

## Clinical Study

# Integrating Caregiver Support into Multiple Sclerosis Care

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With loss of mobility in Multiple Sclerosis (MS) comes increase in caregiver assistance, burden, stress, and depression. This 6-month feasibility study used a pre-post design to test integration of a validated, behavioral, caregiving intervention into an ongoing MS clinic. Because the program focused on caregivers, there were no additional services provided to the persons living with MS other than usual medical care. Twenty-five MS caregivers received REACH VA (Resources for Enhancing All Caregivers' Health in the VA), a six-session behavior-focused intervention during two to three months designed to increase caregiver skills in managing their own stress and burden and MS related issues and concerns, with a focus on mobility. Caregivers were assessed at baseline, three, and six months. Caregivers' expectations of the program were to receive education on MS, caregiving and stress management skills, and support. The major benefits caregivers reported were understanding their loved one's condition and how to better provide care. At six months, caregivers reported statistically and clinically significant improvements in depressive symptoms and bother with challenging MS behaviors. Persons with MS reported benefit for their caregivers and for themselves; 71% reported that their caregivers had helped them with mobility and function. Study results suggest that the addition of the brief REACH caregiver intervention into an MS clinic would benefit both caregivers and persons with MS. Although the intervention was six sessions over three months, benefit persisted at six months, suggesting durability of effects. This trial is registered with ClinicalTrials.gov NCT02835677.

## 1. Introduction

It is estimated that around one million people in the United States are living with Multiple Sclerosis (MS) [1]. Between 80% and 90% of informal care for people with MS occurs in the home, typically by a spouse who spends from 4 to 12 hours per day caring for their loved one [2, 3]. MS caregivers report greater stress-related symptoms and lower life satisfaction than noncaregivers, have higher needs for mental health services, and report a wide range of problems related to caregiving [4, 5]. Caregiver burden in MS is a multidimensional response

to physical, psychological, emotional, social, and financial stressors associated with caregiving, often leading to higher risk of depression and lower quality of life [6].

Caregiving demands are related to physical, emotional, and health status of the person with MS [7]. With loss of mobility in MS comes increase in amount and type of caregiver assistance needs, with concomitant increase in caregiver burden, stress, and depression [8–11]. The more severe the symptoms, the higher the cost and burden on the caregiver [9, 12, 13]. Caregiver depression is associated with less perceived social support, higher MS disease severity, and greater

comorbidity for veterans [14]. Caregiver depression and lack of social support contribute to quality of life decreases in persons living with MS [14].

Providing caregivers with education, coping skills, problem solving, and support can increase quality of life for both the caregiver and person with MS [15, 16]. Including caregivers in the treatment plan may help caregivers perform their tasks while avoiding injury to themselves and the person with MS [8]. This feasibility study tested the integration of a validated behavioral caregiving intervention into clinical practice to provide services to caregivers of people with MS.

## 2. Materials and Methods

**2.1. Overview.** The study was a two-year feasibility pilot, July 2016–June 2018 registered in <https://clinicaltrials.gov/> and funded through Small Projects in Rehabilitation Research (SPiRE) of the Department of Veterans Affairs (VA) Rehabilitation Research and Development Service. Eligible participants were caregivers of ambulatory persons with MS being treated by the Neurology Service at the Memphis Veterans Affairs Medical Center (VAMC). Recruitment occurred through the clinic via brochures and clinician referrals. The study was conducted under the oversight of the Memphis VAMC Institutional Review Board (IRB). Consent was obtained during clinical visits or informed consent calls for the caregiver and the person with MS, followed by baseline data collection with each.

**2.2. Intervention.** REACH VA (Resources for Enhancing All Caregivers' Health in the VA) helps caregivers manage care recipient behavioral concerns and their own stress [17–19]. The behavioral intervention is based on a stress/health process model and focuses on information and skills to help caregivers diminish, tolerate, or master situational demands [20, 21]. The intervention is structured through a Program Coach Manual that specifies activities to occur at each session to ensure that the main caregiving risk areas (information on the disease and its course, safety for the care recipient, caregiver health and emotional well-being, social support, and management of care recipient problem behaviors) are covered. It is targeted through a brief Risk Assessment that identifies caregiving risk areas for the dyad. The Risk Assessment [22] asks caregivers to identify their specific concerns about frustrations, vigilance, social support, physical, and emotional well-being, care recipient safety issues, and number of and bother about care recipient problem behaviors/concerns. The Risk Assessment is used by the Program Coach to target information and skills building to the caregiver's greatest areas of need; component scales are not summed for an overall risk score. The Risk Assessment and the Caregiver Notebook were developed with the assistance of national MS subject matter expert clinicians, researchers, and MS caregivers. The MS Caregiver Notebook has practical strategies in 15 chapters focused on care recipient concerns (e.g., lifting and moving, pain) and 19 chapters focused on caregiver concerns (e.g., asking for help,

challenging emotions) and provided practical strategies and worksheets based on research and clinical practice. A caregiver focuses on only those chapters that are related to the caregiving risks experienced by that dyad, although the Notebook serves as a resource for any future problems.

