



The effect of online home care training on the burden of caregivers for patients with multiple sclerosis

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Abstract

Background: Caregivers of individuals with multiple sclerosis (MS) often face significant emotional and physical burdens. Nurses play a crucial role in alleviating this burden for caregivers of MS patients.

Objectives: This study aimed to evaluate the effectiveness of an online home care training program in reducing caregiver burden (CB) among those caring for patients with MS.

Methods: This interventional study involving 80 caregivers of individuals with MS, who received support from the Isfahan Welfare Organization, was conducted in 2021. Eligible caregivers were randomly divided into two groups of 40. The intervention group participated in eight sessions of online home care training, which included 14 video clips ranging from 15 to 30 minutes each, shared via the WhatsApp application. All participants completed a demographic questionnaire and the Zarit Burden Interview before the intervention, immediately after, and one month later. Data analysis was performed using chi-square tests, independent samples t-tests, and repeated measures analysis of variance.

Results: At baseline, no significant differences were observed in the mean CB scores between the two groups ($P>0.05$). However, a significant difference was noted immediately after the intervention ($P<0.05$). By one-month post-intervention, no significant difference remained between the two groups ($P>0.05$).

Conclusion: The online home care training program effectively reduced CB among those caring for patients with MS. It is recommended that nurses and relevant authorities develop and implement similar training strategies to support caregivers of MS patients.

Keywords: Home care, Multiple sclerosis, Caregiver, Caregiver burden, Nursing.

Introduction

Multiple sclerosis (MS) is a chronic and often debilitating disease that affects the central nervous system. Its prevalence is on the rise globally, though it varies by region. The number of individuals diagnosed with MS has surged from 2.1 million in 2008 to 2.8 million in 2020.^[1] Recent studies indicate a significant increase in MS incidence rates in Iran, which have reached 3.4 per 100,000 people.^[2] In Isfahan, the incidence from 2016 to 2021 was reported at 71.8 per 100,000, with a prevalence rate of 183.9 per 100,000 in 2021.^[3]

Patients with progressive forms of MS often endure a range of symptoms, including both physical and cognitive impairments, which can complicate caregiving for family

members.^[4] These caregivers face numerous challenges due to the disabilities and mobility limitations of their loved ones, alongside the progressive nature of the disease. Such circumstances can lead to feelings of fatigue, isolation, and inadequacy in their caregiving roles.^[5] The demands of patient care can significantly impact caregivers' physical and mental well-being, affecting their morale, job performance, financial stability, social interactions, relationships, and even their intimate lives.^[6,7]

Family caregivers of individuals with chronic illnesses often find themselves in precarious situations, sometimes referred to as "hidden patients," as they grapple with high levels of stress and caregiver burden (CB).^[8] Caregiver

burden encompasses the physical, emotional, psychological, social, and financial strains that arise from caring for someone with a health condition or disability. This burden can profoundly affect both patients and their families.^[9] Caregivers frequently report experiencing various health issues, elevated anxiety and depression levels, social isolation, feelings of inadequate support, strained family relationships, and compromised patient care—all of which may ultimately lead to patient abandonment.^[10] Research has shown that around 70% of family caregivers encounter at least two significant challenges related to patient care, treatment, and adapting to their caregiving responsibilities.^[11]

Nurses play an essential role in educating both patients and their family caregivers, providing rehabilitation services, and fostering independence among patients.^[12] It is generally recommended that individuals with long-term and complex health conditions receive care in the comfort of their own homes.^[13] As a result, community-centered models of care and rehabilitation are increasingly emphasized. These models aim to promote self-care through collaboration and active participation from both clients and their families.^[14] They focus on home care and the education of patients and their caregivers.^[15] Evidence suggests that home care training can empower patients and their families, enhancing their quality of life and satisfaction while also instilling a sense of importance.^[14,16-18] Additionally, such training can help reduce the limitations often faced by patients.^[19]

A variety of training methods have been utilized to educate both patients and their family caregivers, including lectures, discussions, and demonstrations.^[20] The rise of communication technology, along with the increasing use of electronic media and social networks, has paved the way for online training approaches that cater to patients and their families.^[21] E-learning allows individuals to access educational resources without the limitations of in-person instruction, enabling them to learn from a distance.^[22] This flexible method removes barriers related to time and location, empowering learners to engage in self-study at their convenience, whether at home or elsewhere. Additionally, it allows participants to tailor content to fit their unique learning schedules.^[23]

