

Outcomes of a Day Wellness Program for People With Multiple Sclerosis Before and During the COVID-19 Pandemic

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ABSTRACT

BACKGROUND: The John A. Schafer, MD Multiple Sclerosis Achievement Center (MSAC) conducts wellness programs that include exercise, cognitive stimulation, education, emotional support, and socialization for people with multiple sclerosis and their care partners. Patient-reported outcomes (PROs) are collected annually. Four-year outcomes encompass the COVID-19 pandemic when some of these programs were offered virtually.

METHODS: Beginning in 2017, baseline data were collected for 110 MSAC day wellness program participants through PRO measures. Of those 110, 52 completed PROs annually through 2021. Outcome measures included the Multiple Sclerosis Impact Scale (MSIS-29); Multiple Sclerosis Self-Efficacy Scale (MSSE-10); Godin Leisure-Time Exercise Questionnaire (GLTEQ); and the Neurology Quality of Life domains of Anxiety, Depression, Emotional and Behavioral Dysregulation, Positive Affect, Cognition, Ability to Participate in and Satisfaction with Social Roles and Activities, and Satisfaction with Social Roles and Activities. Analysis using *t* tests compared baseline with 4-year data. A separate analysis compared outcomes collected in January 2020 and January 2021.

RESULTS: Analysis of 4-year data demonstrated statistically significant improvement in MSIS-29 and GLTEQ. Statistically significant improvements noted at years 2 and 3 in the Ability to Participate in Social Roles and Activities were no longer significant at year 4. Other notable changes included significant decreases in MSSE at year 4 when compared with baseline and year 3.

CONCLUSIONS: Individuals who participated in a weekly, structured day wellness program showed improvements in self-reported disease impact and physical activity at year 4 vs baseline. Decreases in self-efficacy and social domains were seen, corresponding with disruptions caused by the COVID-19 pandemic. Further analysis is needed to understand the effects of the pandemic on program participants.

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Multiple sclerosis (MS) is a chronic disease of the central nervous system most commonly diagnosed in people between 20 and 50 years old. MS debilitates normal body function and can cause serious disruptions to daily living, including “work, physical independence, mobility, social interaction, and participation in leisure activities.”¹ In general, people with MS have a normal life span; therefore, many, particularly those who receive a diagnosis early in life, must live a long time with the physical, cognitive, and psychological effects of MS. They often experience isolation from family and friends. As such, interventions to enhance quality of life are essential to helping people with MS live well.

The John A. Schafer, MD Multiple Sclerosis Achievement Center (MSAC) in Sacramento, California, provides adult day services, which, broadly, encompass a system of professionally delivered, integrated, home- and community-based therapeutic, social, and health-related services for individuals to sustain living in the community.² The wellness programs include individual and group exercise programs, individual cognitive stimulation using activities and applications on a tablet, group discussions in areas of overall health and MS-specific management that are facilitated by a health care professional, emotional support, and socialization with other people with MS. In addition to the day wellness programs, community outings provide other social and recreational opportunities. Some people have been participating since the program’s inception in 2014.

Adult day programs also offer respite for caregivers.³ The MSAC provides a professionally facilitated support group for caregivers and loved ones of people with MS. Since its inception in 2016, 91% to 95% of participants in the MSAC support partner program report that they agree or strongly agree that the program is beneficial to their health and well-being.

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Programs incorporating physical activity, emotional wellness, cognitive stimulation, education, and socialization can be tools to improve the quality of life of people with multiple sclerosis.

These programs can serve as an important complement to an individual's medical care by providing interventions in a group setting that often are not available through the regular medical model of care.

The COVID-19 pandemic necessitated a shift from in-person care to virtual care. For day programs, this shift provided an opportunity to keep otherwise isolated people connected. ■

Research results on day programs are mixed. A scoping review of older adults who participate in activities at adult day centers (ADCs) concluded that ADCs have positive impacts on health-related, social, psychological, and behavioral outcomes.⁴ In addition, a study found that caregivers showed significant decreases in depression, improvement in their ability to manage memory lapses and difficult behaviors, and improvement in self-perception of overall well-being with participation in an Adult Day Services (ADS) Plus program (a community-based program for adults living at home plus care management services). All these changes were seen at 3 months, but no statistically significant differences were seen long term (up to 12 months).⁵

Investigators in another study did not find clinically significant effects on standardized measures of physical and mental health-related quality of life (HRQOL) or health care utilization after 1 year.⁶ Scores on the physical component scale of the 12-Item Short Form Health Survey were statistically significant for those with MS attending ADS, but the difference was not considered clinically meaningful. Investigators in a qualitative study from the same data set did conclude that these programs have a profound influence on the participants' psychosocial health, which the authors attribute to membership in a socially cohesive community.⁷

