to be assessed (Dodd, Taylor, Denisenko, & Prasad, 2006; Fuhrer, 2000; Kasser, 2009; Peters, 1995). Qualitative interviews offer a complementary source of information to assess the impact of fitness interventions on individuals with MS and other groups. For instance, Dodd et al. (2006) reported results from qualitative interviews that assessed the perceived positive and negative effects of a 10-week strength training intervention for adults with MS. They coded interviews with seven women and two men and documented the physical, psychological, and social benefits of participations. Participants’ attitudes and beliefs about factors that facilitated program completion were documented and defined as extrinsic (e.g., knowledgeable leadership and group dynamics) and intrinsic (e.g., enjoyment, determination, signs of progress). Similarly, Kasser (2009) interviewed 12 adults with MS to gain insight into the meaning and motivation of exercise behavior. The author found that maintaining function and health, enhanced exercise self-efficacy, and feelings
of hope and optimism were important sources of motivation. The influence of role models and similar others in the exercise context was linked to exercise behavior and more clearly interpreted within the self-efficacy portion of social-cognitive theory (Bandura, 1997). These findings suggest that the perceived context of a fitness intervention may be linked to motivation and self-efficacy. Our intent was to extend these findings with multiple interviews, including a follow-up interview and the use of the PAD model to better understand factors linked to the maintenance or discontinuation of physical activity behavior following the program.

The purpose of this study was to use mixed methods to assess the perceived impact on QOL of a 4-month progressive resistance training program for eight women with MS. A secondary purpose was to examine factors that facilitated or impeded exercise behavior immediately after and at 8 months completion of the resistance training intervention.

**Method**

**Participants**

Eight individuals from the local community volunteered to participate in a 4-month progressive resistance training program. Table 1 shows a summary of participant characteristics along with their assigned pseudonyms. The participants were eight females between the ages of 40–63 years (Mage = 49.86, SD = 6.94) who were diagnosed with relapsing remitting MS between 2–16 years (M = 11.2, SD = 5.7) before study enrollment. Four participants reported performing 45–60 min of physical activity, 1–6 d/wk, while two reported 15–30 min of activity, 2–3 d/wk, and three reported 15 min or less of activity, 1–3 d/wk (i.e., walking, swimming, cycling). All participants signed an informed consent form that was approved by the university institutional review board before the start of data collection and all study procedures. The consent form also included the permission to use verbatim quotations for publication. The second author on this manuscript conducted all interviews. Inclusion criteria were (a) medical clearance for study participation, (b) confirmed diagnosis of relapsing remitting MS in remission (3 months), (c) disability scoring (according to the EDSS < 6.5/10). Participants with a documented stable dose of disease modifying agents and symptom management medications (spasticity, depression) were included.

**Study Design**

A dominant/less-dominant mixed-method design was employed that relied on interviews and fitness assessments (Giacobbi, Poczwardowski, & Hager, 2005). This research design relies on one dominant source of data to form major conclusions with the less dominant form of data used as a form of triangulation or corroboration. The dominant source of data here was from open-ended interviews with percent of improvement on three measures of walking serving in a complimentary or less-dominant source of information. Walking assessments and interviews were conducted at 0 and 16 weeks with a follow-up interview at approximately 8 months after completion of interview 2. The first and second interviews occurred in a laboratory setting while the eight month follow-up interview was by phone.
Table 1  Participant Pseudonyms, Demographic, Physical, and Health Related Characteristics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Diagnoses (Years Ago)</th>
<th>Loss of Balance Due to Dizziness</th>
<th>Bone Fractures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lisa</td>
<td>61</td>
<td>12</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Sophie</td>
<td>51</td>
<td>16</td>
<td>Yes</td>
<td>Toes</td>
</tr>
<tr>
<td>Lori</td>
<td>55</td>
<td>2</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Lucy</td>
<td>45</td>
<td>2</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Tammy</td>
<td>40</td>
<td>1.5</td>
<td>Yes</td>
<td>Toe</td>
</tr>
<tr>
<td>Veronica</td>
<td>44</td>
<td>12</td>
<td>Yes</td>
<td>Leg, foot, hand</td>
</tr>
<tr>
<td>Denise</td>
<td>55</td>
<td>10</td>
<td>Yes</td>
<td>N/A</td>
</tr>
<tr>
<td>Paula</td>
<td>48</td>
<td>15</td>
<td>No</td>
<td>None</td>
</tr>
</tbody>
</table>