However, research on the effectiveness of e-learning in reducing CB presents mixed findings. Some studies have highlighted the success of remote nursing training^[24] and psychological support programs in alleviating CB among caregivers of patients with COVID-19.^[25] Systematic reviews indicate that online training initiatives for caregivers of individuals with dementia have enhanced

their caregiving knowledge, boosted self-efficacy, and reduced feelings of anxiety, depression, and overall care burden.^[26,27] Furthermore, one study found that an online mindfulness program effectively lessened CB in caregivers of patients with MS.^[28]

Despite these promising outcomes, some research suggests that the benefits of such interventions may be short-lived or minimal, with many caregivers continuing to experience significant stress and challenges even after participating in training programs.^[29,30] Considering the progressive nature of MS and the crucial role that home care plays in the lives of these patients, there is a significant gap in research exploring how e-learning can affect caregiver burden among those caring for individuals with MS. Addressing this gap could provide valuable insights into whether e-learning can serve as an effective resource to ease the challenges faced by family caregivers of MS patients

Objectives

This study aims to explore the effects of an online home care training program on caregiver burden in those caring for patients with multiple sclerosis.

Methods

Study design and participants

This interventional study employed a pretest-posttest design. Conducted between April and October 2021, the research focused on caregivers of patients with MS who were receiving support from the Isfahan Welfare Organization.

Inclusion criteria for participation included being between the ages of 18 and 65, providing care for only one patient with MS, having no history of substance abuse, not having previously participated in home care programs, being able to read and write in Persian, possessing access to a smartphone compatible with WhatsApp, and demonstrating proficiency in using smartphones. Exclusion criteria encompassed any decision to withdraw from the study at any point, loss of access to the patient or caregiver due to death or travel, and receipt of home care services from other providers.

The sample size was determined based on findings from a previous study that assessed the impact of group psychoeducation on caregiver burden among family members of MS patients. This earlier research indicated a reduction in mean caregiver burden from 31.62 ± 5.5 before the intervention to 27.3 ± 4.9 immediately afterward.^[31] Considering Type I and II error rates of 0.05 and 0.1 respectively, along with standard deviations $S1 = 5.5$ and

$S^2 = 4.9$, the sample sizes for each group were estimated to be 31. To account for a potential drop-out rate of 20%, we ultimately recruited 40 participants in each group [Formula 1].

$$n = \frac{\left(z_{1-\frac{\alpha}{2}} + z_{1-\beta}\right)^2 (\sigma_1^2 + \sigma_2^2)}{(\mu_1 - \mu_2)^2}$$

Formula 1. Sample size calculation

Data collection instruments

Data collection involved two primary instruments: The Revised Zarit Burden Interview (ZBI) and a demographic information questionnaire. The demographic questionnaire gathered information regarding the patient's age, sex, education level, duration of MS since diagnosis, as well as details about the caregiver, including their age, sex, education level, marital status, occupation, relationship to the patient, and the average number of hours spent daily providing care.

The Revised ZBI consists of 22 items categorized into four dimensions: individual (9 items), social (4 items), emotional (7 items), and financial burden (2 items) experienced by caregivers. Each item is rated on a 5-point Likert scale ranging from "0 = never" to "4 = always." The total caregiver burden scores can range from 0 to 88, with higher scores indicating greater caregiver burden.^[24,25] The ZBI has been translated into Persian and has demonstrated strong validity and test-retest reliability ($r = 0.91$). The validity of the short form of the Persian ZBI was confirmed by Rajabi-Mashhadi et al., and its reliability was established with a Cronbach's alpha of 0.78.^[32] In our current study, we found the Cronbach's alpha for the ZBI to be an impressive 0.97.

Procedures

To initiate the study, a list of patients diagnosed with progressive MS was compiled with the assistance of the Isfahan Welfare Organization. Using the medical records of these patients, the researcher generated a list of those eligible for participation. Subsequently, the researcher reached out to each patient's primary family caregiver using the contact information available in their files. During this communication, the researcher provided an overview of the study's objectives and procedures, inviting them to take part in the research. If both the caregiver and the patient expressed their willingness to participate, their names were added to the list of study participants. This process continued until the desired sample size was

achieved, resulting in a final list of 80 participants. The samples were randomly assigned to two groups: control and intervention.