An evaluation of a concentrated 4-day wellness program for people with MS showed improvements in self-efficacy

and self-perceived health-related outcomes. Improvement in these health-related outcomes was not dependent on initial disability as measured by the Expanded Disability Status Scale.⁸

The COVID-19 pandemic affected people with MS in many ways. Several studies have reported increases in depression^{9,10} and anxiety.^{9,11} However, results of another study showed improvements in social interactions.¹² In a survey of 1145 people with MS, many reported delays in and difficulties with several aspects of their medical care due to the pandemic, including delays to disease-modifying therapy administration and non-MS-related medical procedures, delays to medications and complementary and alternative medicine services, and postponement or cancellation of medical appointments. In addition, more than those who did not self-quarantine, respondents who self-quarantined reported that the pandemic had a significantly negative impact on their diet, personal finances, and exercise.¹³ Finally, as patients returned to in-clinic visits after isolation due to the pandemic, clinicians noted increased weakness, spasticity, balance issues, and pain related to deconditioning.

Results of a recent study evaluating a virtual wellness program during the pandemic showed an association between participation and improved quality of life.¹⁴ The wellness program was offered 17 times over 6 months and included exercise, mindfulness programs, and guest speakers. Those with higher attendance rates demonstrated improvements in emotional well-being and pain measures at 6 months when compared with baseline.

At MSAC, participants report that they are "more confident," "more active," and "more connected" to others through engagement in our programs. Because many people have attended for multiple years, we have had the ability to analyze outcome measures longitudinally, something that has not been previously reported in the literature. In comparison with the COVID-19 pandemic data, our participants also reported increases in anxiety and depression but disagreed with the research results above, indicating that their social interactions decreased and they felt more isolated.

The purpose of this analysis was to review the results of the outcome measures regarding the impact a day wellness program may have on participants' quality of life, the impact of their MS, mood, and level of physical activity, with a particular focus on learning more about the results and any changes that may be noted during, and perhaps because of, the pandemic. The primary purpose of this data collection was to assess program gaps and guide the development of program content.

METHODS

Program measures were collected annually for all individuals enrolled in the program at the time and those who had left the program. Data analysis was retrospective. The chairman of Dignity Health's Sacramento/Sierra regional institutional review board reviewed our project proposal and

determined it to be a quality improvement project; therefore, board review and approval were not required.

Initial measures were collected in January 2017 (baseline) and then annually through January 2021. Measures collected in January 2021 reflect a little more than 8 months of the pandemic. During that time, the MSAC offered only virtual programs (April and May 2020) and hybrid in-person and virtual programs (June through December 2020). All participants were offered 5 hours of weekly programming during the virtual-only and hybrid programs, but they were spread throughout the week instead of in a single 5-hour day per week.

Measures

Multiple Sclerosis Self-Efficacy Scale-10 (MSSE-10)

The MSSE-10 was developed and is validated for measuring self-efficacy in function maintenance and control over MS from the patient's perspective. The MSSE-10 is highly correlated with the original MSSE.¹⁵

Multiple Sclerosis Impact Scale-29 (MSIS-29)

The MSIS-29 is a physical (20 items) and psychological (9 items) measure and has been found to be an accurate, valid, and reliable patient-based outcome measure of the impact of MS from the patient's perspective.¹⁶

Godin Leisure-Time Exercise Questionnaire (GLTEQ)

The GLTEQ is a valid self-reported measure of physical activity in people with MS and is an appropriate, simple, and effective tool to describe patterns of physical activity and examine correlates and outcomes of physical activity, thereby providing an outcome for measuring change in physical activity after an intervention.¹⁷

Neurology Quality of Life (Neuro-QoL)

The Neuro-QoL instrument includes 13 scales that assess physical, emotional, cognitive, and social domains and is used for a variety of neurological illnesses.¹⁸ The Neuro-QoL assesses several domains of well-being not typically assessed using traditional MS-specific patient-reported outcome (PRO) measures. Analysis examined the domains of Anxiety, Depression, Emotional and Behavioral Dyscontrol, Positive Affect, Cognition, Ability to Participate in Social Roles and Activities, and Satisfaction with Social Roles and Activities.

