

A feasibility study of a manualized resilience-based telehealth program for persons with multiple sclerosis and their support partners

Elizabeth J Halstead , Victoria M Leavitt, Damian Fiore and Kim T Mueser

Multiple Sclerosis Journal—
Experimental, Translational
and Clinical

July–September 2020, 1–11

DOI: 10.1177/
2055217320941250

© The Author(s), 2020.
Article reuse guidelines:
sagepub.com/journals-
permissions

Abstract

Background: Resilience is a protective factor that emerges when individuals are faced with challenges and stressors. Multiple sclerosis (MS) is a chronic neurological disease that introduces a great deal of stress for the individual and his/her support partner. We designed a telehealth resilience-building dyadic program for persons with MS (PwMS) and their support partners.

Objectives: To evaluate the feasibility of the resilience intervention. The secondary objective was to assess the benefits of the intervention.

Methods: Sixty-two participants ($M=49.5$ years, 31 dyads of PwMS) and support partners) were recruited to participate. Out of the 31 dyads, 26 were spouses, 2 were cohabiting partners, and 3 were parent–child dyads.

Results: The feasibility goals of the intervention were met, as determined by high participant satisfaction and acceptable completion rates. Preliminary outcomes relating to resilience were positive, suggesting that this intervention had a positive impact on participants.

Conclusions: To the best of our knowledge, this is the first resilience-building intervention delivered via telehealth for both PwMS and their support partners. The study showed an increase in resilience-building skills for addressing the challenges faced by PwMS and their support partners. These skills can be promoted and taught, clinically supported by telehealth, an affordable, accessible healthcare solution. Trial Registration at ClinicalTrials.gov (NCT03555253).

Keywords: Multiple sclerosis, quality of life, resilience, caregiver, support, telehealth, intervention

Date received: 19 January 2020; Revised received: 15 June 2020; accepted: 21 June 2020

Introduction

Resilience is defined as an individual's ability to cope with stress and recognize the available resources when faced with challenges.¹ Resilient individuals demonstrate positive adjustment, reflected in physical, psychological, and social functioning, despite adversity.^{2,3} Psychological variables have been found to be stronger predictors of positive adjustment to multiple sclerosis (MS) than illness-related factors.⁴ For persons with MS (PwMS), fostering resilience has the potential to improve the

long-term management of MS, leading to better adaptation and quality of life.^{5,6}

Resilience-building is an increasing focus of both preventative approaches and as a treatment for different disorders. Therefore, interventions targeting resilience focus on building a range of associated protective factors to improve outcomes in mental and physical health. To the best of our knowledge, two studies have evaluated a resilience-specific program for PwMS.^{5,6} The Everyday Matters Program, delivered via teleconference, included training on

Correspondence to:
Elizabeth J Halstead,
Healios LLC, Flemington,
NJ 08822, US.
Elizabeth.halstead@myhealios.com

Elizabeth J Halstead,
Healios LLC, Basel,
Switzerland

Victoria M Leavitt,
Translational Cognitive
Neuroscience Laboratory,
Columbia University Irving
Medical Center, New York,
NY



Damian Fiore,
Genentech Inc. south San
Francisco, CA

Kim T Mueser,
Centre for Psychiatric
Rehabilitation, Boston
University, Boston, MA

the principles of positive psychology, including courage, social skills, honesty, optimism, perseverance, and hope. The intervention found significant improvements in resilience and satisfaction with social roles, compared with a wait-list control group.⁵ The Acceptance and Commitment (ACT)-based group resilience program included training on the six core principles of ACT: acceptance, cognitive defusion, being present, self as context, values, and committed action. The intervention found significant improvements in resilience, physical- and mental health-related quality of life, depression, and stress.⁶ Other studies exploring resilience in PwMS have identified that social connection, social support, positive emotions, self-efficacy, life meaning, planning ahead, and physical and psychological wellness all contribute to resilience.^{7,8}

Social support has also been reported to be important for positive adjustment in MS.⁹ Higher levels of social support have been found to predict lower levels of anxiety in PwMS.¹⁰ The quality and type of social support is important.⁸ Many PwMS live with a family member who provides informal care, such as assisting with activities of daily living. Therefore, the inclusion of the primary support partner in an intervention could increase the perceived social support of the PwMS. A meta-analysis of couple-oriented interventions for chronic illness found that these interventions had significant effects on improving depressive symptoms, marital functioning, and pain in patients, and were more efficacious than either individual therapy or usual care.¹¹ For couples with MS, communication challenges have been identified to contribute to caregiver burden and stress, which can reduce relationship satisfaction, and lead to poorer well-being and quality of life.^{12,13} One couples-based intervention – Relationship Matters – for PwMS and their partner included training on communication skills, conflict resolution skills, and relationship maintenance techniques in the context of coping with a chronic illness. The intervention, delivered either in person or via teleconference, found improved relationship satisfaction for both partners compared with a control group who received no intervention. In addition, significant improvements were found in mental health-related quality of life, communication, conflict resolution, and the ability to handle MS-specific relationship issues.¹⁴

