

Benefits of Multiple Sclerosis Adult Day Program Participation for People with Multiple Sclerosis

A Qualitative Study

Jocelyn Marrow, PhD; Allison Roeser, MHS, PCC; Joseph Gasper, PhD; Nicolas G. LaRocca, PhD;
Debra Frankel, MS OTR

Background: Multiple sclerosis adult day programs (MSADPs) are nonmedical service programs that provide care and support to people with multiple sclerosis (MS) experiencing levels of impairment that interfere with employment and activities of daily living. The purpose of this study was to identify how program participants think MSADPs benefit them.

Methods: We conducted in-depth interviews with 95 people with MS who were MSADP participants. Interviews occurred as part of site visits to ten programs across the country. We supplemented participant interviews with interviews of program staff and ethnographic observation of activities at each site over 1 to 3 days.

Results: Participants reported several benefits from participating in an MSADP. Almost universally, participants explained that receiving and giving social support were the most important benefits. Other positive outcomes described included increased emotional well-being, better understanding and acceptance of MS, practical know-how for accomplishing ordinary tasks, and increased mobility and improved motor functioning.

Conclusions: Participants believe that MSADPs have a profound influence on their psychosocial health, much of which they attribute to membership in a socially cohesive community. Clinicians and policy makers should consider recommending these programs for people with MS who have unmet psychosocial needs and experience functional impairments. *Int J MS Care.* 2020;22:201-207.

Impairments secondary to multiple sclerosis (MS) make maintaining normal life routines, including employment and family, social, and recreational activities, difficult. Symptoms of MS include pain, fatigue, and impairments to mobility, cognition, vision, sensation, and balance.¹ Individuals experiencing MS-related impairments are frequently in their early adult or middle adult years—the time of life when most people

are raising young families, building careers, and earning a livelihood.²

Impairments related to MS can affect nearly every aspect of social life. Fatigue and impaired mobility may end the careers of people with MS well before they reach retirement age.³ People with MS may find that going out to see relatives and friends and participating in recreational activities in the community are increasingly tiring and difficult, resulting in fewer, and less close, relationships outside the home.⁴ Some individuals with MS find their daily activities increasingly limited to self-care and light household chores because completing simple tasks consumes increasing amounts of time.³ Furthermore, some individuals' mobility or cognition may become so impaired that they need constant aid

From Westat, Rockville, MD, USA (JM, AR [now a consultant in San Francisco], JG); and the National Multiple Sclerosis Society, New York, NY, USA (NGL, DF [both now retired]). Correspondence: Jocelyn Marrow, PhD, Westat, 1600 Research Blvd, Rockville, MD 20850, USA; e-mail: jocelynmarrow@westat.com.

DOI: 10.7224/1537-2073.2019-019

© 2020 Consortium of Multiple Sclerosis Centers.

and supervision due to difficulties with feeding, toileting, and taking medications, further compounding the difficulties associated with maintaining friendships in community settings. Avoiding social isolation can be a challenge for people with MS.

Studies demonstrate that social exclusion and lack of social support exacerbate depression and anxiety in people with MS. Depression is associated with stigma, isolation, and more severe MS symptoms.⁵⁻⁸ Overall, people with MS are at high risk for depression, with the lifetime prevalence estimated to be approximately 50%.⁵ One study demonstrated that low social support predicts anxiety in people with MS.⁹ Depression may increase the difficulties of coping with MS, and research suggests that depression actually makes the disease, and disease-related impairments, worse. Depression worsens MS disease progression¹⁰ and exacerbates functional limitations.¹¹

Surveys of people with MS and their professional health care providers resoundingly describe emotional and social support as the greatest unmet need of people with MS. British respondents with MS who participated in a survey reported that their top needs were to have better social connections and to feel less depressed.⁹ A study of Australians with MS found that respondents with the most disabling MS symptoms were those who were the most dissatisfied with the existing support groups, psychological counseling, and health education services offered to them.¹² Furthermore, a survey of health professionals in Germany found that professionals perceived an important unmet need for “support from family and friends” because patients “could barely cope with being uprooted from their previous life ... [and] suffered from low social acceptance accompanied with stigmatization and social exclusion.”^{6(p146)}