Statistical Analysis

The above PRO measures were collected on an annual basis beginning in January 2017. Data were analyzed using paired *t* tests for the different outcome measures at baseline (ie, 2017, even though some individuals had participated prior to that date), 1 year, 2 years, 3 years, and 4 years. An additional analysis was done comparing years 3 and 4 (ie, 2020 and 2021), which includes the first 8 months of the COVID-19 pandemic. Raw scores were analyzed and reported for the MSSE-10, MSIS-29, and GLTEQ; *t* scores were reported for the Neuro-QoL scales. The paired *t* tests were

TABLE 1. Baseline Demographics of Program Participants in Analysis, n (%)

Sex	Female: 46 (89%)	Male: 6 (11%)
Marital status	Married/domestic partnership: 31 (60%)	Not married: 21 (40%)
Employment	Not employed: 50 (96%)	Employed: 2 (4%)
Race	White, not Hispanic: 36 (69%)	All other: 16 (31%)
Average age	60.47 (SD, 8.01)	
Average years of diagnosis	16.47 (SD, 10.18)	

taken without correction based on an a priori hypothesis. Significance was accepted at $P < .05$.

RESULTS

Data were collected from 119 people with MS who participated in the MSAC's day wellness programs from 2017 to 2021. Of the 119 individuals, data analysis was limited to 52 individuals for whom all 4 years of data were available. At baseline, the average length of MSAC participation was 16 months since some participated in MSAC programs prior to initial data collection in 2017. **TABLE 1** reflects the baseline demographic characteristics of those individuals.

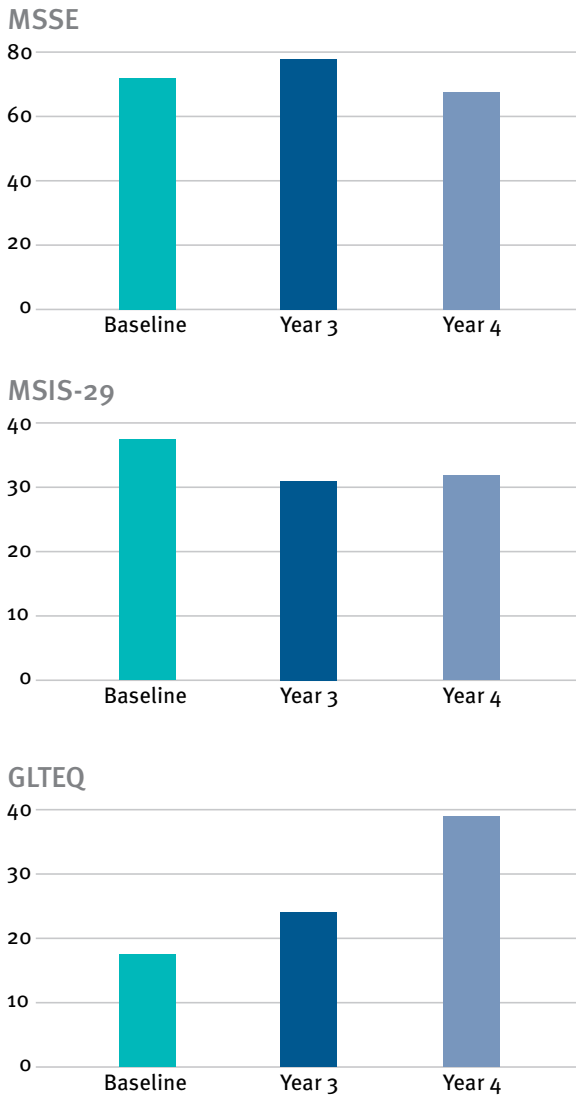
The mean MSSE-10 scores were 71.76 (SD, 19.66) at baseline, 78.18 (SD, 18.47) at year 3, and 67.70 (SD, 24.47) at year 4. A statistically significant improvement was seen at year 3 when compared with baseline ($P = .02$). No statistically significant difference was seen at year 4 when compared with baseline ($P = .18$). However, when comparing years 3 and 4 there was a statistically significant decrease in MSSE-10 scores ($P = .0001$) (**FIGURE**). MSIS-29 mean scores were 39.08 (SD, 20.72) at baseline, 31.96 (SD, 14.99) at year 3, and 32.89 (SD, 14.65) at year 4. A statistically significant improvement was seen at year 3 ($P = .03$) and maintained at year 4 ($P = .01$). However, when comparing years 3 and 4, there was not a statistically significant change in MSIS-29 scores (Figure).