Inclusion of the support partner in a resilience-building intervention could have additional direct benefits for the support partner, such as decreased

caregiver burden. Caregivers can experience strain and burden as a result of the need to provide progressively greater levels of assistance to a partner with MS.¹⁵ Supports for caregivers are often limited, especially those addressing the emotional consequences of their role.¹⁶ Resilience may therefore be protective not only for patients facing the disease, but also buffer the effects of stress on caregivers.¹⁷ Interventions for caregivers in non-MS populations that have addressed resilience have resulted in positive outcomes.^{18,19} For example, one study assessed the effect of a family resilience reinforcement program with caregivers of elderly patients with dementia.¹⁸ The program included training on finding strengths and overcoming difficulties, enhancing family cohesion and resources, and communication skills. The intervention found significant improvements in family resilience, family adaptation, and perceived health status, along with decreased caregiver burden, compared with a control group who received usual care. To our knowledge, prior research has not targeted resilience in couples with MS. We therefore designed a new resilience-building intervention for both the PwMS and their family support partner (e.g., spouse, child, parent).

This new intervention utilized a resilience framework to guide the intervention content.²⁰ The framework identifies four levels at which resilience can be enhanced: individual (e.g., behavior, biology), family (e.g., support and family cohesion), social context (e.g., social networks, work) and social policies (e.g., health, education). Within the context of the framework, our resilience-building intervention sought to increase resilience by teaching information and skills that (a) focused on building individual resilience and associated factors (e.g., coping strategies, self-efficacy, acceptance, seeking support) in both the PwMS and their support partner, and (b) aimed to increase family support and cohesion to facilitate positive psychological adjustment and overall well-being through teaching communication skills.

The symptoms of cognitive impairment have been reported to have an impact on several factors for both the PwMS and their partner, including increased communication challenges and decreased relationship quality. In addition, changes to daily living (e.g., role changes and emotional responses) have led to increased caregiver burden and feelings of isolation for the PwMS.²¹ Support partners have reported needing to better understand the cognitive symptoms of MS and how they affect their family

member.²² Therefore, in the intervention we included information and skills focused on managing the effects of cognitive impairment.

Considering the mobility difficulties associated with MS, telehealth may be an especially useful modality for delivering support programs to PwMS and their caregivers compared with more traditional in-person approaches. A recent review found the use of telemedicine interventions to be beneficial, cost-effective, and satisfactory for MS patients.²³ Similarly, a systematic review of telehealth interventions that focused on family caregiver outcomes found the majority of studies to be beneficial and satisfactory to participants.²⁴ The systematic review focused on interventions delivered to parental caregivers and caregivers of adult populations with chronic disease or disability. The majority of studies reviewed were pilot/feasibility studies (51%) or randomized controlled trials (29%). The review found more than 95% of studies reported significant improvements in family caregiver outcomes, and that caregivers were satisfied and comfortable with telehealth. As the remaining 5% found telehealth interventions to be as effective as face to face alternatives, it was suggested telehealth tools can enhance the care of both patients and caregivers.²⁴ Accordingly, we are delivering the new resilience-building intervention via telehealth.

Previous research has suggested that caregivers may benefit from access to tailored information and increased communication with healthcare providers.²⁴ In a previous study, support partners expressed a preference for a few sessions in a

couple-based intervention to be conducted with them alone to address some of their needs.²¹ Thus, to consider these individual needs, we focused more sessions in our intervention on the support partner, to promote both their well-being and with the aim of positively affecting their partner with MS.

This study was a pilot of a new resilience-building intervention for PwMS and their primary family support partner, delivered via telehealth. The primary objective was to evaluate feasibility of the intervention and participant satisfaction with the program. The secondary objective was to explore the potential benefits of the intervention, therefore several outcomes targeted by the intervention were evaluated.

Method

Design

Prior to enrolment, this study was registered on ClinicalTrials.gov (identifier: NCT03555253) and approved by the Advarra Institutional Review Board. Participants were screened for eligibility, and informed consent was obtained. All participants were asked to complete outcome measures with the study coordinator at baseline, post-program, and at 3-month follow-up. To minimize patient burden, all aspects of the study were designed to enable subjects to participate remotely (i.e., no study visits were required). The study was delivered through a secure web-based portal “MS Hub,” custom developed for this study. The MS Hub enabled participants to access related program software, including an HTML-based linear presentation (the “virtual living room”, see Figure 1), Adobe