The intervention was delivered in six individual hour-long sessions by telephone or in person during three months (approximately every two weeks) by a trained and certified masters-level Program Coach. The Program Coach taught problem solving, and the Coach and caregiver identified practical, action-oriented behavioral strategies from the Caregiver Notebook to address caregiving problems or care recipient behaviors identified by the Risk Assessment. Each caregiver developed at least two problem solving plans, one focused on function/mobility of the person with MS and one on a problem of the caregiver's choosing (which could also target mobility). The Program Coach provided training and skills building around mood management/cognitive reframing (to think differently about situations that cannot be changed), and stress management (signal breath, stretching, guided imagery, pleasant events). A physical therapist met once with the person with MS and caregiver, following enrollment, to evaluate and create a tailored home exercise program. This program was often the basis for the function/mobility problem solving plan.

**2.3. Data and Measures.** Data collection occurred either face to face or by telephone at baseline, end of intervention (3 months), and at 6 months. Demographic data were collected at baseline for the caregiver and the person with MS. For the person with MS, baseline clinical data included the Expanded Disability Status Scale (EDSS) [23], the physical and psychological impact of MS on day-to-day life (MS Impact Scale-29—MSIS-29) [24], which is positively correlated with caregiver activities, and the Modified Fatigue Impact Scale (MFIS) [25], which measures how fatigue impacts physical, cognitive, and psychosocial functioning.

At 6 months, both caregiver and person with MS were asked if they had benefited from the program and from its components. Caregivers were asked to rank degree of benefit, confidence, and ability to care for self and loved one, on a scale from not at all (1) to extremely (5). The person with MS was asked to rate benefit for self and caregiver using the same scale. Caregivers and persons with MS were also asked qualitative open-ended questions about what they were hoping to achieve, usefulness of the intervention, and their experiences with the program, focusing on satisfaction, benefit, and utility.

Data were collected for three primary caregiver well-being outcomes: anxiety, depression, and burden. Anxiety was measured with the 7-item Generalized Anxiety Disorders Scale (GAD-7) with sensitivity of 0.89 and specificity of 0.82 [26]. These items were scored from not at all (0) to nearly every day (3), and higher total scores indicate more symptoms. The 9-item Patient Health Questionnaire (PHQ-9) assessed caregiver depression on a scale from not at all (0) to nearly every day (3) with higher total scores indicating more symptoms [27]. The PHQ is widely used in the VA and has a Cronbach's alpha of 0.86 [27]. Burden was measured by the 12-item Zarit

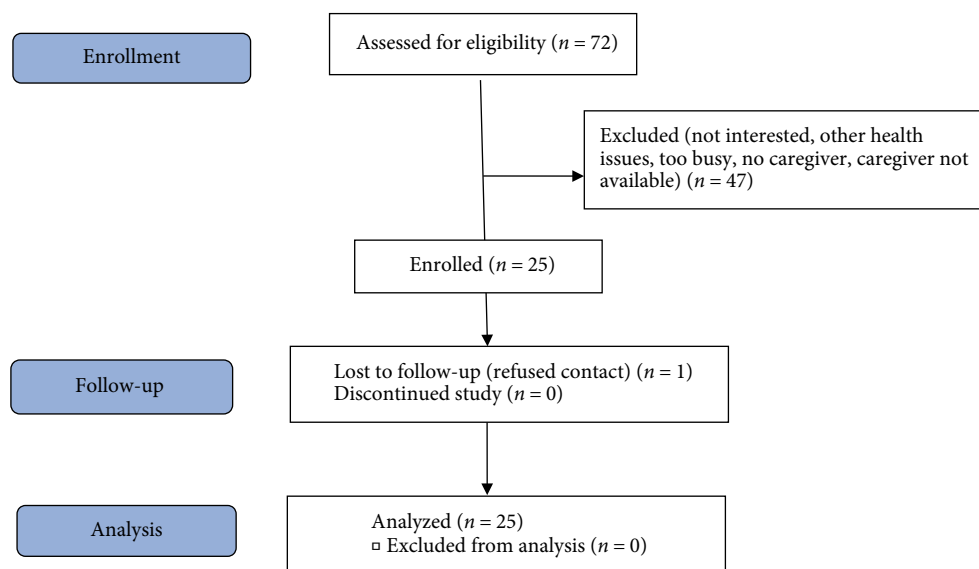


FIGURE 1: Sampling and flow of participants.