Scores in the Ability to Participate in Social Roles and Activities and Satisfaction with Social Roles and Activities domains of the Neuro-QoL had statistically significant improvement at years 2 and 3. As with the MSSE-10, statistically significant changes were not maintained at year 4. Mean scores at baseline and years 2, 3, and 4 *P* values are included in **TABLE S1**. Scores on other domains of the Neuro-QoL did not show statistical significance at any point during the 4-year period. Cognition in year 3 approached significance ($P = .06$).

When compared with baseline ($P < .001$), results from the GLTEQ showed some increase in participation in physical activity during leisure time during year 3 ($P = .14$) and a statistically significant improvement in year 4, as well as between years 3 and 4 ($P = .005$) (Figure).

No significant changes, positive or negative, were observed in other outcome measures compared with baseline unless otherwise noted.

FIGURE. MSSE-10, MSIS-29, and GLTEQ Comparisons



GLTEQ, Godin Leisure-Time Exercise Questionnaire; MSIS-29, Multiple Sclerosis Impact Scale; MSSE-10, Multiple Sclerosis Self-Efficacy Scale.

DISCUSSION

Over 4 years of data collection and analysis, we saw that individuals who participate in a weekly, structured day wellness program have had significant improvements in overall quality of life.

ADS participants at MSAC who have been enrolled and completed PROs over the course of 4 years have demonstrated improvements in disease impact and participation in physical activity during leisure time. Improvements were also noted in areas of self-efficacy and Ability to Participate in and Satisfaction with Social Roles and Activities through year 3; however, negative changes were noted in year 4 during the pandemic.

Changes in social domain scores occurred first and may be directly related to the social interaction inherent in the

MSAC wellness program. The program encourages, promotes, and teaches the benefits of being socially engaged and this may have directly impacted self-efficacy. Increases in physical activity were noted in years 2 and 3 but were not statistically significant until year 4. These data are similar to the study results of another wellness program that demonstrated improvements in self-efficacy after 6 months, but no change in physical activity measures.⁸ Although self-efficacy has been correlated with physical activity,¹⁹ we saw a decrease in self-efficacy with the greatest increases in physical activity. This may be, in part, due to the MSSE being a scale that measures an individual’s perspective of self-efficacy in function maintenance and control over MS,¹⁵ not specific to one’s ability to engage in physical activity.

The results of this study are similar to and different from other studies of adults with MS in day programs. Results from our study and the study done by Gasper et al⁶ show statistically significant positive effects on quality of life. However, in the Gasper study, the statistically significant improvements in the SF-12 physical component scale were not clinically meaningful. In our analysis, unlike the Gasper study, we did see significant improvements in social domains; however, changes were not detected until the second year of program participation.

Qualitative results reported by Marrow et al⁷ demonstrated that MS ADP programs have a profound effect on psychosocial health due to the socially cohesive environment. These results are consistent with our results in the social domains of the NeuroQoL. These scores were the first to improve with participation in our programs, and this improvement could certainly be attributed to the group environment.

Our study’s reported changes in self-efficacy were similar to those reported by Ng et al,⁹ although ours did not occur as quickly. This may be due to differences in program design and/or because we may not have captured some of the initial changes because the beginning of data collection did not occur until many participants had already taken part in the program for up to 3 years.

Presumed Implications of the COVID-19 Pandemic

Changes in some domains between years 3 and 4, as well as between baseline and year 4, may be due to the COVID-19 pandemic. Statistically significant at year 3, quality-of-life and self-efficacy measures were no longer statistically significant at year 4 when compared with baseline. The social domains of the Neuro-QoL returned to baseline, whereas the self-efficacy measures fell below baseline measures. The traditional format of our programs encourages socialization, which may provide greater internal motivation for behavior change. Although further analysis is necessary in order to confirm, we believe the significant improvements in both physical activity and disease impact during year 4 correspond with people learning to access other avenues for physical activity, such as videos and virtual exercise sessions, while being sheltered at home. Both the GLTEQ

and the MSIS-29 address questions related to physical activity, and both showed statistically significant improvements in year 4. Although the MSIS-29 also addresses mood, we believe the reductions in our other measures of self-efficacy and quality of life, combined with a decreased self-reported impact on the MSIS-29, support our hypothesis that the year 4 changes on this scale reflect an increase in physical activity, not changes in mood. However, a subanalysis of the MSIS-29 was not conducted to confirm this hypothesis. These data are also contrary to those from a recent study that reported a decrease in physical activity during the pandemic for people with MS.²⁰ Activities based in physiotherapy centers, gyms, or pools decreased, whereas walking increased. A majority of participants did not use technology as part of their physical activity program. Since we did not specifically ask about the type of exercise, we do not know which types of activity impacted the GLTEQ scores. However, we are aware that many of our participants were active in the virtual exercise programs we offered during COVID-19 lockdowns.