Multiple sclerosis adult day programs (MSADPs) are nonmedical service programs designed to provide care and support to people with MS experiencing disability and functional limitations that interfere with employment and activities of daily living (ADLs).¹³ Adult day programs provide supervision, wellness services, activities, exercise, health education, emotional and social support, and varied levels of assistance with ADLs. A typical program includes several types of “classes” that aim to improve and maintain cognitive or physical functioning. Classes oriented toward cognitive skills may include strategy board games, pencil-and-paper puzzles, or discussions of current events, readings, or movies. Classes oriented toward mobility and physical functioning include cardiovascular exercise, strength training,

stretching, yoga, and modified sports (bowling, T-ball, skiing, etc). The MSADPs usually run during work hours. Therefore, individual participants live off-site and commute to the program 1 to 5 days each week.

The purpose of MSADPs is two-fold. Well-designed programs provide conservative management of MS to participants,¹¹ including a focus on improving and maintaining mobility, fitness, cognition, mood, and psychosocial well-being.¹³ At MSADPs, participants work on mobility and cognition and receive psychosocial support in a setting responsive to the chronic and unpredictable nature of MS. The second focus of MSADPs is on caregiver relief.¹⁴ Programs aim to provide respite from caregiving so that informal caregivers do not become overwhelmed and burn out.

We conducted this qualitative study in conjunction with a survey of participants at ten MSADPs across the country. Survey findings demonstrated that participants were highly satisfied with their experiences at MSADPs, although positive changes in self-reported health-related quality of life (HRQOL) over 1 year were not clinically meaningful.¹⁵

The rationale for this analysis was to understand the discrepancy in the survey findings between participants’ high satisfaction with MSADPs and the lack of self-reported positive health outcomes across 1 year of participation. Why do participants regard MSADPs so highly, yet their responses to standard HRQOL scales suggest that the programs are not useful for increasing social support, reducing depression and anxiety, and improving physical functioning over the course of a year? To address this question, we sought to discover how people with MS benefited from MSADP participation by considering their own explanations for how the programs help. Data collection consisted of in-depth interviews and participant observation of participants’ experiences of the programs. The methods allowed participants to describe MSADP benefits and outcomes in terms of what was most important to them and how they thought program features contributed to their well-being. We also conducted interviews with MSADP participants’ informal (unpaid) caregivers and MSADP staff members about how they understood the advantages of program participation. In this article, we refer to caregiver and staff member perspectives only when they illuminate participants’ perspectives.

Methods

This study is part of a larger mixed-methods study that includes surveys of participants’ HRQOL, descriptions of the

funding and structure of existing MSADPs, and qualitative inquiry into MSADP satisfaction, benefits, and recommendations from the perspectives of MSADP participants and their informal caregivers. The institutional review boards of Westat (Rockville, MD) and those associated with each site approved the procedures for the study.

Interviewees

We recruited MSADP participants, their informal caregivers, and MSADP staff members from ten MSADPs across the country. Program staff members informed MSADP participants of the study and distributed an informational brochure about the study asking for volunteers. Staff members asked MSADP participants to explain the study to their informal caregivers, if applicable. Staff members scheduled MSADP participants who volunteered for interviews. We scheduled informal caregivers at their convenience because some needed appointment times after business hours. At the sites, Westat interviewed every site director. We interviewed nearly every staff member who provided direct service to participants with MS and who was available on the day of our visit. In total, we interviewed 95 MSADP participants, 26 informal caregivers, and 44 administrators and staff members.

Data Collection

The MSADP participants, administrators, and staff were eager to speak with us about MSADPs. We conducted interviews with MSADP participants, administrators, and staff at each MSADP in the context of a site visit. Participant interviews lasted between 20 minutes and 1 hour. Interviews with administrators and staff lasted approximately 1 hour each. We conducted interviews with informal caregivers at the site or via telephone if the caregiver was not available during MSADP hours. Caregiver interviews lasted between 40 minutes and 1 hour. We gave participants and caregivers a \$25 Target gift certificate as appreciation for their participation in the study.