Burden Interview (ZBI-12) [28], which has a Cronbach's alpha of 0.85 [29]. These items were scored from never (0) to nearly always (4), and higher total scores indicate more burden.

Caregiver outcomes relating to providing care to the person with MS were also collected. For the Risk Assessment, the subject matter experts identified a list of 27 MS-related potentially challenging behaviors or concerns, such as falling or tripping, muscle spasms or spasticity, chronic pain, or problems with decision making, confusion, or multiple tasks. Caregivers were asked to report number of challenging MS behaviors/concerns occurring in the past month and bother with these reported behaviors. Other data included demographics, relationship to the person with MS, when caregiving began, and, for the person with MS, demographics and type and clinical severity of MS. Problem solving ratings were also collected. As caregivers work on problem solving plans they rate progress on a five-point scale from a lot worse to the same to a lot better.

**2.4. Data Analysis.** For qualitative satisfaction and benefit data, three reviewers used transcriptions of comments of caregivers and persons with MS, to sort descriptions, concepts, and central ideas into potential themes that occurred repeatedly using the scrutiny techniques of repetitions and similarities and differences [30]. Topics that occurred repeatedly were linked to verbatim quotes [31]. Standards for reporting qualitative research were followed in the conduct of the study and reporting of results [32].

Primary outcomes were measured for caregivers at baseline, three, and six months. Data analysis used repeated measures mixed effects linear models to analyze baseline and post-intervention follow-up (3 month and 6 month) data. Each outcome measure was treated as independent of the others.  $P$  values  $\leq .05$  were considered statistically significant. Effect size was used to indicate clinical significance [33]. For continuous variables, an effect size (Cohen's  $d$ ) of at least 0.2 SD improvement was considered clinically significant. Small

effect sizes begin at  $d = 0.2$ , which are common in behavioral interventions [33]. Effect sizes are estimated as mean change relative to estimated population standard deviation [33].

### 3. Results

**3.1. Participants.** There were 72 veterans in the MS clinic, of whom 25 were ambulatory and had caregivers who were interested in participating (Figure 1). Of the 25 caregivers, 72% completed all six sessions. Those who completed six sessions were about a decade older ( $M \pm SD$ ,  $58.2 \pm 10.9$  vs.  $46.0 \pm 15.8$ ,  $p = .038$ ). Completers had higher burden scores than non-completers ( $8.1 \pm 7.5$  vs.  $2.6 \pm 2.3$ ,  $p = .010$ ) and reported more behaviors/concerns that caused them bother than non-completers ( $7.4 \pm 5.8$  vs.  $2.9 \pm 2.9$ ,  $p = .016$ ).

As shown in Table 1, caregivers were mostly female, about 55 years old, and predominantly Black or White; none were Hispanic. Most were married and were the spouse of the person with MS. Average education was post high school. Fewer than half were employed either full or part time; two-thirds began providing care at the MS diagnosis, or at the emergence of MS symptoms.

Also shown in Table 1, about three-quarters of the persons with MS were male and about 56 years old; most were Black or White; one was Hispanic. About 2/3 were married. Average education was post-high school. Twelve percent were employed full or part time, and about 2/3 made work changes since being diagnosed with MS. Most were diagnosed with Relapsing Remitting MS. Most had mild/moderate MS disability as measured by the EDSS.

**3.2. Expectations and Benefit.** Caregivers hoped the program would provide them with education on MS, caregiving and stress management skills, and support. For example, one caregiver wanted, "To understand the illness better, understand the disease and how to cope with it, better deal with situations

TABLE 1: Demographics of caregivers ( $n = 25$ ) and persons with MS ( $n = 25$ ).

