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Research Paper

The Feasibility of Telephone-delivered Self-management Intervention in Multiple Sclerosis

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ABSTRACT

Background: Self-management plays a significant role in people's active participation in treating multiple sclerosis (MS), improving quality of life, suppressing symptoms, and reducing treatment costs. People with MS face many physical, mental and emotional challenges that negatively affect their quality of life.

Objectives: This study aims to determine the feasibility of telephone-delivered self-management intervention in people with MS.

Materials & Methods: This quasi-experimental study employed a pretest-posttest and a two-month follow-up design. A total of 20 MS patients registered in the nationwide MS registry of Iran (NMSRI), Guilan, in 2020 took part in this study. The participants were selected through a public callback using judgmental sampling. The telephone-delivered self-management intervention, delivered through educational video files and telephone calls, included evidence-based cognitive behavioral therapy and psychological strategies to assist participants. The intervention was delivered in 8 weekly sessions. The MS self-management scale–revised (MSSM-R) and the short-form health survey (SF-36) were used to collect study data.

Results: The participants had a disproportionate distribution in gender, marital status, place of residence, employment status, and income. The intervention affects the self-management total score ($P<0.001$), the treatment adherence/barriers subscale ($P=0.024$), the MS knowledge and information subscale ($P<0.001$), and health maintenance behavior ($P=0.004$). It also influenced the quality-of-life total score ($P=0.049$) and mental health domain ($P=0.018$).

Conclusion: Telephone-delivered self-management intervention in patients with MS has positive effects in many of the investigated areas, and this intervention can be used to improve the quality of life of these patients.

Keywords: Self-management, Multiple sclerosis, Quality of life

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Highlights

- Self-management plays a significant role in people's active participation in treatment, improving quality of life, suppressing symptoms, and reducing treatment costs.

- Among the multiple sclerosis patients, this intervention affects the self-management total score, the treatment adherence/barriers subscale, the multiple sclerosis knowledge subscale, and the behavior related to health maintenance.

- Self-management influenced the quality of life score and mental health domain in multiple sclerosis patients.

Introduction

Multiple sclerosis (MS) is an autoimmune disease of the central nervous system which is chronic and degenerative. It affects approximately 2 million people worldwide [1] and is the second leading cause of non-traumatic disability in young people [2]. MS typically emerges in adults aged 20-40, with patients having a regular life expectancy [3]. It is more prevalent in women, especially in the white population. Key symptoms include cognitive and movement issues, sensory deficits, visual problems, balance impairments, fatigue, and pain [4, 5]. MS patients face daily physical, mental, and emotional challenges [1, 5]. Psychological issues like anxiety and mood disorders are common [6, 7], leading to significant disability in some cases [8]. Consequently, it impacts the quality of life [9]. While incurable, lifelong symptom management is crucial, requiring active self-management for treatment adherence, decision-making, self-care, and well-being [10-14].

Self-management in chronic diseases involves acquiring skills to lead a fulfilling life despite illness challenges, leading to improved quality of life, symptom reduction, and cost savings [11]. These strategies enhance understanding, knowledge, diet and well-being, benefiting health outcomes [15, 16]. There is significant evidence of health benefits after self-management interventions in chronic and long-term diseases such as diabetes, arthritis, and heart diseases [17, 18]. Individuals with chronic illnesses take charge of treatment adherence, exercise, social engagement, and healthcare choices, highlighting its pivotal role in addressing the condition and its secondary effects [17-19].

Telephone-based interventions improve the quality of life in people with MS by promoting physical activities like walking and exercise, leading to enhanced mental and physical performance [20, 21]. Research into the effectiveness and design of telephone interventions is vital due to knowledge gaps. While some studies indicate that interventions focusing on physical activity and self-management can moderately enhance healthy behaviors and quality of life, a lack of comprehensive understanding persists. Despite its acknowledged importance in chronic disease management, the limited research on self-management among people with MS accentuates the need for this research. Addressing these gaps can bridge evidence divides and potentially provide impactful strategies for promoting healthy behaviors, especially among MS patients.

Materials and Methods

This quasi-experimental study involved 20 MS patients selected from registered patients in the nationwide MS registry of Iran (NMSRI), Guilan, in 2020. Individuals were selected through a public call using judgmental sampling. The sample size was calculated based on the factor repeated measure approach's formula with a 95% confidence level, 85% power and 0.33 effect size. According to the previous study [22] information, the G*Power software, version 3.1.9.4 calculated the sample size as 20. The study employed a pre-test-post-test with a two-month follow-up design. Inclusion criteria were MS diagnosis per McDonald's 2017 criteria, age 20-55 and willingness to participate. The exclusion criteria were incomplete training and disagreement to participate in the study. A pre-test was taken before the intervention, and then training was implemented online and via telephone. The post-test was conducted immediately after the intervention and two months later using an online survey.