The interview protocols were standardized to maintain uniformity; interviewers asked each category of interviewee (MSADP participant, caregiver, administrator, staff member) the same questions. Questions were open-ended and focused on satisfaction with the services offered, the benefits to MSADP participants, and any recommendations for improving the programs.

Analysis

Data consisted of transcriptions of in-depth interviews and notes on observations of activities. We imported data into a qualitative analysis software program (NVivo; QSR International, Burlington, MA) to facilitate organization of data into themes.

We first parsed the textual data using a coding scheme that mirrored our interview protocols. We organized data by the topics addressed: satisfaction with services, benefits to MSADP participants, and recommendations. The second pass at coding further divided each primary code based on the content therein. For example, the code "benefits to participants" was divided into more specific descriptions of the reported benefits, such as "social support," "improved mood," and "improved mobility." The third step involved close reading

of the text to determine how and why participants believed they received a given benefit from MSADP participation. In the case of participants who reported improved mood, we interrogated the data to understand why participants believed MSADP participation improved their mood: What was their evidence that their mood improved? How did they explain why the change occurred? Analysis at this stage included references to interviewees' own ideas about causality (eg, a participant may have explained that she felt less isolated because she attends the MSADP, and this improved her outlook), but it also included hypothesized correlations that we postulated by examining multiple interviewees' perspectives.

Analysis at the final level included identifying patterns within and across interviewee responses that were evident only at the aggregate level. For example, while reading text under the code "social support," it became clear that when participants elaborated on what they meant by social support, they often referenced the importance that giving support to other MSADP participants had on their own well-being. As this theme emerged across interviews, we hypothesized that social reciprocity was an important component of well-being to participants. To assess the robustness of this theory, a final step included examining the remaining data for contradictions and inconsistencies. For example, if some participants had described caring for others at the MSADP as a burden, we would have needed to reformulate the hypothesis so that it accounted for the conditions under which supporting other members was fulfilling and the conditions under which it was problematic, and qualify the conclusions accordingly. Finally, to lend strength to the hypothesis that social reciprocity was part of the experience of social support at MSADPs, we corroborated participants' insights about its importance by referencing statements made by staff members and caregivers on social support.

Results

The benefits of MSADP participation as described by participants with MS included the following: 1) increased emotional well-being, 2) increased receipt and provision of social support, 3) acceptance and lack of stigma, 4) practical know-how for accomplishing ordinary daily tasks, and 5) improvement in physical functioning. We discuss each theme in the following subsections.

Increased Emotional Well-being

Many participants across all programs described feeling "depressed" before joining their MSADP. We heard many comments similar to the following: "This program is a lifesaver for me. I was in the doldrums. I was very, very depressed. It doesn't matter that I was depressed—they [other participants and staff members] wouldn't let me sit in the background—they made me join." Likewise, most informal caregivers noticed a difference that they attributed to the MSADP. For example, one said

that since his spouse joined the program, “She doesn’t do that weeping thing and such. ... I don’t know if that’s the Prozac—but then again—I don’t think it is. ... She has a more positive outlook. ... It raises her spirits.”

Participants across many programs told us that they were surprised by how positive and upbeat the climate of their program was. They said that they imagined “it was going to be all about people sitting around complaining—and it is none of that.” When asked what she thought when she first joined, one participant said, “This is not your—everybody sits around the table and complains—that kind of thing it is not. This was high energy. The people were high energy. ... I was like, ‘Yeah, this is going to be good and needed. Needed by me badly.’” A participant of another program who had joined only 2 weeks before the interview remarked on the program’s climate with astonishment: “This is so positive. ... I come to this program with a smile on my face and I leave with a smile on my face.”

Social Support and Reciprocity

Participants reported that the greatest benefit of MSADP participation is social. Nearly every participant with whom we spoke described their MSADP’s community as one of the most important supports in their lives. Participants said that they felt appreciated, understood, and supported by other participants and by staff members.