Training Program

During the 4-month training period in a university based adult fitness center, participants performed three supervised weekly exercise sessions using conventional weight lifting machines in a climate controlled environment. Each participant was trained independently by personnel with previous experience working and training for individuals with MS. Before the onset of training, participants were familiarized with the equipment, proper lifting techniques, and had an opportunity to practice each exercise. Training protocols were standardized but also individualized to accommodate differences in fitness. Each training session began with a standardized warm-up of 6–8 repetitions (light effort) and light range of motion stretching for each muscle group used during the exercise session. During the initial 2 weeks of training, exercise volume was progressively increased to three sets of 8–15 repetitions for leg press, leg extension, leg curl, chest press, seated row, shoulder press, back flexion, and extension and plantar flexion and dorsiflexion using body weight. When a participant completed 15 reps with proper technique for two consecutive training sessions, the resistance was increased by 2–5%. To accommodate day-to-day variability in fatigue status, training weights were adjusted based on participant comfort. Participants were paid for their time and travel during the investigation. No continued consultation was provided to participants after completion of the 4-month training period; community support was made available (e.g., Y.M.C.A.) to facilitate continued PA support.

Measures

**Twenty-five foot walk.** The timed 25-foot walking test was used to assess mobility and leg function performance test and has high interrater and test-retest reliability and has been suggested to provide more precise information regarding ambulation in MS than other measures (Schwid et al., 1997). The fastest time of two
walking trials was used as the performance score and the percent of improvement from pre- to posttest is reported. A digital timing system (Brower IRD-T175, Salt Lake City, Utah) for walking timing was used because of its reliability.

**One-hundred foot walk.** Participants also completed a timed 100-foot walking test to complement the 25-foot walk using the same equipment and procedures as described above. While this measure does not have established reliability and validity, it was used here to determine whether potential mobility changes would be consistent across two tests as we felt it was a logical complement to the other walking tests.

**Six-minute walk.** The 6-minute walk test was used as a measure of exercise tolerance and overall functional capabilities (Guyatt et al., 1985) and has been well validated as an overall measure of ambulatory capacity for use with persons with MS (Goldman, Marrie, & Chen, 2008). The test was conducted as described by McGavin (McGavin, Gupta, & McHardy, 1976) and used standardized encouragement in the form of verbal prompts during each trial.

**Interview guide.** The interview questions were open-ended and nonleading in nature. The first interview focused on the following: (a) the participants’ physical activity, sport, and exercise experiences throughout their lives; (b) the nature, etiology, and impact of MS on daily life; (c) how MS has influenced their physical activity participation; (d) typical activities of daily living and any physical or psychological barriers to these aspects of life. The focus during interview 2 was on each participant’s thoughts, feelings, and overall attitudes about the resistance training intervention and factors that impeded or enhanced training program participation. Finally, interview 3 focused exclusively on the degree to which physical activity behavior was maintained 8 months after the intervention and factors that facilitated or impeded continued involvement. In all three interviews, various probes were used to encourage each participant to expand upon specific incidents that highlighted their experiences. Interviews lasted 20–60 min and were audiotape recorded.

**Data analysis interview data analytic procedures.** Interviews 1 and 2 were audio-tape recorded and transcribed verbatim while field notes were used for the third interview. Interviews were conducted by the same investigator to foster trust and rapport with the research participants (Fontana & Frey, 2000) and maintain consistency in data collection. The field notes and transcribed interviews were read thoroughly line-by-line by the first and second authors. During this preliminary stage of analysis, semantically similar units of information were coded and stored along with exemplar quotations that allowed us to characterize the participants’ experiences into more general categories of information during subsequent stages.