Study intervention

The educational program was a telephone-delivered self-management intervention and a standard intervention developed by Ehde et al. [23], including 8 weekly sessions of 45 to 60 minutes by phone with MS patients in a group setting. Self-management intervention is over the phone (audio, video and educational files and phone

Table 1. Telephone-delivered self-management intervention

Approach	Self-management (Cognitive Behavioral) Skills Training, In-session Rehearsal of Skills
Treatment goals	Engage participants in learning and applying self-management skills tailored to their strengths, priorities and target symptoms. Key self-management skills included self-monitoring, identifying strengths and priorities, goal setting, behavioral activation, relaxation techniques and managing thoughts and emotions.
1st session	This session covered an introduction to self-management, the philosophy of self-management, self-monitoring and identifying strengths.
2nd session	This session covered goal setting and identifying stressors, priority exploration, goal setting, stress response and diaphragmatic breathing.
3rd session	This session covered problem-solving relaxation and progressive muscle relaxation.
4th Session	This session covered energy management, exploring engagement, energy management strategies, prioritizing energy use, and controlled breathing.
5th session	This session covered identifying thoughts, labeling thoughts, thought stopping, distraction and autogenic relaxation.
6th session	This session covered challenging unhelpful thoughts, evidence gathering, creating alternatives, brief breathing and progressive muscle relaxation.
7th session	This session covered managing emotions, understanding control, life now, nurturing positive emotions, gratitude, emotion management, and guided imagery.
8th session	This session covered life now, building resilience, building a personal master self-management plan, skills relapse, prevention and resilience.
Homework	This session covered tailored goals, the practice of self-management skills from session content and relaxation practice using relaxation recording. Homework review included checks for adherence and troubleshooting barriers to meeting goals.

calls), including evidence-based cognitive-behavioral and psychological strategies to help participants manage pain, depression, and fatigue in everyday life. The therapist communicated with the participants on a scheduled basis to discuss the educational implications with them. Also, the academic content of each session was provided to the participants in the form of an electronic booklet, audio, and educational videos so that they could refer to them if they wanted to understand more about the training. Training sessions aimed at familiarizing self-management, goal setting, identifying stressful factors, problem-solving and relaxation training, energy management, working with thoughts, emotion management, and building resilience (Table 1).

Study tools

The MS self-management scale–revised (MSSM-R)

Bishop and Frein developed this self-report tool and has 24 items and 5 subscales: Healthcare provider relationship and communication, treatment adherence/barriers (TA/B), social/family support (S/FS) (three items: 6, 10, 13), MS knowledge and information (MSKI) and health maintenance behavior (HMB). The scoring method of the questionnaire was based on a 5-point Likert scale (completely disagree=1 to completely agree=5). The higher score indicates a high level of self-management; questions 21, 23 and 24 are scored in reverse. The range of changes in this tool is between 24 and 120 [24]. The psychometric assessment of the Persian-translated version of this scale was done by Saadat et al. The results showed that this scale has acceptable face and content validity. The confirmatory factor analysis showed that 24 items had acceptable factor loadings in 5 subscales. The internal consistency results of this scale were calculated by the Cronbach α method and the test-re-test reliability for the test subscales was reported between 0.70 and 0.89 [15].

The short form health survey (SF-36)

This questionnaire aims to assess the physical and mental health state. It has 36 items that evaluate 8 different subscales of health (physical functioning [PF], role physical [RP], bodily pain [BP], general health [GH], vitality [VT], social functioning [SF], role emotional [RE] and mental health [MH]). A lower score means a lower quality of life. In a study, the internal consistency of the first version of this questionnaire was between 0.72 and 0.94 with the Cronbach α [25]. Also, in Iran, Motamed et al. in Shiraz checked its reliability and estimated the Cronbach's α of the Persian questionnaire to be 0.87 [26].

