



National
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California Chapter

Living Well With Multiple Sclerosis: Lessons Learned from a 12-Week Community Based Quality of Life Program

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Giesser, B., Coleman, L., Fisher, S., Guttry, M., Herlihy, E., Nonoguch, S., Nowack, D., Roberts, C. & Nowack, K.

Abstract

Living Well is a comprehensive wellness program created by the Southern California Chapter of the National Multiple Sclerosis Society and the Marilyn Hilton MS Achievement Center at UCLA to optimize the quality of life of those living with the challenges of MS. **Living Well** is a 12 -week health and wellness program that helps individuals with MS pursue a comprehensive approach to well-being within the context of life with a chronic illness. The program is designed to facilitate the development of intentional lifestyle choices--positive health habits for living well with MS.

The program places a strong emphasis on personal responsibility and the maximum enhancement of physical, mental, social, intellectual and spiritual health. The program offers a broad spectrum of education and experiences that go far beyond the medical management of MS (e.g., nutrition education, fatigue and stress management, exercise). Participants were self-identified who may meet one or more of these 3 criteria: 1) Recent MS diagnosis of less than 5 years; 2) Possessing minimal MS symptoms; and 3) Employed. The participants met 3 hours one-day a week for 12 consecutive weeks.

Participants: Program participants included 148 men and women (64.4% female) who were currently employed (85.7%), college educated (93.0%), and had a mean age of 42.4 (SD=9.6). Less than half were single or divorced (48.6%) and the majority (75.8%) is currently using some type of approved MS treatment drug.

Measures: Measures of stress, fatigue, coping style, physical health, and psychological well-being were utilized in the **Living Well** program and administered at both the beginning and end of the 12-week wellness

program. The measures included the Profile of Mood States (POMS), Modified Fatigue Impact scale (MFIS), Stress Profile Inventory, 3-item Spirituality Index, Marlowe Crowne Social Desirability scale and Taylor Manifest Anxiety scale. A 5-item Post-Then measure of current health and functioning was specifically developed to evaluate the overall program outcomes.

Analysis: An analysis of variance was performed controlling for age, gender and education. Effect sizes were determined for practical significance (change in scores divided by the standard deviation). Effect sizes of 0.2, 0.5 and 0.8 are considered small, moderate and large, respectively. All analyses were exploratory and no other adjustments were made. In all, the analyzed data, $p < .05$ were regarded as significant or otherwise noted.

Program Goals, Knowledge and Confidence: It was hypothesized that participants in the 12-week **Living Well** program would report less stress, anxiety and depression, a greater sense of personal control, enhanced coping skills, increased knowledge of the MS disease, and a reduction in fatigue symptoms. Overall, 60.0% of the program participants reported successfully meeting their personal wellness goals set at the beginning of the program either to a "high" or "very high" extent and 37.8% reported meeting them at a "moderate extent." Participants also reported being more knowledgeable about MS and more confident about being able to cope with it (83.0% and 73.5%, respectively, rated "high" or "very high") on the post-then evaluation.

Stress and Fatigue Outcomes: Participants reported significantly less sleep difficulties and reduced fatigue (cognitive and physical) at the end of the program (all p 's $< .01$) compared to initial levels (Modified Fatigue Impact Scale, POMS and Stress Profile Sleep/Rest scale).

Lifestyle, Psychological and Health Outcomes: Participants reported significant improvements in subjective ratings of stress, social support, outlook in life, eating/nutrition habits, physical activity/exercise, psychological well-being and reduced anxiety at the end of the 12-week program (all p 's $< .01$).

Participants also reported a significant increase in assessment of his/her current health status and less health problems that interfere with daily living (all p 's $< .01$) at the end of the program (Table 1).

Spirituality/Coping Outcomes: Participants reported significant improvements in spirituality (sense of life purpose and satisfaction) and coping with their MS symptoms as a result of the **Living Well** program. Specifically, program participants reported significantly more self-efficacy and coping skills in managing life with MS and increased knowledge about the disease. Participants reported using greater positive appraisal, less negative appraisal, more threat minimization and more problem focused coping approaches (StressScan coping scales) in the face of work and life stress at the end of the program (all p's < .01).

Conclusion: Statistically significant self-reported changes in increased global health, exercise/physical activity, eating/nutritional habits, self-efficacy, wellness coping skills, psychological well-being, spirituality and reductions in fatigue and anxiety were observed in the participants as a result of the 12-week **Living Well** program (Table 1).

Effect sizes suggest the most dramatic changes occurred in increasing confidence in managing MS, increasing knowledge about MS, enhancing overall perceptions of health, reducing work/life stress, confidence to cope and re-framing the illness in a positive and meaningful manner (Spirituality Index) and increasing levels of physical activity.

Living Well Program Changes (N=148)

Research Variable	Time 1 Mean	Time 2 Mean	p	ES ^a
Knowledge of MS ^d	2.8	4.1	.01	2.09
Confidence in Managing MS ^d	2.6	3.9	.01	1.82
Current Health ^d	3.2	3.8	.01	.77
Perceived Stress ^c	55.5	49.4	.01	.71
Spirituality Index ^c	9.9	11.4	.01	.70
Exercise/Physical Activity ^c	44.8	50.7	.01	.60
Cognitive Hardiness ^c	47.0	52.6	.01	.57
Psychological Well-Being ^c	46.0	51.9	.01	.56
Coping--Positive Appraisal ^c	49.9	55.8	.01	.54
Coping--Problem Focused ^b	50.1	55.6	.01	.52
Eating/Nutrition ^b	50.8	55.9	.01	.51
MFIS Fatigue—Physical ^c	19.9	15.8	.01	.50
Rest/Sleep ^b	47.4	52.2	.01	.48
Health Problems	2.81	2.39	.01	.47
MFIS Fatigue—Total ^c	41.0	32.4	.01	.46
Coping--Negative Appraisal ^b	50.9	45.6	.01	.44
Type A Behavior ^b	48.9	44.2	.01	.44
POMS: Tension ^b	5.7	4.1	.01	.43
MFIS Fatigue—Psychological ^b	4.4	2.8	.01	.41
POMS: Anxiety ^b	5.3	3.8	.01	.40
Coping—Threat Minimization ^b	50.8	54.5	.01	.36
POMS: Depression ^b	5.5	4.1	.01	.35
MFIS Fatigue—Cognitive ^b	16.9	13.8	.01	.31
POMS: Fatigue ^b	9.4	7.9	.01	.31
Social Support ^b	48.8	52.9	.01	.28

^aES= Effect Size

^bES=0.2 small effect. ^cES=0.5 moderate effect. ^dES=0.8 large effect.

For Additional Information:

Denise Nowack, RD

Executive Vice President, Programs & Services

National Multiple Sclerosis Society

Southern California Chapter

2440 S. Sepulveda Blvd., Ste 115

Los Angeles, CA 90064

tel +1 310 479 4456

fax +1 310 479 4436



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