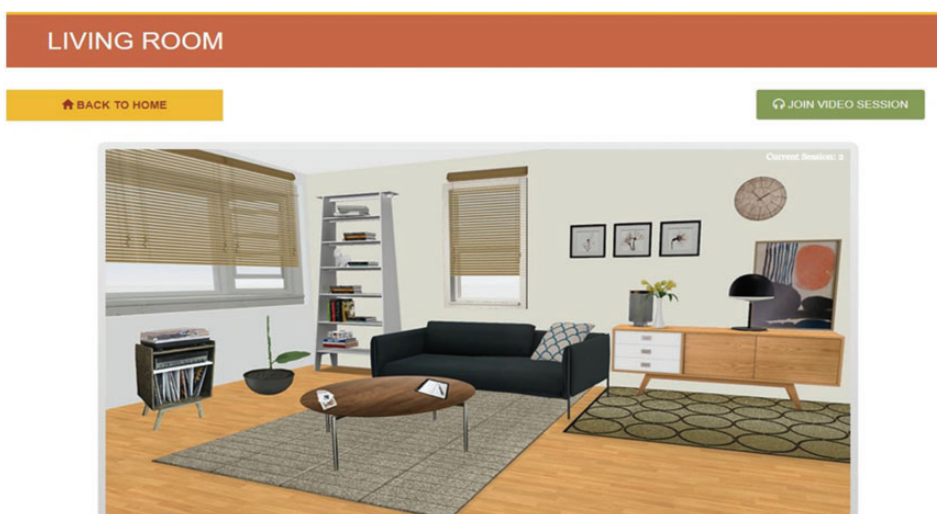


Figure 1. Virtual living room in MS Hub.

Connect (video tele-conferencing), and Adobe Sign (completion of electronic consent forms).

Participants

To be eligible for the study, both partners (PwMS and their close family member) had to live together in the United States, be between 18 and 65 years old, and have access to a computer with a stable internet connection in a private setting. Each PwMS was required to be diagnosed with MS (based on self-report of MS type and date of diagnosis) and to have cognitive difficulties, as measured by a score greater than 20 on the Perceived Deficit Questionnaire.²⁵ The family member of the PwMS (referred to as the “support partner”) needed to have a long-standing relationship with the person (e.g., spouse, partner, or child) and provide informal caregiver assistance.

Participants were recruited via website postings, social media, non-profit organizations (e.g., Multiple Sclerosis Association of America), the North American Research Committee on Multiple Sclerosis (NARCOMS), and medical centers.

Recruitment included both targeted groups and events for PwMS and also support-partner-only support groups. The majority of interest came from local state MS support groups or the National Multiple Sclerosis Society (50%) and NARCOMS (35%). In total, 107 participants were screened (PwMS or their support partner); of those, 29 were ineligible, 47 were not interested, and 31 dyads gave signed informed consent and enrolled. Of these, 26 dyads were spouses, two were cohabiting partners, and three were parent–child dyads. Demographic details and recruitment sources can be found in Table 1.

Resilience-based skills program

The intervention included both education and practical skills on the following 10 topics, delivered in six 45-min weekly sessions:

1. Session 1: (a) Positive adjustment to MS, (b) Acceptance, and (c) Education about resilience in MS;
2. Session 2: (d) Information: Symptoms of MS;

Table 1. Participant demographic information.

	PwMS	Support partner
	<i>N</i>	<i>N</i>
Female	25	10
Male	6	21
Mean time since diagnosis	13.2 years	
MS type		
Relapsing–remitting	29	
Secondary progressive	1	
Progressive relapsing	1	
Employment status		
Employed full time	5	21
Employed part time	1	6
Unemployed	20	1
Other	5	3
Ethnicity		
White or Caucasian	28	27
African-American	2	2
Hispanic	1	2
Recruitment source		
NARCOMS	15	
MS support group	10	
Medical centers	1	
Healios database	1	
Study participant referral	1	
ClinicalTrials.gov	1	

PwMS: Persons with multiple sclerosis; NARCOMS: North American Research Committee on Multiple Sclerosis.

3. Session 3: (e) Communication skills;
4. Session 4: (f) Healthy coping strategies, (g) Seeking support, and social connection;
5. Session 5: (h) Advocacy skills, and (i) Self-care for the support partner;
6. Session 6: (j) Identifying and accessing resources.

Two of the six modules (the first and last) were designed to be attended by both participants (i.e., the PwMS and the support partner), the four intermediate sessions were designed for the support partner only. In line with previous research, Session 2 focused on cognitive symptoms of MS.²¹ The objectives of each session are presented in Table 2. Sessions were led by a “resilience coach,” which in this study was an experienced licensed social worker, with prior experience working closely with caregivers.

Each session was structured to include an introduction/review of the previous session; new information (Q & A/videos); role play/vignettes; connect the dots (How does this relate to me?); and selecting

activities to practice at home. All session content was available to both participants via the MS Hub online portal, which included supplementary reading and videos to access at the participants’ convenience after the session was completed. As the program was for any family member who was a primary support partner, each session included activity and role-play options designed to be applicable to each type of family relationships (e.g., spouse, child, parent).