In addition to being a source of social support, participants experienced their MSADP participation as providing purpose and meaning in their lives. For example, a participant explained: “When you come here, you’re not a burden. That’s what you’re here for. They [other participants] say, ‘That’s what we’re here for; we’re here for you.’ You never hear that anywhere else: ‘We’re here for you.’ You’re here for *me*? When you’re out there, you feel like, ‘I don’t even belong on this planet anymore. I have nothing here anymore. I don’t help anyone anymore. I’m disabled. They took me off my job. I can’t help people anymore. ... I’m unproductive. I’m nothing anymore.’ But when you come here, you’re building yourself back up. You’re part of a group. You’re somebody again. And it makes you say, ‘I can still go on living. I can be somebody again.’” This participant lost her role as helper when her MS became disabling. However, in the community at her MSADP, reciprocal relationships of caring revived her sense of purpose.

Social reciprocity, and the strength of the MSADP’s community of participants, was a theme consistently

raised by participants when discussing MSADP benefits. For example, the wife of a participant explained that her husband liked the MSADP because “I think he has an optimism, and it gives him a feeling that there’s a place he can speak and he’s heard by people that understand, because they’re going through it or they went through it. I think it also validates him; he’s got this wisdom and experience and he can help others.” A participant of another program said, “We all have a problem and we’re here to help each other. The clients go out of their comfort zone to help each other.” Another participant of the same program explained, “My end goal ... is helping my fellow man because I really feel that’s what we’re supposed to do while we’re here. Regardless if I’m in a wheelchair or not, I need to help my fellow man and raise him up, and in turn, they do that for me too.” A staff member from a third program remarked that participants “are a great support for each other in that they understand and are willing to lend assistance to someone who is struggling.” During one site visit we participated in a conversation among a group of women participants about the impending death of one participant’s husband due to a protracted illness. Other participants encouraged her to visit their retirement community to see whether it might be a good fit for her after her husband passes. Two participants told her that they would be there for her and with whatever she needs, wherever she ends up living.

In addition to providing emotional support, participants help each other in concrete ways. For example, participants at one program knew that one individual had trouble paying for his transportation to and from the program. Staff reported that other participants gave him money so that he could continue to attend. At another site, five participants who live near each other carpool in one participant’s converted accessible van to the MSADP. One of the commuters explained, “This is the first time I’ve ever commuted with people. It’s great fun. ... We all get in—and it’s like—we catch up with each other. At the end of the day, we talk about what happened during the day—who did what. ... I couldn’t come without them because I don’t drive anymore.” At the programs, we frequently observed participants who were mobile helping other participants by fetching a drink, food, or materials. As one participant explained, “It’s easier for me to go get water because my legs work, so I get [other] people water.”

It was common for us to hear that participants stay in contact with each other outside the MSADP meet-

ings and sometimes even meet outside the MSADP. The stepmother of a participant described how her stepson became involved with other men at the MSADP: “This group of guys that started when he did—they bonded so quickly. [Stepson’s name] is very social and outgoing. He’s kind of the ringleader, and he’s the youngest. He took a big role in calling them outside the group, and even there’s been some effort to get together outside the group—[there’s] a lot of camaraderie and support. They’re on the phone a lot with each other.” Participants at most programs explained to us that they make efforts to connect with other participants who are ill or absent from the program for unknown reasons. A participant who had been at an inpatient rehabilitation unit for some time said, “When I was not here, they sent me cards at the rehab center. They [participants] became like family pretty much.... When you come through the door everybody says, ‘Hi [participant’s name]! How are you doing? Where were you last week?’ Everybody seems to know what was going on last week that I wasn’t here. That’s really positive.” This participant was touched because while she was away from the MSADP other participants missed her and worried about her.

Acceptance and Lack of Stigma

Participants described not feeling self-conscious at the MSADP. For example, a participant said that people who do not have MS “feel sorry” for her, but when she is with her group at the MSADP, she is “just a normal person.” Another member found it a relief that others at the MSADP understood the subjective experience of MS: “It’s frustrating for us. I know it’s frustrating for the doctors too. They don’t know what is going on with us. It’s just wonderful to be in an environment where everyone gets it.” Other participants said that it is helpful to be among others who “understand the frustration of losing things that you used to be able to do.”