After the open-coding process was completed, focused-coding procedures were conducted whereby commonly mentioned raw data themes were sorted into categories (Corbin & Strauss, 2008). We examined the participants’ interview responses and coded information that revealed how the fitness training program impacted QOL in the areas of overall physical functioning, emotions, and participation in activities of daily living.
We used a constant comparative method to explore similarities and differences in the participants’ perceptions and experiences (Charmaz, 2000). This involved making comparisons (a) between responses reported by different participants, (b) within the same individuals’ reports across the three interviews, (c) with critical incidents and other incidents experienced by the same and different participants, and (d) from data derived within and between conceptual categories.

During the latter part of the coding process, sensitizing concepts allowed use of deductive processes by organizing and interpreting the emergent findings consistent with the extant literature. Sensitizing concepts provide ways to interpret qualitative data in a manner consistent with current theory and research (Charmaz, 2000; Corbin & Strauss, 2008). We used recent discussions centered on QOL and the PAD theoretical model as sensitizing concepts. Thus, we coded the participants’ statements to reflect QOL categories (Dijkers, 2005; Fuhrer, 2000; Hays et al., 2002; Tate et al., 2002) along with the constructs in the PAD model.

**Issues of data quality.** There is much debate about data quality, trustworthiness, or credibility among qualitative methodologists (see e.g., Corbin & Strauss, 2008). As this is a mixed-method design that relied primarily on qualitative data, we drew upon pragmatic conceptions of validity with several noteworthy criteria that can be used to judge the quality of the overall study generally and the qualitative interviews specifically. Ongoing discussions among the authors about the interviews, data analysis, and our overall conclusions were conducted throughout the investigation. Other more specific methodological procedures offered credibility and trustworthiness to our data as described by qualitative methodologists (Lincoln & Guba, 1985). First, the second author established prolonged engagement with the participants by conducting all three interviews in an effort to establish trust and rapport with the research participants. Second, the first two authors examined the raw data independently and discussed observed similarities and differences in the coding of the participants’ experiences. This discourse established general agreement about the observed data (Fontana & Frey, 2000; Lincoln & Guba, 2000). Later in the coding process, the third and fourth authors were involved in this discourse by helping us combine the fitness results with the interview data to add greater context to the overall findings. Third, an individual unacquainted and unfamiliar with the study conducted an independent audit by linking verbatim quotations with the labels in Tables 2 and 3 (Creswell, 1998). This process resulted in 88% agreement with the conceptual categories created by the authors. Fourth, the walking data from each participant are presented as a form of triangulation with the interview results. Fifth, first-person quotations provided by the participants were consistent with our own field notes, memos, and observations about the impact of the fitness intervention on participants. Indeed, our highly contextualized findings link aspects of the intervention, QOL concepts, and major determinants of PA behavior and offer a range of practical applications for exercise prescription and policy. Thus, applicability has been achieved as described by Corbin and Strauss. Sixth, negative cases are provided that demonstrate varied responses to the fitness intervention. Finally, we present richly detailed quotations from the participants along with pre- and posttest results from walking tests. Pseudonyms are used throughout the results and discussion to maintain participant anonymity.
Results

Mobility

Walking performance was obtained from six participants. Pre to post walking scores across the three tests (25-foot, 100-foot, and 6-min walk) showed an average improvement of 13.08% (SD = 7.11). Changes in individual walking measures are included below.

Interview Results

The focused coding resulted in two general dimensions labeled as physical and psychosocial responses to the intervention (see Tables 2 and 3). The open-ended nature of the interview questions resulted in responses coded as perceived

Table 2  Participants’ Perceived Physical Responses to the Intervention

<table>
<thead>
<tr>
<th>Participant</th>
<th>Standing</th>
<th>Walking</th>
<th>Balance</th>
<th>Endurance</th>
<th>Strength</th>
<th>Daily Tasks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lisa</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Sophie</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Lori</td>
<td>NM</td>
<td>↑</td>
<td>NM</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Lucy</td>
<td>↑</td>
<td>↑</td>
<td>NM</td>
<td>↑</td>
<td>↑</td>
<td>NM</td>
</tr>
<tr>
<td>Tammy</td>
<td>NM</td>
<td>NM</td>
<td>NM</td>
<td>↑</td>
<td>↑</td>
<td>NM</td>
</tr>
<tr>
<td>Veronica</td>
<td>NM</td>
<td>NM</td>
<td>NM</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Denise</td>
<td>↑</td>
<td>↑</td>
<td>NM</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Paula</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
</tr>
</tbody>
</table>