Feasibility and outcomes

Feasibility was defined as the willingness of eligible couples to participate in the program, and the extent of participation for those who were interested. We set our initial goal for program completion at 75% of the sample. To assess satisfaction with the overall program, a self-report measure of participants’ experience was developed. This included one 5-point Likert scale question (“How satisfied were you with the program?”), two yes/no questions (“Would you recommend the program to someone in a similar situation to you?” and “Did the amount of support you received in the program meet your

Table 2. Session objectives for the resilience intervention.

Session number	Session title	Session objectives
1	<i>“Staying Strong: Resilience”</i>	<ol style="list-style-type: none"> 1. Introduce the program, provide an overview, and orient users to the support hub. 2. Describe the concept of resilience and its implications for support partners. 3. Teach strategies for incorporating techniques related to resilience-building into day-to-day life.
2	<i>“The Forgotten Symptoms of MS: Cognition, Fatigue, and Mood”</i>	<ol style="list-style-type: none"> 1. Provide an overview of the lesser described symptoms of MS: cognition, fatigue, and mood. 2. Describe how these symptoms present and how they impact the support partner–patient relationship, and teach strategies for dealing with them.
3	<i>“Overcoming Isolation: The Importance of Social Connections in MS”</i>	<ol style="list-style-type: none"> 1. Identify MS-specific everyday challenges that impact functioning. 2. Learn strategies that other MS patients have successfully employed to manage similar challenges.
4	<i>“Putting On Your Own Oxygen Mask First: Self-Care for Support Partners”</i>	<ol style="list-style-type: none"> 1. Increase awareness in the support partner about ways in which their role may be affecting them. 2. Teach strategies for reducing the stress of caregiving.
5	<i>“Running On Empty: Recognize When It’s Time To Ask For Help and Refuel”</i>	<ol style="list-style-type: none"> 1. Teach strategies for identifying resources to reduce stress on support partners.
6	<i>Conclusion: End of Study: “Next steps” via video and program summary</i>	<ol style="list-style-type: none"> 1. Review key points from all sessions and provide a roadmap for the future.

MS: multiple sclerosis.

needs?”), and four open-ended questions (“What was the best thing about the program?” “What was the worst thing about the program?” “How could the support be improved?” and “What effect did the program have on you?”). Responses to the open-ended questions were coded and categorized into topic themes, using a constant comparison method,²⁶ and reported in a narrative.

To establish the potential benefits of the program, changes in several outcomes targeted by the intervention were evaluated at baseline, post intervention, and at 3-month follow-up. For both the PwMS and their support partner these included knowledge of MS, resilience, satisfaction with life, positive and negative emotions, relationship satisfaction (completed only by married or cohabiting couples), and mental health outcomes including anxiety, depression, and stress. For the PwMS, we also evaluated perceived support, and for the support partner we also evaluated self-efficacy, feelings of being able to care for their partner with MS, and perceived burden.

Knowledge of MS was measured by a 10-item questionnaire created by the authors (EH and VL) to assess knowledge of the information presented in the program. Resilience was measured by the 10-item Connor–Davidson Resilience Scale; responses are rated on a 5-point scale.¹ Satisfaction with life was measured by the 5-item General Life Satisfaction Survey; responses are rated on a 7-point scale.²⁷ Positive and negative emotions in the last week was measured by the Positive and Negative Affect Schedule; responses to 20 emotions are rated on a 5-point scale.²⁸ Relationship satisfaction was measured by the 7-item Burns Relationship Satisfaction Scale; responses are rated on a 7-point scale.²⁹ Anxiety and depression was measured on the 14-item Hospital Anxiety and Depression Scale; the measure has two subscales, each comprising 7-items, and responses are rated on a 4-point scale.³⁰ Stress was measured on the 14-item Perceived Stress Survey; responses are rated on a 5-point scale.³¹ Perceived support was measured by the 18-item Modified Social Support Survey (MSSS).³² The MSSS has four subscales: Emotional Support, Tangible Support, Affective Support, and Positive Support and responses are rated on a 5-point scale. The four subscales create a total score of overall support. Self-efficacy was measured by the 10-item General Self-Efficacy Scale; responses are indicated on a 5-point scale.²⁷ Feelings of being able to care for their partner with MS was measured by

the 27-item Sense of Competence Questionnaire (SCQ).³³ The SCQ covers three domains: consequences of involved in care for the personal life of the caregiver (8-items), satisfaction with one’s own performance as a caregiver (12-items), and satisfaction with the person (with chronic illness) as a recipient of care (7-items). Each domain is rated on a 5-point response scale. Total scores are created for the three domains along with a total score for overall sense of competence as a caregiver. Caregiver burden was measured by the 22-item Zarit Burden Interview, responses are rated on a 5-point scale.³⁴ For future exploratory purposes, we also included measures on fatigue,³⁵ work productivity,³⁶ and objective caregiver burden.³⁷

Statistical approach

To evaluate changes in the outcome measures we conducted linear regression analyses on the outcome measures for each member of the dyad (PwMS or support partner) across three time points (baseline, immediate follow-up, 3-month follow-up). When Mauchly’s test was violated ($<.05$) degrees of freedom were corrected, and the appropriate correction based on the test statistic is reported. Post hoc tests were not included due to low power. It was hypothesized that the intervention would lead to improvements in several of the outcome measures selected, therefore, all results are reported for one-tailed tests.