Variable	M $\pm$ SD or n (%)
<b>Caregiver</b>	
Sex, female	21 (84)
Age, years	54.8 $\pm$ 13.3
Race	
White	10 (40)
Black	14 (56)
Asian/Pacific Islander	1 (4)
Ethnicity, Hispanic/Latino	0
Marital status	
Married/living as married	19 (76)
Single, never married	2 (8)
Divorced	2 (8)
Widowed	2 (8)
Education, years	13.5 $\pm$ 3.1
Employed, full-time or part-time	11 (44)
Military service	3 (12)
Relationship to person living with MS	
Spouse	17 (68)
Parent	3 (12)
Sibling	3 (12)
Child	2 (8)
Point began providing care	
Prior to MS diagnosis	6 (24)
As soon as person with MS diagnosed with MS	7 (28)
When person with MS began displaying MS symptoms	9 (36)
When person with MS could no longer care for self	1 (4)
When previous caregiver could no longer care for Person with MS	1 (4)
Other	1 (4)
Made work changes due to caregiving	6 (24)
<b>Person with MS</b>	
Sex, male	19 (76)
Age, years	55.9 $\pm$ 11.6
Race	
White	12 (48)
Black	13 (52)
Ethnicity, Hispanic/Latino	1 (4)
Marital status	
Married/living as married	16 (64)
Single, never married	5 (20)
Divorced	4 (16)
Education, years	14.4 $\pm$ 2.0
Employed, full-time or part-time	3 (12)
Made work changes since MS diagnosis	17 (68)
MS type	
Relapsing Remitting MS	21 (84)
Primary-Progressive MS	2 (8)
Secondary-Progressive MS	2 (8)
<b>EDSS</b>	
Mild (0–2.5)	12 (50)

TABLE 1: Continued.

Variable	M $\pm$ SD or n (%)
Moderate (3.0–5.5)	4 (17)
Severe ( $\geq$ 6.0)	8 (33)
Modified fatigue impact, total (0–84)	47.4 $\pm$ 3.8
Physical (0–36)	22.9 $\pm$ 1.7
Cognitive (0–40)	19.8 $\pm$ 2.0
Psychosocial (0–8)	4.6 $\pm$ 0.5
MS impact, physical (0–100)	49.1 $\pm$ 4.5
MS impact, psychological (0–100)	40.9 $\pm$ 5.6

TABLE 2: Benefits of participation reported by caregiver and person with MS.

Benefit	M $\pm$ SD <sup>a</sup>
<b>Caregiver</b>	
Overall benefited from participating	4.3 $\pm$ 1.2
Feel more confident as a caregiver	4.2 $\pm$ 0.9
Improve ability to care for self	4.0 $\pm$ 1.0
Improve ability to care for person with MS	4.2 $\pm$ 1.0
Improve ability to assist person with MS with mobility and exercise	3.6 $\pm$ 1.5
How often person with MS completed exercise/stretching plan at home	3.0 $\pm$ 1.3
How often caregiver completed exercise/stretching plan at home	2.8 $\pm$ 1.4
Exercises helpful for mobility of person with MS	3.6 $\pm$ 1.4
Better understand MS and its effects on person with MS	4.1 $\pm$ 1.2
<b>MS</b>	
Feel more confident in dealing with these effects	4.3 $\pm$ 0.9
Better understand MS's effects on caregiver	4.0 $\pm$ 1.2
Feel more confident in dealing with these effects	4.3 $\pm$ 0.8
<b>Person with MS</b>	
Overall benefited from participating (self)	3.0 $\pm$ 1.3
Caregiver benefited from participating	3.8 $\pm$ 1.2

<sup>a</sup> Scale from 1 (not at all) to 5 (extremely).

that arise and things to watch and look for before or when it happens.” A caregiver hoped for “Easier ways to help my husband. The safest and most helpful, easiest, and relaxing ways to help him... Less stressful.”

After the intervention, 96% of caregivers reported their expectations were met. They reported the program had improved their confidence and ability to care for their loved ones and themselves. They also reported better understanding of MS and its effects on their loved one and themselves (Table 2). Caregivers reported a higher rating for overall benefit from participating in the program than their loved ones attributed to them (4.3 vs. 3.8).

From their comments, caregivers identified three themes related to perception of benefit: increased skills; having someone focus on them; and understanding the disease and taking care of their loved one. Caregivers reported benefit for themselves in increased skills. As one caregiver said, “Learning the relaxation skills was the most helpful. The problem solving helped me, too. Learning how to identify the problem and think

TABLE 3: Mixed model analysis of caregiver outcomes.