Note. ↑ = Perceived improvement; ↓ = perceived decline; NM = not mentioned during interview

Table 3  Psychosocial Responses to the Intervention

<table>
<thead>
<tr>
<th>Participant</th>
<th>Social Impact</th>
<th>Energy/Vigor</th>
<th>Emotional Responses</th>
<th>Confidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lisa</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Sophie</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Lori</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Lucy</td>
<td>↑</td>
<td>NM</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Tammy</td>
<td>NM</td>
<td>↓ after exercise</td>
<td>↑</td>
<td>↑</td>
</tr>
<tr>
<td>Veronica</td>
<td>↑</td>
<td>↑</td>
<td>NM</td>
<td>NM</td>
</tr>
<tr>
<td>Denise</td>
<td>↑</td>
<td>NM</td>
<td>↑</td>
<td>NM</td>
</tr>
<tr>
<td>Paula</td>
<td>↑</td>
<td>NM</td>
<td>↑</td>
<td>↑</td>
</tr>
</tbody>
</table>

Note. ↑ = Perceived improvement; ↓ = perceived decline; NM = not mentioned during interview
improvement, perceived decline, or no mention. These nonleading interview questions were inductively coded and defined by the first-order themes of standing, walking, balance, endurance, strength, and daily tasks. The participants’ psychosocial responses were defined by social impact, emotional responses, energy/vigor, and confidence.

Physical Responses

Standing. Five participants indicated that the progressive resistance training program had a positive impact on their ability to stand while the remaining three made no mention of this during the interviews. For instance, Lisa stated “I can stand longer. I have trouble doing that but I can tolerate more. . . It’s [resistance training] made a big difference, a good difference.” Lucy stated “It’s easier to get up and down . . . Just literally getting up and down . . . standing up and down. It’s a lot easier.”

Walking. Similar to standing, six of the eight participants reported they perceived improvements in their ability to walk while the other two made no mention of information related to this theme. Paula, who improved an average of 13% on the three walking measures, stated “I feel more confident going up steps.” Denise’s average improvement on the walking tests was 24% and she stated, “I can do things that I didn’t. I walked down the stairs for the first time in eleven years.” Lori improved an average of 19% on the walking measures. Her responses to the interview questions were congruent with these observations. She offered the following about a recent shopping experiences: “I have not used any of those electrical carts in any of the big stores in a long time now” and she went on to state “As fast as I push myself to walk . . . it was almost starting to be a slow run and I really didn’t think I could run anymore.”

Balance. Three participants perceived improvements in their balance while the remaining individuals made no mention of balance during the interviews. Paula, who improved 13% on the three walking measures stated “I feel more confident like going up steps . . . than I did before. Cuz I can feel my balance is better.” Sophie improved 7% on the walking measures and offered the following:

A year ago, I can remember having to go up a flight of steps carrying the stuff in somebody’s house. It was like “whoa oh” because the balance with the thing, you know being off balance and stuff. That’s better.

Endurance. All eight participants reported enhanced muscle endurance or delayed muscle fatigue that impacted a range of tasks of daily life. For instance, Lisa offered the following:

I can do a lot more. I can go to the mall and not wear myself out in an hour. I can stay there longer and do more of that. I was able to go to the Gardens a couple weeks ago.

She went on to state that she could “get around better and “I can stand up longer” while Sophie, who improved 7% on the walking measures, offered a similar view. “It [the exercise intervention] has helped me because I’m able to do things longer and walk longer.” Lucy stated, “I think I’m doing a lot more at home without getting
as tired.” Finally, Denise’s improvements across the three walking measures was 24% and her interview statements confirmed these observations. “It has affected my endurance a whole lot . . . I am able to go longer, farther, and feel pretty good by the time I get there.”