Results

Feasibility

Of the 31 dyads who enrolled, completion rate of the full program was 83.8% (26/31). Five dyads withdrew from the study due to scheduling conflicts (e.g., family bereavement or medical-related issues). Two dyads withdrew after three sessions, three dyads withdrew after Session 1. The following findings are from the 26 dyads who fully completed the program.

Satisfaction with the program

At the end of the intervention, 92% of participants reported that the program met their needs and 96% said they would recommend the program to others. At the end of each session, participants rated satisfaction from 1–5 (5 being the highest score). Mean scores for each session ranged from 4.4–4.74, Session 1 scored the lowest and Session 5 scored the highest. On a 5-point Likert scale, the mean overall satisfaction reported by the PwMS was $3.65 \pm \text{SD}$, and the mean overall satisfaction reported by the support partners was $4.76 \pm \text{SD}$.

At baseline, support partners reported significantly higher mean positive emotions (35.83 ± 6.28 ; 32.23 ± 7.2 ; $t = -2.12$ (60), $p = .039$) and lower depression (3.64 ± 2.98 , vs 5.32 ± 3.55 ; $t = 2.02$ (60), $p = .048$) than PwMS. No significant baseline differences between the PwMS and their support partner were found for any other variables.

All participants who completed the intervention completed the measures at all three time points. One support partner was removed from the analyses due to being an extreme outlier (greater than 2 SD from mean) across most of the support partner measures at baseline. Upon review of the characteristics of this participant it was discovered that the support partner was experiencing significant neuropathy and other medical problems. The PwMS was not excluded as they were not an extreme outlier.

The qualitative data from the intervention evaluation provided some key considerations on the satisfaction of program. Some participants reported technical issues with the online format (e.g., “my computer was not working properly”). Some PwMS reported not feeling engaged with the program and wishing they had had more involvement. Several support partners reported finding individual sessions helpful as these provided them with opportunities to focus independently on information and skills relevant to them. Several participants commented that the focus on resilience was a positive experience and they could relate it to their lives. Participants reported the emphasis on symptoms relating to cognitive impairment was helpful. Some participants indicated they would like to see additional topics addressed, including how to adjust to changes relating to employment and financial situations. Some participants said that participating in this program would have been even more beneficial to them earlier in the course of the MS.

Benefits of the program

The mean scores of each outcome measure at the three time points are reported in Table 3. Significant overall linear effects of the analysis are reported.

Feelings of being able to care for their partner with MS were found to significantly increase in the domain measuring satisfaction with one's performance as a caregiver, $F(2,48) = 5.61$, $p = .007$. The overall score and the other two domains (measuring caregiver satisfaction with care recipient, and the

consequences of involvement in care for the personal life of the caregiver) did not change significantly.

Perceived social support was found to increase in PwMS. Both the total score ($F(2,50) = 4.58$, $p = .015$) and the Emotional Support subscale increased significantly ($F(2,50) = 5.06$, $p = .010$). The three other subscales (Tangible Support, Affective Support, and Positive Support) did not change significantly.

Stress decreased both for support partners ($F(2,48) = 3.79$, $p = .030$) and for PwMS ($F(2,50) = 10.91$, $p < .001$). Anxiety also decreased both for support partners ($F(2,48) = 4.06$, $p = .024$) and for PwMS ($F(2,50) = 9.84$, $p < .001$). For relationship satisfaction (reported by spousal couples only), Mauchly's test indicated the assumption of sphericity had been violated $\chi^2(2) = 18.6$ for the support partners, thus degrees of freedom were corrected using Greenhouse–Geisser estimates of sphericity ($\epsilon = .623$). The results indicated that relationship satisfaction increased for support partners ($F(1.25, 26.16) = 5.41$, $p = .022$), but there was no significant change for PwMS.

For PwMS, satisfaction with life increased ($F(2,50) = 6.78$, $p = .002$), positive emotions in the last week increased ($F(2,50) = 4.73$, $p = .013$), resilience increased ($F(2,50) = 8.29$, $p = .001$), and negative emotions in the last week reduced ($F(2,50) = 4.38$, $p = .018$).

The qualitative feedback indicated that both PwMS and support partners reported several benefits of the program, including: positive changes in interactions with their partner (e.g., increased patience from the support partner), improved communication, learning new skills to improve coping, understanding and awareness of the impact of cognitive changes, practical skills to cope with memory difficulties, increased sense of closeness in their relationship, and increased awareness of each other's roles. Support partners also reported increased self-care, feeling less alone in dealing with a partner with MS, and increased knowledge of the importance of seeking support. PwMS reported feeling more supported by their partner's willingness to participate in the program. Participants reported feeling validated about their own resilience skills.