Intervention

The researcher established two groups within the WhatsApp application: one for the intervention group and another for the control group. The primary family caregivers for each group were added to their respective WhatsApp groups. In these groups, the researcher introduced herself and outlined the study's purpose, process, and expectations for participation.

Following this introduction, links to an electronic consent form, a demographic information questionnaire, and the Revised ZBI were shared with all members. Participants were asked to complete these forms on the same day. Subsequently, the intervention group received home care training via their designated WhatsApp group.

To ensure the educational content addressed the specific needs of both patients and their caregivers, the researcher conducted a thorough review of patient files, consulted with welfare staff who interacted with these patients and their families, and conducted telephone interviews with caregivers to assess their educational needs. The training materials were created in various formats, including video clips, spoken text, written documents, and images. These materials were designed following key principles of multimedia education, such as hierarchy, coherence, variety, and other established guidelines.

A total of 14 video clips, each lasting between 15 and 30 minutes, were produced under the title "Home Care Training for Patients with MS." Each week, caregivers received one educational video, resulting in a total of fourteen pieces of content delivered over eight consecutive weeks. In some weeks, two videos were sent, covering topics such as managing movement disorders, gastrointestinal symptoms, urinary issues, sexual dysfunction, swallowing and speech difficulties, pain management, fatigue, pharmacotherapy care, and nutritional guidance for patients with MS. Each training segment was uploaded to the WhatsApp group as it became available.

To ensure caregivers fully understood and implemented the training content, two follow-up phone calls were made to each caregiver before the next training material was distributed. The first call confirmed that they had received and viewed the training file, while the second call - conducted four days later- utilized a checklist to verify their understanding and application of the material. After all educational content had been delivered, caregivers were asked to complete the questionnaires again one month

later.

The control group caregivers only received links to the questionnaires at three intervals that coincided with those of the intervention group and were similarly asked to complete them on the same day. To uphold ethical standards in research, the educational content was also provided to the control group at the end of the study, with the researcher available to answer any questions they had.

Data Analysis

Data analysis was conducted using SPSS version 22. The data exhibited a normal distribution by Kolmogorov-Smirnov test. To compare the personal characteristics of the two groups, the chi-square test was employed. The independent samples t-test was utilized to assess differences in mean CB between the study groups. Additionally, repeated measures analysis of variance was performed to evaluate CB across three time points: before the intervention, immediately after, and one month later. The Bonferroni test was applied for pairwise comparisons between these measurement intervals. A significance level of $p < 0.05$ was established for all analyses.

Ethical Considerations

This study received approval from the ethics committee at Isfahan University of Medical Sciences (IR.MUI.RESEARCH.REC.1398.067) and was registered with the Iranian Registry of Clinical Trials (IRCT20190712044181N1). All participants provided written informed consent after being thoroughly briefed on the study's objectives and methodologies. They were assured that their information would be kept confidential, that they could withdraw from the study at any time without consequence, and that there would be no fees associated with any services provided during the research.

Results

Eighty eligible caregivers were initially recruited for the study, with a simple randomization method allocating 40 participants to each group. Ultimately, 80 individuals were included in the final analysis [Figure 1]. There were no significant differences in demographic characteristics between the intervention and control groups ($P > 0.05$) [Table 1].

Table 1. Comparison of caregiver and patient characteristics in the intervention and control groups