**Strength.** All eight participants perceived improvements in their strength and these experiences impacted performance and perceptions of confidence on a variety of daily life tasks. Lucy stated, “I think it [the resistance training intervention] made me stronger and it’s helped my confidence.” Paula’s average improvement on the three walking tests was 13% and she offered the following:

> Like I can tell the difference even getting in and out of my car or . . . we have a truck and I have to climb up so I’m able now to at least put my foot up there and kind of push myself on up in the truck. I can just feel the strength and I guess I have even more confidence in doing things now because of that.

Sophie stated, “It’s been good. I’m feeling better. I’m more toned. I can see it which is nice. I’m stronger. I actually have muscle.” Lori shared the following experience:

> I definitely feel stronger. I feel like I’m able to do more. One day about a week ago I was trying to get ready for something in our home and I wanted to repot a few plants outside. I was able to get the big bag of dirt that we had bought . . . . I went to the store and bought it and got it into the pushcart. I think a guy did help me get it into the car, but once home . . . 0I was able to move it to . . . 15 feet or something, but move it and deal with it and that was one of those really big bags of pine soil . . . I was less capable of doing that before.

**Daily tasks.** Six participants reported improved physical capabilities that impacted performance on daily tasks that included yard work, shopping, and chores around the house, while two made no mention of daily life tasks during the interviews. The other two made no mention of impact on daily tasks. Lori shared more information about shopping “I have not used any of those electric carts in any of the big stores in a long time now” and household chores “I think I’m doing a lot more at home without getting as tired.” Veronica, who improved 6% in walking performance, stated “Some of the chores I do at home like taking the garbage to the dump once a week is a little easier. Picking up the garbage bag out of the compactor is a little easier than it used to be.” Denise shared the following:

> Those activities it’s made it possible to physically do the things in a couple of hours that it was taking me four hours to do. So things are getting done. My daily routine has changed because of the fact that I can get more things done which means that I got more time for me.

**Psychosocial Responses**

Psychosocial responses to the intervention were defined by the first-order themes of social impact, emotional responses, and confidence. As the quotations below reveal, program participation was perceived to have a positive impact on overall emotional well-being and participants’ family and friends.
Social impact. Seven participants perceived a social impact linked to the intervention that included making new friends, camaraderie with the other participants and research staff, being less of a burden on caregivers, and the development of a support network: the remaining participant made no mention of social impact. Lisa offered the following: “I think it’s just easier for everybody. I mean, for my husband. He’s so wonderful. He’s done a lot for me. I can do more. I’m more able to do the things I should be doing.” She went on to offer the following sentiments about the study that reflected what all the other participants expressed:

I think it’s been beneficial to everyone . . . we talk to each other and compare notes . . . we’ve become real friendly and we talk about everything . . . I’m just so glad that I’ve been able to get in the study. It’s been so beneficial to me . . . and I’m happy.

Denise had an improvement of 24% in her walking performance and suggested that her experiences were very positive. She gained perspective and insights that had an important impact upon her:

I’ve gotten to meet some of the most fantastic people . . . including the people that are conducting the study. . . . I learned that I am not the only person in this boat. But I’ve also learned that there are more people out there than you would imagine that have what I have than I have ever imagined that’s willing to work with me or to understand what’s going on. But the experience with the program has been fantastic and I am really going to miss it.

For several participants, the perceived social impact and benefits served as motivation to maintain adherence during and after the intervention. Lisa stated, “Meeting people made me come” while Denise, who improved 24% on the walking tests, stated “I gotten really to care a lot about the participants and wondering how they are doing and seeing them.” Veronica offered the following:

Everybody here was encouraging for me to go on saying they thought it was the right thing. . . . You sort of have a built in support group right here with other people who do the same drug or go through the same stuff.

Energy/vigor. Four participants reported generalized improvements in their energy levels, three made no mention of this theme, one individual discussed decreased energy the day after exercise. Sophie stated, “I have more energy, particularly [immediately] after I exercise. . . . Since I’ve been doing this I’ve been having stuff every single day of the week. In the past I would do something one day and then rest the next day.” Lisa said “I never have to lay down or nap or something like that anymore at all. I’ll sit down for a while but not being real active I can get back up and do more.”