Discussion

This study sought primarily to evaluate the feasibility of the intervention and participant satisfaction

Table 3. Mean scores of outcome measures at each time point.

Measure	Subscale	Time 1		Time 2		Time 3	
		<i>Support partner</i>	PwMS	<i>Support partner</i>	PwMS	<i>Support partner</i>	PwMS
		<i>n</i> = 25	<i>n</i> = 26	<i>n</i> = 25	<i>n</i> = 26	<i>n</i> = 25	<i>n</i> = 26
Knowledge		15.04	15.50	15.63	16.54	16.12	16.38
Life satisfaction		26.28	23.46	27.28	25.31	27.48	26.54
Resilience		31.44	27.58	31.72	30.58	32.12	29.46
Stress		35.44	39.34	33.04	34.50	32.88	34.69
Anxiety		5.92	6.81	4.44	4.96	4.32	4.73
Depression		3.20	5.23	2.76	4.46	2.28	4.73
Positive emotions		36.72	31.65	36.56	34.81	37.24	32.23
Negative emotions		16.00	18.50	13.80	16.08	14.24	14.92
Self-efficacy		39.68		40.20		40.20	
Burden		21.52		20.24		19.04	
Sense of competence	<i>Satisfaction as a caregiver</i>	46.12		49.20		48.72	
	<i>Consequences of involvement in care</i>	28.16		29.12		30.12	
	<i>Satisfaction with care recipient</i>	29.80		30.00		29.84	
Social support	<i>Tangible</i>		16.71		17.57		16.54
	<i>Emotional</i>		31.68		34.36		32.76
	<i>Affective</i>		13.15		13.42		12.92
	<i>Positive</i>		11.77		12.23		11.77
Social support total			73.96		77.68		74.36
		<i>Support partner</i>	PwMS	<i>Support partner</i>	PwMS	<i>Support partner</i>	PwMS
		<i>n</i> = 22	<i>n</i> = 23	<i>n</i> = 22	<i>n</i> = 23	<i>n</i> = 22	<i>n</i> = 23
Relationship satisfaction		32.50	37.13	35.50	36.13	36.23	34.43

PwMS: Persons with multiple sclerosis.

with the program, and secondarily, to evaluate the preliminary effects of a new program delivered via a telehealth platform for couples in which one person has MS. The program aimed to increase understanding of MS and resilience when coping with challenges. The program had six sessions in total, with both partners attending sessions 1 and 6 and the support partner attending sessions 2–5. The feasibility of the program was supported by several indicators including successful recruitment and engagement of couples into the program, and the high rate of completion of the program (83.8%). Other Web-based and telemedicine-based interventions have also shown good participant retention rates and good outcomes for participants.^{38–40}

Satisfaction with the program was supported by participant satisfaction ratings given at the end of each session and at the end of the program. A total of 92% of the participants reported that the program

met their needs. Furthermore, session satisfaction ratings (between 1 and 5) completed at the end of each session by the support partner were uniformly high (ranging between 4.4 and 4.74), as was overall satisfaction at the end of the program (overall mean = 4.76). Although overall satisfaction (rated between 1 and 5) was also high for participants with MS (mean = 3.65), it was significantly lower than the support partners' (4.76).

We developed our program as a set of skills for shared resilience improvement. However, we focused more sessions on the support partner, to focus on their individual needs, with the aim of positively affecting their partner with MS. Indeed, the highest scoring session for the support partners was Self-care, and many support partners said that it was refreshing to have the focus of the program on them, and they were disappointed when the program came to an end. Support partners also reported that the

focus on MS symptoms related to cognitive impairment during the intervention was very helpful. Support partners reported an improvement in their knowledge of these symptoms, and a new understanding as to how symptoms affect communication between the dyad. Some of the participants commented that the program helped initiate difficult conversations for them as a couple that had previously been avoided. Therefore, future modifications to the program could include more attention on communication skills, delivered together as a couple.

The lower satisfaction ratings of the partner with MS, combined with their qualitative feedback, could reflect that some of these participants did not feel fully engaged in the program, or felt left out by the preponderance of sessions conducted with only the support partner. In line with the changes in satisfaction with the program, relationship satisfaction increased for the support partners, but not for the partner with MS. These findings suggest that the decision to conduct individual sessions for the support partner but not the partner with MS may have resulted in the disproportionate benefits of the program for the support partner. Support partners reported benefiting from the individual sessions, therefore the optimal number of individual and dyadic sessions may still need to be determined; however, it is important to consider offering the same number of individual sessions to both partners in future adaptations of the program.

Though support partners indicated greater improvements in relationship satisfaction after the program than their partner with MS, and indicated greater satisfaction with the program, the partner with MS improved more on several other outcome measures. In particular, the partners with MS improved more in positive and negative emotions, resilience, and satisfaction with life after the program than their support partners. These differential changes may in part reflect that fact that partner with MS had lower levels of positive emotions at baseline than their support partners, and thus had more room to improve over the course of the program.

