A Pilot Study of a Manualized Resilience-Based Telehealth Program for Support Partners of Persons with Multiple Sclerosis

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INTRODUCTION

- Cognitive difficulties are a prominent and well-recognized symptom of Multiple Sclerosis (MS),[1] yet the impact on persons with MS and their families is not well understood
- In a previous study, we interviewed 15 individuals with MS and their spouses about how cognitive impairments impact their daily lives. We found that
  1. Cognitive impairments impact both the person with MS and their support partner by affecting their health-related quality of life, communication, relationship quality, and daily activities. However, there are ways to help buffer this impact by promoting resilience and coping strategies.
  2. The support partner plays a major role in helping the person with MS adjust to cognitive impairments.
  3. Participants expressed a desire for more support, such as, to learn more about successful strategies to overcome regularly occurring challenges in communication and in activities of daily living.
- Based on these findings, we designed a tele-health resilience-building intervention for individuals with MS and their support partners.

OBJECTIVES

- The primary objective was to conduct an evaluation of the feasibility of the resilience program by examining participant recruitment, willingness to participate, and satisfaction in the program.
- Secondary objectives were to assess the potential long-term benefits of the program including increased perception of emotional support (from the participants with MS); resilience, stress and positive and negative emotions.

METHODS

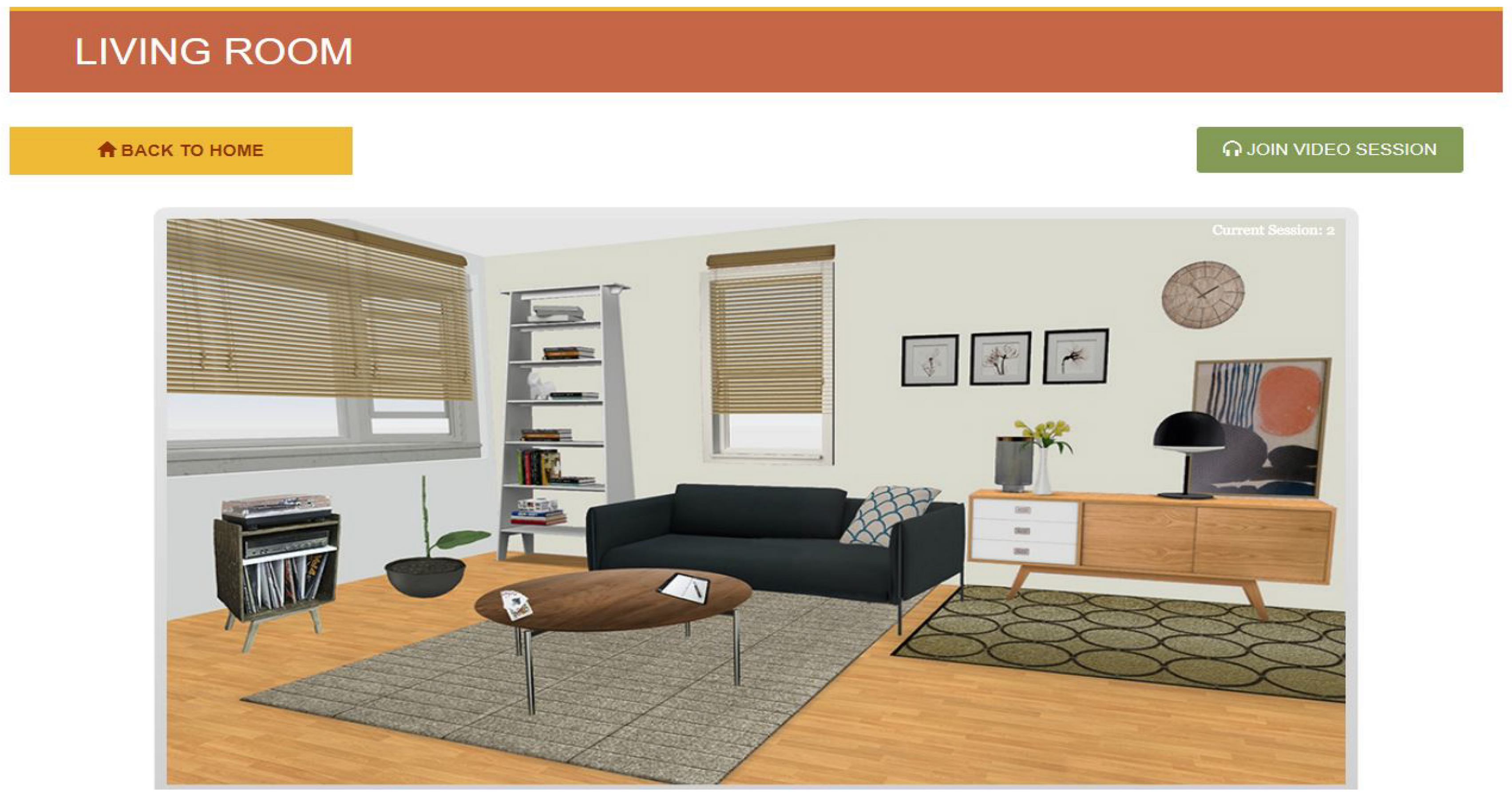
- 62 participants in the US were recruited to participate in a six session interactive online resilience-related skills program led by a coach.
- Support partners participated in all six sessions and their partner with MS participated in sessions 1 and 6 only.
- Each pair completed baseline, post-coaching and 3 month follow up measures relating to the secondary objectives and had access to materials through a personalized website.
- Out of the 31 pairs, 26 were spouses, 2 were cohabiting partners, and three were parent-child dyads. 27 pairs were White or Caucasian, 2 African-American, 1 Hispanic, and 1 interracial.
- This study was registered on ClinicalTrial.gov (NCT03555253) and was approved by the Advarra Institutional Review Board.