In contrast, Tammy, whose walking performance improved by 8%, stated that exercise resulted in decreased energy or increased fatigue the day following a scheduled workout; however, she perceived her increased fatigue in a positive manner as demonstrated by the following:

I felt good. I was tired. Like worn out tired but it was a good tired because you knew you worked out. So I usually went home except for on Wednesdays
when I went to go volunteer at the rehab hospital. But when I went home from there, I was just completely worn out tired but it felt good to be tired like that.

**Emotional responses.** Six participants claimed they had positive emotional responses due to the exercise program that included pride of accomplishment and being happy or in a better mood. Paula walking performance improved by 13% and she stated, “Even though we’re fatigued and tired we leave [with] that sense of accomplishment once you’ve gotten home and accomplished something.” Paula went on to describe the pride she felt sharing her experiences with her son:

The excitement of going to exercises like when my son comes home, I tell him about the exercising. It’s funny to them because they had seen me where I couldn’t do anything and now I’m telling them the exercises that I do and everything and they’re excited.

Lisa stated, “I smile a lot more and that’s good. . . . It’s been so beneficial to me and I just thank everybody because it’s wonderful and I’m happy” while Lori said, “I feel good about myself.” The following quotation from Lucy shows the linkage between her emotional responses to the intervention and how it influenced her general sense of self:

I think I’ve been in a better mood because just exercise and getting [an] exercise schedule is really good. And then building that muscle and then I was feeling better about myself and it tumbles over into everything else in your life.

A contextual analysis of Veronica’s situation revealed the difficulties she experienced on top of her disease and the complexities of intervening with individuals who have multiple and competing demands. She indicated during interview 1 that she was taking care of her 86-year-old mother-in-law, who was incontinent and had Alzheimer’s disease. She described her responses to the intervention during interview 2 and suggested that she became a better caregiver.

It [exercise] has definitely affected my mood. I am almost principle caregiver for my 86-year-old mother-in-law and she is getting worse. I’m able to deal with that a lot better. I don’t get as angry. I don’t get as impatient and I let a lot more things go because I’ve learned that there [is not] a darn thing I can do about it anyway.

**Confidence.** The final psychosocial theme that emerged concerned confidence and was characterized by a renewed sense of hope and motivation to try new activities and maintain an active lifestyle. Six of eight participants shared information and experiences consistent with this theme while the remaining two made no mention of this theme. Lisa stated, “I’m planning on being just extremely confident” while Lucy offered the following:

I think it made me stronger and it’s helped my confidence. I guess it has made me want to get out more to do things. I’ve got more confidence so I think I try more now even if I can’t do it. I’ll try it and see. I’ll get in the car and see I want to go to CVS [Customers Value Service] and just walk around with my walker.
Facilitators and Barriers to Exercise Behavior

A secondary purpose of this study was to assess factors that impeded or facilitated exercise behavior immediately after the completion of the study and at 8 months follow-up. These results are summarized in Table 4 and show that six participants continued to exercise immediately after the study was completed while two did not. Only three individuals reported that they were engaging in some physical activity at the time of the follow-up interviews. Those who did not maintain activity reported changes in medication, the holidays, surgery, and a lack of motivation as reasons for not exercising. Two individuals reported that they continued the same program of exercise once the study had ended while another two participants reported discontinuation and suggested that their lack of participation resulted from not having the same support systems in place as occurred during the 4-month intervention. In terms of facilitating factors, three individuals reported social support from family, other participants in the study, and facility staff were important factors during the study. However, since their overall levels of physical activity had declined since the study ended, these three participants were unable to discuss specific aspects of the intervention that facilitated PA maintenance after program completion.