Future analysis will include data collected after returning to the type of in-person programming offered prepandemic. The results will help inform whether the reductions in quality of life and self-efficacy measures during the pandemic return to levels seen at years 2 and 3. In addition, we can assess whether behavior changes were sustained.

Limitations

The MSAC opened in February 2014, and some of our participants have been enrolled in the day wellness program since the first day. However, the outcome measures that have been used for our reports of baseline data and throughout this reporting period did not begin until 2017, which does not reflect a true baseline for all participants.

Additionally, the data only include information for individuals who have been participants of the day wellness program for the duration of the 4-year reporting period. The data do not include individuals who were participants for only a portion of that time. Although the analysis did not include a control group, the period leading up to the pandemic (2017-2020) could be considered a control for purposes of post-COVID-19 data analysis. Although this was not a preplanned analysis, the pandemic did provide an interruption to our time-series data collection approach. Considering the time prior to the pandemic as a control provides greater confidence that significant changes during and after the pandemic are, at least in part, due to COVID-19 restrictions.

The wellness programs offered at the MSAC are voluntary. Individuals enroll in programs open to anyone in the community with MS and, therefore, may include selection bias. The outcomes collected were primarily for purposes of program development and monitoring individual progress toward their goals, not as data for a prospective research study. The authors acknowledge that statistical analysis was performed without correction and is therefore subject to type 1 error.

In year 4, because of the pandemic and the need for portions of our program to be provided virtually, the outcome

measures were collected online. Prior to that time, they were collected onsite during program hours via pen and paper. Outcome measures for year 4 were emailed to program participants and completed online. Every precaution was taken to send the measures directly to the program participant; however, because staff were not present at the time of completion, we cannot guarantee that a family member or caregiver did not respond on behalf of the participant.

Lastly, our participants do not engage exclusively in MSAC activities. Some participate in other interventions, including rehabilitation services, gym memberships, and other medical treatments. Their participation in these additional interventions may be reflected in their responses to our outcome measures.

Other Possible Implications

The estimated total economic burden for people with MS in 2019 was \$85.4 billion, and this figure is expected to increase to \$108.1 billion by 2039. When compared with matched controls without MS, the average excess medical cost per person for someone with MS was \$65,612; for someone older than 65 years, the excess cost per person increased to \$66,356.¹

Research assessing adult day programs concludes that the various services provided can address health system challenges such as providing appropriate care for older individuals and enabling them to age in place while also providing low-cost services for a growing demographic group.³ Additional research assessing adult day programs during the COVID-19 pandemic recommends better support of community-based programs and those they serve, including classifying adult day programs as essential and exploring new ways to finance them.⁶

CONCLUSIONS

The results of this analysis support day wellness programs as an effective means for improving quality of life and, ultimately, physical activity for people with MS. Regarding quality-of-life measures, the impact of in-person programs appears to be more substantial than virtual programs. However, the virtual format may have maintained some areas of quality of life above baseline and resulted in increased physical activity because of the challenges presented by the COVID-19 pandemic. Future analysis will be important to determine whether the return to in-person programming impacted measures of quality of life and self-efficacy while maintaining increases in physical activity. ■

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TABLE S1. Mean t Scores and P Values for Neuro-QoL Domains

Domain	Baseline mean (SD)	Year 2 mean (SD)	P	Year 3 mean (SD)	P	Year 4 mean (SD)	P
Anxiety	52.11 (7.39)	51.92 (7.14)	.91	51.42 (6.75)	.51	52.29 (6.02)	.85
Depression	48.23 (8.63)	48.26 (7.89)	.95	47.08 (7.25)	.15	48.25 (7.44)	.99
Emotional and behavioral dyscontrol	47.74 (9.88)	48.94 (10.40)	.53	46.12 (9.60)	.30	48.33 (9.37)	.64
Positive affect	50.55 (7.47)	49.87 (7.09)	.46	50.41 (8.44)	.87	50.68 (7.17)	.91
Cognition	44.00 (8.31)	43.81 (7.38)	.87	45.78 (8.05)	.06	43.33 (7.98)	.48
Ability to participate in social roles and activities	42.49 (5.51)	44.10 (6.67)	.02*	45.16 (8.38)	.004*	43.36 (7.62)	.27
Satisfaction with social roles and activities	42.59 (3.98)	43.94 (4.95)	.001*	44.48 (5.70)	.004*	42.12 (4.83)	.54

Neuro-QoL, Neurology Quality of Life.

*Statistically significant.