Variable	Baseline M (SD)	3 months M (SD)	6 months M (SD)	Cohen's <i>d</i>	<i>p</i> -Value
Anxiety (0–21)	5.2 (5.3)	4.2 (3.2)	4.7 (4.4)	0.11	.433
Depression (0–27)	5.4 (5.2)	3.7 (3.8)	3.7 (4.7)	0.33	.015
Burden (0–48)	6.6 (6.9)	7.0 (7.3)	7.5 (6.2)	0.13	.630
Challenging MS behaviors, <i>n</i> (0–27)	9.5 (4.7)	8.5 (5.3)	8.0 (5.3)	0.33	.306
Bothered by behaviors, <i>n</i> (0–27)	6.1 (5.5)	4.7 (5.4)	3.9 (4.1)	0.41	.043

of things in a different way.” They also felt that having someone focus on them was a benefit. A caregiver reported, “I benefited by knowing somebody cares and is interested in how I’m doing and feeling. It was good to focus on me. I really appreciate it.” Another caregiver said, “It gave me some good knowledge and allowed me to open up about what’s going on with me.”

However, the main benefit reported by caregivers was in understanding the disease and taking care of their loved one with MS, i.e., “I’ve learned stuff about his disease that I didn’t know. It opened my eyes to things. I learned how to help him better.” Another caregiver said, “As far as the symptoms go, I didn’t understand a lot of them and the book helped me understand those better and how to deal with stress and take better care of him.” Another caregiver echoed this theme of not understanding MS, “At the beginning of all this, the only knowledge I had of MS was surface level. The manual and training sessions were very informative. These questions you ask me make me think of things I need to be aware of.”

These perceptions of understanding the disease and its effects and feeling more comfortable with caregiving were borne out in quantitative data, as was the effect of focusing on themselves. As shown in Table 3, during six months, for caregiver well-being, caregivers showed statistically ( $p = .015$ ), and clinically ( $d = 0.33$ ) significant improvement in depression. At baseline, caregivers reported a PHQ-9 score consistent with mild depression range (5–9); at follow-up, their score reflected minimal depression (range 0–4) [34]. Although anxiety was not statistically or clinically significant, caregivers exhibited a similar pattern as for depression, showing an average mild anxiety score on the GAD-7 at baseline (range 5–9) and dropping below mild anxiety at follow-up [26]. Burden was not statistically or clinically significant and did not approach the clinical cut point of the ZBI-12, which is 17 for severe burden [35]. For caregiver outcomes relating to providing care for their loved one, caregivers showed statistically ( $p = .043$ ), and clinically ( $d = 0.41$ ) significant improvement in bother with behaviors and clinically ( $d = 0.33$ ) but not statistically significant improvement in number of challenging MS behaviors.

Caregivers reported their skills increased as they managed problems related to care of themselves and their loved one.

General problem-solving plans focused on caregiver health ( $n = 5$ ), need for help ( $n = 4$ ), stress ( $n = 3$ ), person living with MS memory ( $n = 4$ ), mobility ( $n = 3$ ), fatigue and pain ( $n = 2$ ), and finances ( $n = 1$ ). By the last session, 55% said the problem they chose to work on for themselves was “a little better,” and 35% said “a lot better.” Caregivers also rated improvement in functional/mobility plans (e.g., helping with exercise, stretching). By their last session, 55% said the problem was “a little better,” and 15% said “a lot better.”

The MS participants reported benefit to their caregivers and to themselves. As one veteran said, “It gives me an opportunity to review my issues based on your questions. It helps me to connect better with my wife as my caregiver. Normally, I would just say I can do this myself.” Another reported, “I have learned to be more conscious of things because of the questions you ask. Really has helped my wife be more understanding. I do my exercises every day. If I didn’t, I know I wouldn’t be walking as well as I am now if not at all.” Most (71%) reported that their caregivers had helped with their exercise, stretching, and mobility program.

#### 4. Conclusions

A major concern for caregivers is always to understand their loved one’s condition and its effects on them, and this was the most common benefit reported by these caregivers. One caregiver summed up her feelings, “When he was first diagnosed, I felt like I had fallen in a hole. This has really helped.” When asked about benefit, caregivers reported becoming a better caregiver more often than they reported personal benefit such as reduction of stress. Their loved ones echoed this benefit. A caregiver reported, “I have learned things that have been quite helpful in giving better care, being more patient, understanding the disease itself, coping skills, and I have a better heads-up about what might occur in the future.” Her loved one with MS reported, “It helped my caregiver better understand what my disease is, how it affects my body and mind, and how I feel about such worries.”

Caregivers and their loved ones also reported practical assistance. They reported improved confidence and ability to care for their loved ones and themselves. One person with MS reported that the study helped “pinpoint areas I need to improve upon and ask for help in those areas,” and the caregiver reported providing that help; “I was able to implement all the suggestions and help keep the energy levels up when doing the exercises.”