Participants reported feeling comfortable discussing sensitive symptoms with peers at the MSADP. For example, a participant explained, “We have nothing in common except our disease. The confidence and the safety that you feel with this group of people.... People talk more...whether it is catheterization among men and women.” In fact, we observed a few informal conversations among mixed-sex groups about catheterization and incontinence. For example, one program featured a presentation from a medical supply salesperson who brought products that he thought might be of interest to the group, including incontinence pads. The mixed-sex

group passed around samples of the pads and discussed the merits of various types and brands at length.

Sharing Information and Practical Know-How

Although participants receive formal health education delivered by professionals as part of MSADP programming, participants described the informal exchange of information and practical knowledge as a key benefit of MSADP participation. Participants exchanged “tips” for accomplishing ordinary chores and shared information about assistive technology, medication, and where one might find services or medical supplies to manage impairments.

Many participants described informal discussions of how to manage everyday household chores and self-care tasks with an impairment as crucial to their continued functioning with MS. For example, a participant told us that at the MSADP “You learn things that you’re not going to learn from your doctor just by talking to someone [with MS]. ‘How do you do this?’ ‘How do you do that?’ ‘That works better.’ ‘Don’t use that; use this.’” Another participant, who explained to us how she had benefited from others’ informal experiments to manage tasks of daily living, exclaimed, “There are just so many things you can do with MS.” How to chop, cook, and bake with one hand was a topic that recurred across sites. Participants shared tips on how to cut an onion, peel a grapefruit, and mix batter using one arm.

Other MSADP participants were an invaluable resource on the subjective experience of medications, particularly adverse effects. A participant recalled that when she was about to begin a new medication, “I found out what Rebig was going to do—as far as side effects—here. The doctor doesn’t tell you anything. I shouldn’t say that. The doctor will say anything, but until you’re around people that lived it, then you know what’s going to happen.” Another participant explained, “If you’re thinking about changing medications, somebody in the group has probably been on it.”

Improvement in Physical Functioning

At least 18 participants described improvements in their ability to walk, write, transfer, or perform other ADLs due to MSADP programming. All 18 were members of one of the five MSADPs staffed by professionals certified as exercise physiologists or physical therapists. Among programs that do not have an exercise physiologist or physical therapist on staff, site visitors did not hear of any improvement in ADLs or mobility. The 18 participants who described improvements in physical functioning described one of the following as an out-

come of MSADP participation: sitting upright unsupported, putting on socks, transferring more easily (as discerned by caregivers), standing up unsupported after not standing in years, using a walker to walk after using a wheelchair for years, progressing from using a wheelchair to a walker to a cane or walking unaided, increasing stamina to walk the equivalent of several blocks at one time, writing, and cessation of hand tremors.

The greatest number of reports of improved physical functioning occurred at the most recently established program. This is likely because most improvements occurred near the beginning of participants' enrollment, so they were freshest in the minds of participants in the newest program. For example, a participant explained how she began to walk from using a wheelchair and scooter: "[Staff members] ask you what your goal is and I said, 'I want to walk and I'm stubborn.' He [staff member] laughed and said, 'Okay, we'll work on it.' ... He got me on a walker after my first year and I was on a walker for a while ... everybody [other participants] were going, 'Oh, you're walking!' Everybody was really excited." Another participant explained how she began to sit unsupported: "They have all these exercises here to help you. Last year, I couldn't sit up in my seat. I'd fall over. They [staff] helped me build up my core strength. I could sit up in my seat."

Participants and staff members cautioned that these physical improvements were not evidence of a reversal of disease progression but rather the result of repeated practice due to the encouragement of staff and other participants. For example, a participant who now walks with a cane after using a scooter for 10 years explained that she may have been able to transition to a walker without any help, but without the program she "would not have been brave enough ... and I would have continued to do what was easy."