Although the results are promising, they suggest a need for more rigorous research to determine which outcomes are directly related to the intervention; in addition, our findings are limited by the study not including a control group for comparison. Overall, the results suggest a well-powered study may demonstrate positive effects of this resilience intervention. The qualitative feedback from the participants

also indicated several other avenues for future research on this program. Firstly, that the program would have been helpful in the earlier stages in the MS journey, as many participants felt they had been dealing with the disease for many years and had built up their own coping mechanisms and resilience. However, many participants later in the course of their MS journey appeared to find the program helpful. Overall, it seems the broad-based education and resilience focus of the intervention benefited families in both the earlier and later stages of their MS journeys. One limitation identified from the feedback was that several participants required significant support in relation to the technical aspects of the program, and most were reliant on the study team guiding them through these difficulties. Advances and development of the technology platform are warranted.

A consideration for future research with this intervention is a more targeted approach to participation. In this feasibility study, we included family members (spouses and children). Although we ensured there was flexibility within the intervention for both types of family dyads, more targeted intervention for spouses may be more effective in increasing certain outcomes, such as relationship satisfaction, similar to outcomes in previous studies.¹³

These results are encouraging, and this program could be adapted to address caregiver resilience in other disease areas and populations delivered via telehealth. It could also be expanded to include educational topics in additional areas, such as employment and other areas of well-being e.g. sleep. In addition, to optimize satisfaction of the program for both the partner with MS and the support partner, the format of the intervention should be modified to include further individual sessions for the partner with MS and additional joint sessions. Further pilot studies to evaluate the benefits of these suggested modifications, along with the inclusion of a control group to strengthen the findings, would be beneficial prior to a future full-scale efficacy trial.

Acknowledgements

We would like to thank all the participants and organizations who facilitated the success of the study. In addition, we would like to thank the wider study team including Healios Tech., the study co-ordinators Susan Magosin and Justin Stanley, the resilience coaches, and Drs Amy Martinez and Alys Griffith for their contributions. Thank you to Genentech Inc. for providing the grant for this

study. Statistical analyses were conducted by Dr Elizabeth Halstead.
Please note author EH current affiliation: Department of Psychology and Human Development, University College London, Institute of Education, London, UK.

Conflict of Interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: EH reports employment with Healios LLC for the duration of the study; DF reports employment with Genentech Inc. at the time of the study; VML and KTM reports consulting work with Healios LLC; VML reports being a co-founder of eSupport Health, PBC.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Genentech Inc. provided Healios LLC with the grant for this study.

ORCID iD

Elizabeth J Halstead  <https://orcid.org/0000-0002-5633-1859>

References

1. Connor KM and Davidson JR. Development of a new resilience scale: the Connor–Davidson resilience scale (CD-RISC). *Depress Anxiety* 2003; 18: 76–82.
2. Luthar SS and Cicchetti D. The construct of resilience: implications for interventions and social policies. *Dev Psychopathol* 2000; 12: 857–885.
3. Rutter M. Resilience in the face of adversity: protective factors and resistance to psychiatric disorder. *Br J Psychiatry* 1985; 147: 598–611.
4. Dennison L, Moss-Morris R and Chalder T. A review of psychological correlates of adjustment in patients with multiple sclerosis. *Clin Psychol Rev* 2009; 29: 141–153.
5. Pakenham KI, Mawdsley M, Brown FL, et al. Pilot evaluation of a resilience training program for people with multiple sclerosis. *Rehabil Psychol* 2018; 63: 29–42.
6. Alschuler KN, Arewasikporn A, Nelson IK, et al. Promoting resilience in individuals aging with multiple sclerosis: results from a pilot randomized controlled trial. *Rehabil Psychol* 2018; 63: 338–348.
7. Silverman AM, Verrall AM, Alschuler KN, et al. Bouncing back again, and again: a qualitative study of resilience in people with multiple sclerosis. *Disabil Rehabil* 2017; 39: 14–22.
8. Black R and Dorstyn D. A biopsychosocial model of resilience for multiple sclerosis. *J Health Psychol* 2015; 20: 1434–1444.
9. McCabe MP and O'Connor EJ. Why are some people with neurological illness more resilient than others? *Psychol Health Med* 2012; 17: 17–34.
10. 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.
11. Martire LM, Schulz R, Helgeson VS, et al. Review and meta-analysis of couple-oriented interventions for chronic illness. *Ann Behav Med* 2010; 40: 325–342.
12. Starks H, Morris MA, Yorkston KM, et al. Being in-or out-of-sync: couples' adaptation to change in multiple sclerosis. *Disabil Rehabil* 2010; 32: 196–206.
13. Boland P, Levack WM, Hudson S, et al. Coping with multiple sclerosis as a couple: 'peaks and troughs' – an interpretative phenomenological exploration. *Disabil Rehabil* 2012; 34: 1367–1375.
14. Tompkins SA, Roeder JA, Thomas JJ, et al. Effectiveness of a relationship enrichment program for couples living with multiple sclerosis. *Int J MS Care* 2013; 15: 27–34.
15. Buchanan RJ, Radin D and Huang C. Caregiver burden among informal caregivers assisting people with multiple sclerosis. *Int J MS Care* 2011; 13: 76–83.
16. Buchanan RJ and Huang C. The need for mental health care among informal caregivers assisting people with multiple sclerosis. *Int J MS Care* 2013; 15: 56–64.
17. Halstead E, Ekas N, Hastings RP, et al. Associations between resilience and the well-being of mothers of children with autism spectrum disorder and other developmental disabilities. *J Autism Dev Disord* 2018; 48: 1108–1121.
18. Bang M and Kim O. Effect of the family resilience reinforcement program for family caregivers of the elderly with dementia. *Korean J Adult Nurs* 2016; 28: 71–82.
19. Huey WT and Hashim S. A resilience training module for caregivers of dementia patients. *SHS Web Conf* 2015; 18: 05001.
20. Windle G. What is resilience? A review and concept analysis. *Rev Clin Gerontol* 2011; 21: 152–169.
21. Halstead EJ, Stanley J, Fiore D, et al. The impact of cognitive impairment in adults with multiple sclerosis (MS) and their family caregivers. *Int J MS Care*. Epub ahead of print 15 May 2020. DOI: 10.7224/1537-2073.2019-091.
22. Deibel F, Edwards M and Edwards A. Patients', carers' and providers' experiences and requirements for support in self-management of multiple sclerosis: a qualitative study. *Eur J Pers Cent Healthc* 2013; 1: 457–467.
23. Yeroushalmi S, Maloni H, Costello K, et al. Telemedicine and multiple sclerosis: A comprehensive literature review. *J Telemed Telecare* 2019; 1357633X19840097.
24. Chi NC and Demiris G. A systematic review of telehealth tools and interventions to support family caregivers. *J Telemed Telecare* 2015; 21: 37–44.