Although the sample was small, there were clinically and statistically significant findings consistent with reports of benefit. At six months, caregivers reported improvements in areas that benefited themselves and their loved ones. Caregivers reported fewer challenging MS behaviors that caused bother, from 6.1 at baseline to 3.9 at 6-month follow-up. Because family relationship dynamics, especially between the care recipient and the caregiver, are often strained with MS [30], and because the more severe the symptoms, the higher the cost and burden on the caregiver [9, 12, 13], these are important clinical findings. Caregivers reported improvement in depressive symptoms, which is important because quality of life decreases in persons living with MS whose caregivers are depressed [14].

Caregivers' depression scores also reflected a clinical decrease from mild depression to minimal depression. Caregivers exhibited a similar pattern for anxiety, dropping below their baseline clinical score of mild anxiety at follow-up, although these results were not statically or clinically significant.

Some study limitations should be mentioned. Sample size was small; the number of persons with MS in the clinic was small, and fewer of them than expected had caregivers. All did not identify a caregiver, which could mean that there was no one in the caregiving role. It could also mean that the person with MS did not distinguish between caregiving tasks and family tasks attendant on being a spouse, adult child, or sibling, or did not recognize the amount of care that is provided by the caregiver. This finding is consistent with other work that has shown that MS caregivers adopt the caregiving role to various degrees [36]. Other limitations include possible lack of generalizability relative to the persons with MS. MS is more common in women; in our study, as is consistent with a veteran sample, three-quarters of the persons with MS were male. Although average MS age of onset is 29, average age in this sample was 55 years; however, we did not have years since diagnosis to determine onset age. It is unclear how, or if, these possible limitations of generalizability would impact caregivers of younger and female persons with MS.

One of the major recommendations from recent caregiver summits, reports, and the 2018 RAISE Act [37–41] is to include the caregiver in the care recipient's care plan. This is a laudable goal. A trend in caregiving during the past few decades is increased reliance on the family to perform complex medical tasks at home in support of the care recipient [42]. However, excellent care for the care recipient may lead to negative physical, emotional, economic, or social consequences for the caregiver, as the caregiver struggles to meet the needs of daily life and clinical care requirements of the care recipient [43]. In fact, caregivers of people with MS experience changes and losses as they take on this complex and difficult role [36].

In this pilot feasibility study of an integrated model of care, caregivers worked with a coach on their own stress and coping issues, any MS symptoms that were challenging to deal with, and strategies to help increase the mobility and function of their loved one with MS. Study results suggest that addition of the brief REACH caregiver intervention into an MS clinic would appropriately use the caregiver's expertise to help and encourage the person with MS, while also recognizing and enhancing the caregiver's own coping. In addition to the intervention's ability to improve caregiver emotional well-being, caregivers reported improvement in MS caregiving knowledge, and skills, and success in problem solving plans they put in place. Both caregivers and their loved ones recognized these caregiver improvements. Although the intervention was six sessions during three months, benefit persisted at six months, suggesting durability of the intervention's effects.

Future work should replicate this study in other MS care settings. Such a study could have the benefits of larger sample size, a greater number of objective measures of mobility, and a longer time-frame so that objective functional benefit might be better documented. Other measures of the caregiver's engagement in care could also be examined.

## Data Availability

Data are in the Caregiver Center Data Repository, Veterans Affairs Medical Center, Memphis, TN. De-identified data are available with a Data use Agreement with the Caregiver Center.

## Conflicts of Interest

The authors declare that there is no conflict of interest regarding the publication of this paper.

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## References

- [1] M. T. Wallin, W. J. Culpepper, J. D. Campbell et al., "The prevalence of MS in the United States: a population-based estimate using health claims data," *Neurology*, vol. 92, no. 10, pp. e1029–e1040, 2019.
- [2] K. M. Perrone, P. A. Gordon, and M. K. Tschopp, "Caregiver marital satisfaction when a spouse has multiple sclerosis," *Journal of Applied Rehabilitation Counseling*, vol. 37, no. 2, pp. 26–32, 2006.
- [3] H. Carton, R. Loos, J. Pacolet, K. Versieck, and R. Vlietinck, "A quantitative study of unpaid caregiving in multiple sclerosis," *Multiple Sclerosis Journal*, vol. 6, no. 4, pp. 274–279, 2000.
- [4] L. P. McKeown, A. P. Porter-Armstrong, and G. D. Baxter, "The needs and experiences of caregivers of individuals with multiple sclerosis: a systematic review," *Clinical Rehabilitation*, vol. 17, no. 3, pp. 234–248, 2003.
- [5] K. I. Pakenham, "The nature of caregiving in multiple sclerosis: development of the caregiving tasks in multiple sclerosis scale," *Multiple Sclerosis Journal*, vol. 13, no. 7, pp. 929–938, 2007.
- [6] M. Buhse, "Assessment of caregiver burden in families of persons with multiple sclerosis," *Journal of Neuroscience Nursing*, vol. 40, no. 1, pp. 25–31, 2008.
- [7] C. Pozzilli, L. Palmisano, C. Mainero et al., "Relationship between emotional distress in caregivers and health status in persons with multiple sclerosis," *Multiple Sclerosis Journal*, vol. 10, no. 4, pp. 442–446, 2004.