Discussion

Our study used qualitative interviews and walking assessments to evaluate the perceived impact of a 4-month clinic-based progressive resistance training program of eight ambulatory women with MS. Verbatim quotations supplemented with results from walking performance tests revealed improvements in physical health, functional activities of daily living, and mental health constructs (i.e., psychosocial responses). The perceived improvements in overall health and physical function were corroborated with observed improvements in three walking tests. Overall, our findings indicated improvements in all three areas of QOL discussed by Dijkers (2005): subjective well-being, achievements, and utility. While causal conclusions would not be appropriate here, it is hoped that the descriptive experiences of the women who participated in this study will guide program development, education, policy, and clinical efforts focused on exercise behavior for individuals with MS.

Among the perceived benefits of program participation were those related to functional activities of daily living and physical activity behavior (e.g., muscular strength and endurance, walking, standing, other daily tasks), which are closely linked to the utility and achievement conceptual approaches to QOL. All individuals reported improvements in muscular strength and endurance after the study ended, while nearly half reported improvements in walking, standing, and balance. Many participants also noted changes in performance of daily tasks. Their statements included the ability to go to the mall, walk down a flight of stairs, in and out of a car, and stand and talk with others for extended periods of time. In some cases, these experiences were perceived milestones associated with happy and satisfying life events. These first-person descriptions of physical accomplishments and observed changes in walking outcomes for six of the eight participants provide evidence that exercise interventions can, in many instances, enhance the physical functioning and QOL in women with MS.
<table>
<thead>
<tr>
<th>Participant</th>
<th>After Study Completion</th>
<th>Currently Exercising</th>
<th>Physical Activities, Location, and Frequency</th>
<th>Barriers</th>
<th>Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lisa</td>
<td>Yes</td>
<td>No</td>
<td>Weight training at public facility 2 days a week</td>
<td>Holidays, new medication</td>
<td></td>
</tr>
<tr>
<td>Sophie</td>
<td>No</td>
<td>No</td>
<td>None</td>
<td>“No motivation”</td>
<td></td>
</tr>
<tr>
<td>Lori</td>
<td>Yes</td>
<td>No</td>
<td>Swimming, weight training at public facility 3 days a week</td>
<td>Holidays and recent hysterectomy</td>
<td></td>
</tr>
<tr>
<td>Lucy</td>
<td>Yes</td>
<td>No</td>
<td>Weight training at public facility 2 days a week</td>
<td>Urinary tract infection</td>
<td></td>
</tr>
<tr>
<td>Tammy</td>
<td>No</td>
<td>No</td>
<td>None</td>
<td>No reason given</td>
<td></td>
</tr>
<tr>
<td>Veronica</td>
<td>Yes</td>
<td>Yes</td>
<td>Water aerobics, weight training, and cardio-respiratory exercises at 5 days per week</td>
<td>M</td>
<td>Other study participant at gym</td>
</tr>
<tr>
<td>Denise</td>
<td>Yes</td>
<td>Yes</td>
<td>Walking 5 days per week and yard work</td>
<td>M</td>
<td>Social contact with other study participant</td>
</tr>
<tr>
<td>Paula</td>
<td>Yes</td>
<td>Yes</td>
<td>Weight training and stretching at home 6 days per week</td>
<td>M</td>
<td>Social contact with other study participant</td>
</tr>
</tbody>
</table>
The participants’ psychosocial responses to the intervention were consistent with previous research (Dodd et al., 2006; Kasser, 2009). Nearly all the participants reported improved mood and positive emotional states (e.g., excitement, happiness, and pride of accomplishment) to describe their experiences, accomplishments, and relationships developed during the intervention. These findings indicate that some participants’ experienced improvements in subjective well-being, which is the psychological component of QOL noted by Dijkers. While the perceived physical responses to the intervention are important, these psycho-social benefits from the fitness intervention are equally noteworthy since they may serve to motivate individuals for continued involvement in PA behavior.

Three sources of social impact were discussed by participants that reflected satisfaction working with the other participants, research personnel, and perceptions of being less burdensome on family members and caregivers. The perceived lessening of caregiver burden reflected a sense of guilt about the impact of the participant’s condition on family members. These findings are unique from those observed by Dodd et al. (2006) and suggest that PA may impact other family members in ways yet to be clearly determined. It is possible that increased physical function that occurs during and after an exercise program may ease the psychosocial burden for those with this disease and their companions, family members, and other caregivers.