Discussion

A handful of previous studies examining the benefits of MSADPs and similar wellness programs for people with MS are inconclusive. Two studies examined the effect of time-limited wellness programming on the physical functioning and psychosocial well-being of participants after 10 to 12 weeks and found improvements in depression, anxiety, perceived stress, pain, physical functioning, and psychosocial well-being.^{11,16} A third study examined outcomes after 1 year for newly enrolled MSADP participants and compared them with outcomes for wait-listed individuals with MS. In that study, MSADP participants reported less fatigue

and decreased symptom frequency compared with the wait-listed individuals.¹⁷ A fourth study examined the progress of previously enrolled MSADP participants and found that MSADP participants reported experiencing greater social support than a comparison group of individuals with MS not enrolled in MSADPs.¹⁸ The most recent study, conducted in conjunction with this project, examined outcomes for MSADP participants at ten MSADPs across 1 year.¹⁵ In that study, MSADP participants varied in how long they had been enrolled from a few weeks to decades. Gasper et al¹⁵ found that MSADP participants reported increases in physical HRQOL (as measured by the 12-Item Short Form Health Survey) that were statistically significant, yet not clinically meaningful, relative to the comparison group of individuals with MS who were not enrolled in an MSADP. The MSADP participants did not differ significantly from the comparison group on other measures of HRQOL, including pain, fatigue, and social support.¹⁵

However, the results of the survey conducted in conjunction with the present study demonstrate that participants thought that the MSADP provides opportunities for social connection, contributes to a positive mood, and helps with their physical functioning. Most respondents (98.5%) agreed or strongly agreed with the following statement: "The program allows me to get out of the house or socialize with others." Almost as many respondents (96.5%) agreed or strongly agreed with the following statement: "The program contributes to an improved outlook on life for me." Furthermore, 91.5% agreed or strongly agreed with the following statement: "The program helps me maintain or improve my physical abilities."

The literature on adult day programs catering to older adults with impairments related to aging is much more extensive¹⁹ than is the literature about MSADPs; however, findings on participant satisfaction and health outcomes are similar to those for MSADPs. Scholarly reviews suggest that participants generally are satisfied with services^{19,20} and that programs increase participants' emotional well-being,²⁰ but quantifiable evidence of improvement in health or ADLs is lacking.

Participants' descriptions of the benefits they receive from MSADPs suggest the importance of participation in a cohesive community to their health and well-being. At the MSADP, participants described experiencing social inclusion, reciprocity, solidarity, and trust—all components of social cohesion²¹—as important to their well-being. They highlighted the climate of their pro-

grams with words such as “positive” and “upbeat.” They described how feeling that they “belonged” and were “included” at the MSADP lifted their mood. Although it was important to receive understanding, advice, and assistance, they also emphasized that it was crucial to reciprocate understanding, advice, and assistance to peers. Participants described trusting the group—experiencing it as a “safe” place where they can just be a “normal person.” This safety facilitated risk taking, in which participants would “go out of their comfort zone” to help others or to try new activities, such as walking with a walker or trying a new way of cutting an onion.

Participants’ focus on community cohesion suggests that standard questionnaire protocols for measuring social support—which assesses support in dyadic relationships only—may not highlight the most salient benefits of MSADP participation. Corroborating the theory that community support is a unique benefit provided by MSADP participation, participants rarely described one-on-one relationships at the MSADP as key to improving participant health and quality of life. It is not that participants did not form close and fulfilling relationships with individual peers and staff members; indeed, they did. Instead, we suggest that membership in a cohesive community itself may contribute to psychosocial well-being. □

PRACTICE POINTS

- Clinicians should consider recommending MS Adult Day Program (MSADP) participation to their patients with MS with unmet psychosocial needs. Although the few quasi-experimental evaluations of MSADP outcomes are inconclusive, this study, a qualitative evaluation, finds that participants unequivocally report psychosocial benefits.
- The MSADP communities are socially cohesive. These communities provide participants with social support and opportunities to give support to others with MS. Participants described how this social reciprocity was crucial to their psychosocial well-being.
- The MSADP communities are resources for people with MS to share knowledge of, and learn about, managing a wide range of difficulties caused by the disease.
- Some MSADP participants reported initial improvements in mobility and improved motor function after joining.

Financial Disclosures: The authors declare no conflicts of interest.

Funding/Support: The Conrad Hilton Foundation and the National Multiple Sclerosis Society funded the research for this article.