Variables		Control group N (%)	Intervention group N (%)	P value
Patient Education level	Below diploma	26(65)	18(45)	0.236 ^a
	Diploma and above	14(35)	22(55)	
Patient Job	Employed	2(5)	1(2.5)	0.556 ^b
	Unemployed	38(95)	39(97.5)	
Caregiver Sex	Male	16(40)	16(40)	0.99 ^a
	Female	24(60)	24(60)	
Caregiver education level	Below diploma	18(45)	19(47.5)	0.902 ^a
	Diploma and above	22(55)	21(52.5)	
Caregiver job	Employed	20(50)	12(30)	0.284 ^a
	Unemployed	15(37.5)	16(40)	
	Other	5(12.5)	12(30)	
Caregiver marital status	Single	31(77.5)	30(75)	0.702 ^a
	Married	9(22.5)	10(25)	
Relation with patient	Parents or spouse	24(60)	28(70)	0.670 ^b
	Sister or brother	6(15)	2(5)	
	Child	10(25)	10(25)	
Caregiver age (year)		52.28 ± 9.68	48.18 ± 10.79	0.078 ^c
Duration of care per day (hours)		4.68 ± 0.97	4.95 ± 2.47	0.514 ^c
Duration of disease (year)		20.68 ± 7.30	18.18 ± 6.48	0.110 ^c

^a Chi-square, ^b fisher exact test, ^c t-test

The findings revealed that, over time, the intervention significantly reduced the mean CB score among participants ($F=4.33$; $P=0.041$), [Table 2]. To further explore this interaction, a t-test was conducted to compare

the mean CB scores between the two groups at three different measurement points. At baseline, there was no statistically significant difference in mean CB scores between the two groups ($P=0.07$).

However, immediately following the intervention, the mean CB score was significantly lower in the intervention group compared to the control group ($P=0.01$). Four weeks after the intervention, no significant difference was observed between the two groups regarding mean CB scores ($P=0.58$) [Table 2]. The Bonferroni test was employed for pairwise comparisons across the measurement time points. The results indicated that the differences in CB scores between the first and second measurements ($P=0.021$) and between the second and third measurements ($P=0.011$) were statistically significant within the intervention group [Table 3]. In contrast, the control group did not show any significant differences in CB scores across the various measurement times ($P>0.05$) [Table 2].

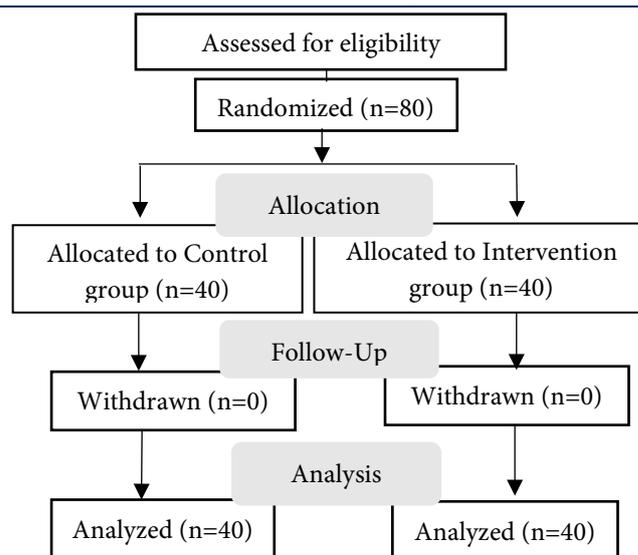


Figure 1. Study flow diagram

Table 2. Comparison of mean care burden scores between and within study groups at three measurement time points

Care burden	Control group (n=40)	Intervention group (n=40)	P-value *	The interaction of time and group	Effect of group
Before intervention (T1)	47.82 ± 5.04	44.75 ± 9.37	0.072	F= 4.330	P=0.21
After intervention (T2)	48.95 ± 4.44	41.45 ± 10.68	0.01	P= 0.041	
4 weeks after intervention (T3)	45.75 ± 7.71	45.20 ± 10.88	0.58	Effect size=0.6247 ^a	
The effect of time	P=0.61	P=0.22			

* *t*-test, ^a The effect size is large.

Table 3. Bonferroni test results for pairwise comparisons between measurement time points.

Group	Comparison variable	Time	Mean difference	Standard error	P- value
Intervention	CB	T2- T1	-3.3	1.123	0.021
		T3- T2	3.75	1.205	0.011
		T3- T1	0.45	1.135	0.068

Discussion

The results indicated that the mean CB score in the intervention group was significantly lower than that of the control group following the intervention. These findings align with those of Sotoudeh et al., who found that family-centered education effectively reduced caregiver burden among families of patients undergoing hemodialysis.^[33] Similarly, Desouki et al. reported that a four-month face-to-face training program significantly decreased CB scores among caregivers of patients with schizophrenia.^[34] These outcomes highlight the positive impact of educational

interventions on enhancing knowledge for both patients and their families.