Our psychosocial findings are consistent with Kasser (2009), who reported that MS participants valued and derived motivation from the social context of exercise behavior. Important individuals in the exercise context included research personnel and other individuals with MS. Once the intervention ended, the participants indicated during follow-up interviews that they did not maintain as intensive of a PA routine; this was not surprising given the level of supervision and incentive provided to participants. These findings suggest that a supportive exercise context could play an important role in exercise adherence.

The participants’ interview responses combined with the fitness outcomes demonstrate that the participants in this study experienced improvements in each of the major components of QOL discussed by Dijkers. Given the current findings and extant literature, it appears that PA behavior is one way to ameliorate the slow and progressive decline for some individuals with MS (McAuley et al., 2007; Motl et al., 2007; Motl & Snook, 2008).

With regard to PA behavior maintenance and facilitating factors, social support and benefits within and outside the exercise facility were seen as crucial for the participants. Upon completion of the program, a majority of the participants returned to preintervention activity levels. Overall, these results support the PAD model as social, physical, functional, and environmental factors were linked to the participants’ intentions and behaviors (van der Ploeg et al., 2004). Indeed, social influences, assistance from research personnel, and the availability of this project in the local community were noted as important environmental factors linked to the participants overall experiences. Once the project was terminated, the environmental factors predicted to maintain PA by the PAD model were no longer present and the follow-up interviews revealed that many returned to a less active level of PA behavior. These findings indicated that even with participants’ intentions and confidence, the absence of environmental facilitators to PA behavior prevented them from being as active as they were during the intervention. The practical implications of these findings are that policy makers and clinicians should attempt
to provide supportive structures and relationships, when feasible, that facilitate the PA behavior of individuals with MS.

While study findings provide new information regarding the physical and psychosocial aspects of clinic based exercise participation in a small group of women with MS, several limitations should be noted. Study participants may have offered biased responses based upon their understanding of the study purposes and/or familiarity with interview questions. A control group was not included thus making it difficult to discern the comparative impact of the exercise program on study outcomes. Clearly, future replications of this investigation are needed that include a control group to corroborate our findings and establish stronger empirical links between exercise and quality of life for women with MS. Another important limitation was the inclusion of only women in this study. A critical examination of participant quotes shows that the perceived impact of the intervention was related to gender roles such as shopping, household chores, and caregiving. Since women’s experiences with MS are vastly different than men (Olsson, Lexell, & Soderberg, 2008), future research should assess the perceived impact of this disease on men’s QOL.

An ongoing challenge in working with research participants involved in exercise interventions relates to the continued participation upon study conclusion. Providing participants with guided exercise for 3 days per week on an ongoing basis is not feasible. Once the formal intervention ended, many participants were unable to maintain PA at the same levels as during the program. One participant, Denise, expressed a sense of loss that the study was concluding during interview 2. In the current study, these ethical concerns were outweighed by the knowledge gained since the long-term prognosis for individuals with MS necessitates that researchers and practitioners search for ways to improve QOL. Indeed, participant concerns are an ongoing challenge in exercise interventions. This research project demonstrated that properly supervised PA interventions are a safe and potentially effective way to positively impact the QOL of women with MS. Although the QOL gains were limited to the time spent in the intervention, it would be unreasonable to expect longer-term changes in PA behavior given the time and resources dedicated to the participants. Future researchers must consider this ethical challenge by nurturing other community resources or home-based models for continued involvement in exercise and PA activities once their interventions end.

Our qualitative findings coupled with other published reports support efforts to encourage physical activity and exercise behavior for individuals with MS (Dodd et al., 2006; Kasser, 2009; Motl & Snook, 2008). Policy makers, clinicians, and health practitioners are encouraged to consider the potential physical and psycho-social benefits of exercise for those with MS and advocate appropriate recommendations for safe activity participation. The social context of fitness participation should include other similar peers, role-models, and fitness practitioners with expertise in MS. Based upon the available evidence, it seems reasonable to encourage, apply, or test different exercise interventions for individuals with MS that include ways to sustain PA behavior for the longer term.

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References