	PwMS (N = 31)	Support Partner (N = 31)
Age (Mean)	49.5 years	49.5 years
Male	19 %	68%
Female	81 %	32%
Time since diagnosis (Mean)	13.2 years	
MS Type:		
Relapsing Remitting	93%	
Secondary Progressive	3%	
Progressive Relapsing	3%	
Employed Full Time	16%	68%
Employed Part Time	3%	19%
Unemployed	65%	3%
Other	16%	10%

- Recruitment for this study included non profit organizations, social media, Multiple Sclerosis Association Of America and was supported by the North American Research Committee on Multiple Sclerosis (NARCOMS), which is a project of the Consortium of MS Centers.

PROGRAM OUTLINE

1. "Staying Strong: Resilience and Caregiving"
2. "The Forgotten Symptoms of MS: Cognition, Fatigue, and Mood"
3. "Avoiding Landmines in Interpersonal Communication: Positive Communication Strategies for MS"
4. "There's No Problem Too Big: Practical Approach to Problem Solving in MS"
5. "Putting On Your Own Oxygen Mask First: Self Care for Support Partners"
6. "Running On Empty: Recognize When It's Time To Ask For Help and Refuel?"



RESULTS

Feasibility:

- Completion rate was 83.8% (26/31), with four pairs withdrawing from the study for scheduling conflicts (e.g. family bereavement or medical related issues). Satisfaction of the intervention was considered good and some example quotes are provided.

Measure		Pre		Post				
	N	Mean	SE	Mean	SE	df	t	p
Modified Social Support Scale[2]	26	72.6	2.34	76.9	1.97	25	- 3.23	.003
Emotional Support Subscale	26	31.00	1.16	33.7	1.08	25	- 4.17	<.001
Satisfaction with Care Subscale[3]	26	45.6	1.41	45.6	1.17	25	- 3.06	.005
Perceived Stress Scale[4]	26	36.23	1.38	33.61	1.38	25	2.46	.021
Knowledge	52	15.26	0.33	16.1	0.26	51	- 2.25	.029
General Life Satisfaction[5]	52	25.61	0.81	26.06	0.79	51	- 2.51	.015
Resilience[6]	52	29.32	1.90	30.3	0.79	51	- 2.22	.031
NB: PwMS (Participant with MS) SP (Support Partner)								

Preliminary Efficacy:

- T tests pre and post intervention were conducted to establish preliminary efficacy of the intervention. Participants with MS reported better overall support along with, in particular, increased feelings of emotional support. Support partners reported higher satisfaction of their care provided to their partner with MS as rated by a subscale in the Sense of Competence questionnaire, and lower levels of stress.
- Overall, participants described increased knowledge, increased general life satisfaction, and increased resilience. Knowledge was measured using a self constructed questionnaire by the study team to measure knowledge on cognition and resilience. Further analysis will be conducted.

"I felt more validated. Some of it was startling, to see how much the cognitive aspect affects my life. I was able to express my needs around cognitive changes to my friends, as SP has been hearing me more and I feel more validated." Participant with MS.

"It was easier for him to recognize when I have been upset or frustrated before it turned worse, before it made me really upset. He is better at being able to understand me, and being able to communicate about those things." Participant with MS.

"I got a lot out of it emotionally, but I also got some eye-opening moments and I liked the way it was presented, very organized." Support Partner.

"The best thing about the support was the breadth of resources. A lot of different ideas, not just one thing to try. Lot of different options, points of view to look into." Support Partner.

"The idea of resiliency helped me more with my own situation. It's opened my eyes, knowing what to look for, and how to maintain resiliency if it gets more difficult." Support Partner.

"Best thing was the way interactive features got the user to talk. I thought it was juvenile at first but it got me to discuss topics I normally wouldn't talk about, as it was less direct. It took my mind off what you were there for, onto the topic. It was a comfortable place to talk." Support Partner.

"It was life-changing for me, because I was definitely stressed and probably not giving the attention to PwMS that she deserves. I was not feeling my life was on a decent track. Now I'm engaged in everything that's going on, and I pay more attention to her." Support Partner.

"The fifth session on self-care is an idea he hadn't put himself into. He thought, it's hard for me, but this let him know it affected him too." Participant with MS.

CONCLUSIONS

The overall study feasibility is considered successful to date with a range of participant ages in both spousal and non-spousal pairs. The study to date shows the benefits of resilience building skills in addressing challenges previously identified in this population. These skills can be promoted and taught clinically via non-therapeutic methods supported by telehealth. Future development of the program includes further personalized modules or group participation.

If you'd like to learn more, visit https://www.myhealios.com/research or get in touch via info@myhealios.com.

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