- [8] J. Dunn, "Impact of mobility impairment on the burden of caregiving in individuals with multiple sclerosis," *Expert Review of Pharmacoeconomics & Outcomes Research*, vol. 10, no. 4, pp. 433–440, 2010.
- [9] J. Pike, E. Jones, K. Rajagopalan, J. Piercy, and P. Anderson, "Social and economic burden of walking and mobility problems in multiple sclerosis," *BMC Neurology*, vol. 12, no. 1, p. 94, 2012.
- [10] N. G. LaRocca, "Impact of walking impairment in multiple sclerosis," *The Patient: Patient-Centered Outcomes Research*, vol. 4, no. 3, pp. 189–201, 2011.
- [11] P. Van Asch, "Impact of mobility impairment in multiple sclerosis 2-patients' perspectives," *European Neurological Review*, vol. 6, no. 2, pp. 115–120, 2011.
- [12] N. F. Courts, A. N. Newton, and L. J. McNeal, "Husbands and wives living with multiple sclerosis," *Journal of Neuroscience Nursing*, vol. 37, no. 1, pp. 20–27, 2005.
- [13] M. Patwardhan, D. Matchar, G. Samsa, D. McCrory, R. Williams, and T. Li, "Cost of multiple sclerosis by level of disability: a review of literature," *Multiple Sclerosis Journal*, vol. 11, no. 2, pp. 232–239, 2005.
- [14] J. K. Bambara, A. P. Turner, R. M. Williams, and J. K. Haselkorn, "Social support and depressive symptoms among caregivers of veterans with multiple sclerosis," *Rehabilitation Psychology*, vol. 59, no. 2, pp. 230–235, 2014.
- [15] R. J. Buchanan, D. Radin, and C. Huang, "Burden among male caregivers assisting people with multiple sclerosis," *Gender Medicine*, vol. 7, pp. 637–646, 2010.
- [16] M. Corry and A. While, "The needs of carers of people with multiple sclerosis: a literature review," *Scandinavian Journal of Caring Sciences*, vol. 23, no. 3, pp. 569–588, 2009.
- [17] S. H. Belle, L. Burgio, R. Burns et al., "Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized, controlled trial," *Annals of Internal Medicine*, vol. 145, no. 10, pp. 727–738, 2006.
- [18] L. O. Nichols, J. Martindale-Adams, R. Burns, M. J. Graney, and J. Zuber, "Translation of a dementia caregiver support program in a health care system—REACH VA," *Archives of Internal Medicine*, vol. 171, no. 4, pp. 353–359, 2011.
- [19] L. O. Nichols, J. Martindale-Adams, R. Burns, J. Zuber, and M. J. Graney, "REACH VA: moving from translation to system implementation," *The Gerontologist*, vol. 56, no. 1, pp. 135–144, 2016.
- [20] S. Cohen, R. C. Kessler, and L. U. Gordon, *Measuring Stress*, Oxford University Press, New York, 1995.
- [21] R. S. Lazarus and R. Launier, "Stress-related transactions between persons and environment," In *Perspectives in International Psychology*, L. A. Pervin, and M. Lewis, Eds., pp. 287–325, Plenum Press, New York, 1978.
- [22] S. J. Czaja, L. N. Gitlin, R. Schulz et al., "Development of the risk appraisal measure: a brief screen to identify risk areas and guide interventions for dementia caregivers," *Journal of the American Geriatrics Society*, vol. 57, no. 6, pp. 1064–1072, 2009.
- [23] S. Rigby, C. Domenech, E. Thornton, S. Tedman, and C. Young, "Development and validation of a self-efficacy measure for people with multiple sclerosis: the multiple sclerosis self-efficacy scale," *Multiple Sclerosis Journal*, vol. 9, pp. 73–81, 2003.
- [24] A. Riaz, J. Hobart, D. Lamping, R. Fitzpatrick, and A. Thompson, "Multiple sclerosis impact scale (MSIS-29): reliability and validity in hospital based samples," *Journal of Neurology, Neurosurgery, and Psychiatry*, vol. 73, pp. 701–704, 2002.
- [25] J. D. Fisk, P. G. Ritvo, L. Ross, D. A. Haase, T. J. Marrie, and W. F. Schlech, "Measuring the functional impact of fatigue: initial validation of the fatigue impact scale," *Clinical Infectious Diseases*, vol. 18, Suppl. 1, pp. S79–S83, 1994.