References

1. Brownlee WJ, Hardy TA, Miller DH. Diagnosis of multiple sclerosis: progress and challenges. *Lancet*. 2017;389:1336-1345.
2. Rokach A. Coping with loneliness among the terminally ill. *Soc Indicators Res*. 2007;82:487-503.
3. Green G, Todd J, Pevalin D. Biographical disruption associated with multiple sclerosis: using propensity scoring to assess the impact. *Soc Sci Med*. 2007;65:524-535.
4. Dyck I. Hidden geographies the changing lifeworlds for women with multiple sclerosis. *Soc Sci Med*. 1995;40:307-320.
5. Cadden MH, Arnett PA, Tury TM, Cook JE. Judgment hurts: the psychological consequences of experiencing stigma in multiple sclerosis. *Soc Sci Med*. 2018;208:158-164.
6. Golla H, Galushko M, Pfaff H, Voltz R. Unmet needs of severely affected multiple sclerosis patients: the health professionals’ view. *Palliat Med*. 2011;26:139-151.
7. Loneragan R, Kinsella K, Fitzpatrick P, et al. Unmet needs of multiple sclerosis patients in the community. *Mult Scler Relat Disord*. 2015;4:144-150.
8. Somerset M, Peters TJ, Sharp DJ, Campbell R. Factors that contribute to quality of life outcomes prioritised by people with multiple sclerosis. *Qual Life Res*. 2003;12:21-29.
9. Henry A, Tourbah A, Camus G, et al. Anxiety and depression in patients with multiple sclerosis: the mediating effects of perceived social support. *Mult Scler Relat Disord*. 2019;27:46-51.
10. Brown RF, Valpiani EM, Tennant CC, et al. Longitudinal assessment of anxiety, depression, and fatigue in people with multiple sclerosis. *Psychol Psychother*. 2009;82:41-56.
11. Hart DL, Memoli RI, Mason B, Werneke MW. Developing a wellness program for people with multiple sclerosis: description and initial results. *Int J MS Care*. 2011;13:154-162.
12. McCabe MP, Ebacioni KJ, Simmons R, McDonald E, Melton L. Unmet education, psychological, and peer support needs of people with multiple sclerosis. *J Psychosom Res*. 2015;78:82-87.
13. Northrop DE, Frankel D. *Serving Individuals with Multiple Sclerosis in Adult Day Programs*. National Multiple Sclerosis Society; 2010.
14. Dabelko-Schoeny H, King S. In their own words: participants’ perceptions of the impact of adult day services. *J Gerontol Soc Work*. 2010;53:176-192.
15. Gasper JM, Lewis M, Kroeger A, Muz B, LaRocca N, Frankel D. Multiple sclerosis adult day programs and health-related quality of life of persons with multiple sclerosis and informal caregivers. *Int J MS Care*. 2020;22:187-192.
16. McGuire KB, Stojanovic-Radic J, Strober L, Chiaravalloti ND, DeLuca J. Development and effectiveness of a psychoeducational wellness program for people with multiple sclerosis: description and outcomes. *Int J MS Care*. 2015;17:1-8.
17. DiFabio RP, Soderberg J, Choi T, Hansen CR, Schapiro RT. Extended outpatient rehabilitation: its influence on symptom frequency, fatigue and functional status for persons with progressive multiple sclerosis. *Arch Phys Med Rehabil*. 1998;79:141-146.
18. Schmitt EM, Sands LP, Weiss S, Dowling G, Covinsky K. Adult day health care participation and health-related quality of life. *Gerontologist*. 2010;50:531-540.
19. Ellen MA, Demaio P, Lange A, Wilson MG. Adult day center programs and their associated outcomes on clients, caregivers, and the health system: a scoping review. *Gerontologist*. 2017;57:e85-e94.
20. Fields NL, Anderson KA, Dabelko-Schoeny H. The effectiveness of adult day services for older adults: a review of the literature from 2000 to 2011. *J Appl Gerontol*. 2014;33:130-163.
21. Carrasco MA, Bilal U. A sign of the times: to have or to be? social capital or social cohesion? *Soc Sci Med*. 2016;159:127-131.