25. Sullivan MJ, Edgley K and Dehoux E. A survey of multiple sclerosis: Part I. Perceived cognitive problems and compensatory strategy used. *Can J Rehabil* 1990; 4: 99–105.
26. Glaser BG, Strauss AL and Strutzel E. The discovery of grounded theory; strategies for qualitative research. *Nurs Res* 1968; 17: 364.
27. Salsman JM, Butt Z, Pilkonis PA, et al. Emotion assessment using the NIH Toolbox. *Neurology* 2013; 80: S76–86.
28. Watson D, Clark LA and Tellegen A. Development and validation of Brief Measures Of Positive And Negative Affect: the PANAS scales. *J Pers Social Psychol* 1988; 54: 1063–1070.
29. Burns DD and Sayers S. Cognitive and affective components of marital satisfaction: Development and validation of a brief relationship satisfaction scale. *Unpublished manuscript*, 1988.
30. Zigmond AS and Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983; 67: 361–370.
31. Cohen S, Kamarck T and Mermelstein R. Perceived Stress Scale. *Measuring stress: A guide for health and social scientists* 1994; 10: 1–2, <https://www.northhottawellnessfoundation.org/wp-content/uploads/2018/04/PerceivedStressScale.pdf>
32. Sherbourne CD and Stewart AL. The MOS Social Support Survey. *Soc Sci Med* 1991; 32: 705–714.
33. Vernooij-Dassen MJ, Persoon JM and Felling AJ. Predictors of sense of competence in caregivers of demented persons. *Soc Sci Med* 1996; 43: 41–49.
34. Zarit SH, Reever KE and Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980; 20: 649–655.
35. Cella D, Lai JS, Nowinski CJ, et al. Neuro-QOL: brief measures of health-related quality of life for clinical research in neurology. *Neurology* 2012; 78: 1860–1867.
36. Reilly MC, Zbrozek AS and Dukes EM. The validity and reproducibility of a work productivity and activity impairment instrument. *Pharmacoeconomics* 1993; 4: 353–365.
37. Schene AH, Tessler RC and Gamache GM. Instruments measuring family or caregiver burden in severe mental illness. *Soc Psychiatry Psychiatr Epidemiol* 1994; 29: 228–240.
38. Moss-Morris R, McCrone P, Yardley L, et al. A pilot randomised controlled trial of an Internet-based cognitive behavioural therapy self-management programme (MS Invigor8) for multiple sclerosis fatigue. *Behav Res Ther* 2012; 50: 415–421.
39. Miller DM, Moore SM, Fox RJ, et al. Web-based self-management for patients with multiple sclerosis: a practical, randomized trial. *Telemed J E Health* 2011; 17: 5–13.
40. Banbury A, Nancarrow S, Dart J, et al. Telehealth interventions delivering home-based support group videoconferencing: systematic review. *J Med Internet Res* 2018; 20: e25.