- [26] R. L. Spitzer, K. Kroenke, J. B. W. Williams, and B. Lowe, "A brief measure for assessing generalized anxiety disorder: the GAD-7," *Archives of Internal Medicine*, vol. 166, pp. 1092–1097, 2006.
- [27] K. Kroenke, R. L. Spitzer, and J. B. Williams, "The PHQ-9: validity of a brief depression severity measure," *Journal of General Internal Medicine*, vol. 16, pp. 606–613, 2001.
- [28] M. Bedard, D. Molloy, L. Squire, S. Dubois, J. A. Lever, and M. O'Donnell, "The Zarit Burden Interview: a new short version and screening version," *The Gerontologist*, vol. 41, pp. 652–657, 2001.
- [29] N. O'Rourke and H. A. Tuokko, "Psychometric properties of an abridged version of the Zarit Burden Interview within a representative Canadian caregiver sample," *The Gerontologist*, vol. 43, no. 1, pp. 121–127, 2003.
- [30] G. W. Ryan and H. R. Bernard, "Techniques to identify themes," *Field Methods*, vol. 15, pp. 85–109, 2003.
- [31] H. Bernard, *Research Methods in Anthropology. Qualitative and Quantitative Approaches*, AltaMira Press, Lanham, MD, USA, 2006.
- [32] B. C. O'Brien, I. B. Harris, T. J. Beckman, D. A. Reed, and D. A. Cook, "Standards for reporting qualitative research: a synthesis of recommendations," *Academic Medicine*, vol. 89, pp. 1245–1251, 2014.
- [33] J. Cohen, *Statistical Power Analysis for the Behavioral Sciences*, Lawrence Erlbaum Associates, Hillsdale, NJ, USA, 2nd edition, 1988.
- [34] L. Manea, S. Gilbody, and D. McMillan, "Optimal cut-off score for diagnosing depression with the Patient Health Questionnaire (PHQ-9): a meta-analysis," *CMAJ*, vol. 184, no. 3, pp. E191–E196, 2012.
- [35] B. Stagg and A. J. Larner, "Zarit Burden Interview: pragmatic study in a dedicated cognitive function clinic," *Progress in Neurology and Psychiatry*, vol. 19, no. 4, pp. 23–27, 2015.
- [36] G. Topcu, H. Buchanan, A. Aubeeluck, and G. Garip, "Caregiving in multiple sclerosis and quality of life: a meta-synthesis of qualitative research," *Psychology & Health*, vol. 31, pp. 693–710, 2016.
- [37] ASPE (Office of The Assistant Secretary for Planning and Evaluation), "National research summit on care, services, and supports for persons with dementia and their caregivers, NIH, October 2017. Report to the National Advisory Council on Alzheimer's Research, Care, and Services," <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-report#FinalRpt>.
- [38] National Academies of Sciences, Engineering, and Medicine, *Families Caring for an aging America*, The National Academies Press, Washington, DC, USA, 2016.
- [39] R. Ramchand, T. Tanielian, M. P. Fisher et al., *Hidden heroes: America's Military Caregivers*, RAND Corporation, Santa Monica, CA, USA, 2014.
- [40] T. Tanielian, K. E. Bouskill, R. Ramchand, E. M. Friedman, T. E. Trail, and A. Clague, *Improving Support for America's Hidden Heroes: A Military Caregiver Research Blueprint*, RAND Corporation, Santa Monica, CA, USA, 2017.
- [41] RAISE (Recognize, Assist, Include, Support, and Engage), "Family Caregivers Act(S.20181028/H.R3759)," 2018.

- [42] C. V. O'Shaughnessy, "Background Paper #84. National Health Policy Forum," *Family caregivers: the primary providers of assistance to people with functional limitations and chronic impairments*, George Washington University, Washington, DC, 2013.
- [43] L. O. Nichols, J. Martindale-Adams, J. Zuber, and M. Graney, "Service member need and supportive services use of military/veteran spouses," *Military Behavioral Health*, vol. 3, pp. 55–63, 2015.