Recognizing that not all training programs yield the same results, we aimed to maximize effectiveness by integrating online training, audiovisual resources, and telephone follow-ups into our approach. Our findings also resonate with a study by Pahlavanzadeh et al., which focused on caregivers of patients with multiple sclerosis.^[31] Additionally, Lami et al., demonstrated that a six-session peer-centered training program significantly reduced CB scores among family caregivers of patients with schizophrenia immediately after implementation.^[35] Hekmatpou et al., further supported these conclusions, noting that caregiver training programs could alleviate caregiver burden in those caring for stroke patients.^[36]

It is widely believed that training family caregivers and promoting home care can mitigate complications associated with chronic diseases. Therefore, it is crucial to implement effective educational strategies to enhance both the quality of care provided by family caregivers and their overall well-being. Such strategies should include tailored teaching methods and optimal physical and mental

conditions for caregivers, all aimed at improving their health and caregiving capabilities.^[32] In this study, we utilized principles of effective multimedia and online education to deliver home care training specifically for caregivers of patients with multiple sclerosis. The results confirm that this intervention successfully reduced caregiver burden.

The current study revealed a significant interaction between time and the intervention. While the mean CB score in the intervention group decreased notably by the end of the intervention and was lower than that of the control group, there was no significant difference between the two groups at the conclusion of the study. This significant interaction suggests that the intervention's impact on caregiver burden evolves over time. It appears that the intervention had a more immediate effect on reducing caregiver burden, but this effect may diminish as time progresses. This underscores the importance of considering the timing of interventions and highlights the necessity for ongoing support for caregivers to effectively manage and alleviate their burden.

Our findings contrast with those of Pehlvanzadeh et al., who demonstrated that a psychoeducational program had lasting effects on caregiver burden in family caregivers of patients with MS for at least one month following the intervention.^[31] Similarly, Lami et al., reported that peer training for family caregivers of patients with schizophrenia led to reduced caregiver burden scores, with effects persisting for at least two weeks post-intervention.^[35] A study focusing on caregivers of stroke patients also found that a four-session family-centered empowerment program significantly reduced caregiver burden, with effects lasting for two months.^[38] However, Figved et al. found no statistically significant differences in caregiver burden scores one month and one year after their intervention.^[39]

The variation in the duration of intervention effects may stem from differences in target populations, types and lengths of interventions, follow-up periods, and individual characteristics of caregivers across various studies. Further research is needed to better understand these factors and to develop more effective interventions to support caregivers of patients with MS.

One limitation of this study was the short follow-up period for caregivers. Additionally, we were unable to conduct home visits due to the COVID-19 pandemic and the associated risks of infection.

Conclusions

The findings from this study indicate that online home

care training is an effective approach for reducing caregiver burden among those caring for patients with MS. Therefore, we recommend implementing home care training programs for caregivers of chronic patients, including those with MS, as these programs can enhance various aspects of their lives and subsequently reduce their caregiver burden. Given the increasing prevalence of MS in Iran and the cost-effectiveness of online training in alleviating caregiver burden, it is crucial for nurses and relevant authorities to plan and execute similar strategies to provide home care training for caregivers of MS patients.

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Competing interests

The authors declare that they have no competing interests.

Abbreviations

Multiple Sclerosis: MS; Caregiver Burden: CB; Zarit Burden Interview: ZBI; Coronavirus disease 2019: COVID-19;

Authors' contributions

Z.K. was responsible for home care training and drafting the article. Sh.A. participated in home care training and played a key role in revising and refining the manuscript. P.A. was involved in developing and implementing the home care training program. All authors read and approved the final manuscript. All authors take responsibility for the integrity of the data and the accuracy of the data analysis.

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Role of the funding source

None.

Availability of data and materials

The data used in this study are available from the corresponding author on request.

Ethics approval and consent to participate

This study received ethical approval from the Isfahan University of Medical Sciences Ethics Committee (ethics code: IR.MUI.RESEARCH.REC.1398.067). The methods employed were consistent with relevant guidelines and regulations, and informed consent was obtained from all participants.

Consent for publication

By submitting this document, the authors declare their consent for the final accepted version of the manuscript to be considered for publication.

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