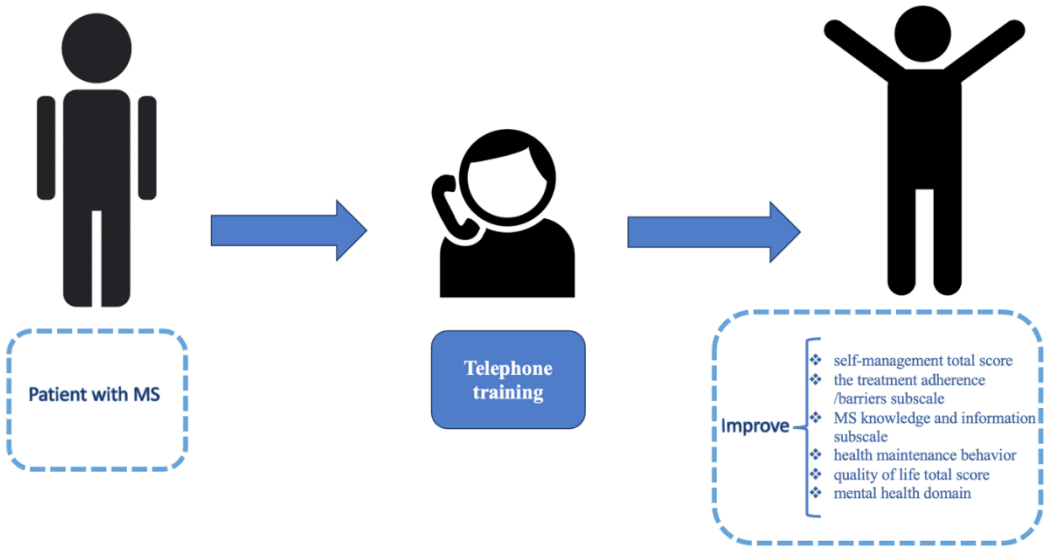

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Figure 1. Improvement of the score and variables of self-management and health-related quality of life of multiple sclerosis patients by telephone-delivered self-management intervention

Statistical analysis

Data were analyzed using IBM SPSS software, version 26. Data were reported by frequency (percentage) or Mean±SD. The Shapiro-Wilk test was used to determine the normality of the distribution. A repeated measure analysis examined the changes in the variables from the pre-test to the follow-up.

Results

Initially, 60 patients referred to the MS Society of Guilan, Iran, participated in this study. Data gathering and intervention continued to reach the determined sample size. Finally, 20 patients completed the sessions, post-test, and follow-up evaluation. The descriptive findings of the study are reported in Table 2.

In this study, 20 individuals with MS participated until the end of the intervention and cooperated in various assessment stages. Their demographic information is presented in Table 2.

The Shapiro-Wilk test showed that the assumption of normality of all variables was established. Therefore, the repeated measures analysis of variance (ANOVA) is used to assess the variable's change over time. The results in Table 3 showed that the intervention affects the self-management total score (P<0.001, F=12.29), TA/B (P=0.024, F=4.11), MSKI (P<0.001, F=8.11) and HMB (P=0.004, F=6.58). It also influenced the quality-of-life total score (P=0.049, F=3.25) and mental health subscale (P=0.018, F=4.46). However, in other variables, there was no significant effect over time (Table 3, Figure 1).

Table 4 presents the pairwise comparison of the three times assessments. The results showed a significant increase in the self-management total score from the pre-test to the post-test (mean difference = 6.85, P=0.001), and it was stable from the post-test to the follow-up (mean difference=0.70, P=0.999). The "MSKI" subscale (mean difference=1.75, P=0.032) and "HMB" subscale (mean difference=1.45, P=0.002) increased significantly between pre-test and post-test and they were stable from the post-test to follow-up by the mean difference=0.250 (P=0.999) and mean difference=0.150 (P=0.999), respectively.

In the quality-of-life total score and all its subscales except the mental health subscale, there were no significant changes between the pre-test, the post-test, and the follow-up. There was a considerable increase in the "mental health" subscale between the pre-test and the post-test (mean difference=15.6, P=0.026). While it decreased after the post-test, the changes between the post-test and the follow-up were not statistically significant (Table 4).

Table 2. Descriptive findings from the participants

Variables		No. (%)
Gender	Women	14(70)
	Men	6(30)
Marital status	Single	3(15)
	Married	16(80)
	Widow (er)	1(5)
Number of children	Without children	7(35)
	One	8(40)
	Two	2(40)
	Three or more	3(15)
Living condition	Alone	2(10)
	With family	18(90)
Address	City	19(95)
	Village	1(5)
Level of education	Diploma/associate	7(35)
	Bachelor	7(35)
	Master/doctorate	6(30)
Employment status	Full-time	3(15)
	Part-time	4(20)
	Housewife	1(5)
	Retired	2(10)
	Unemployed	10(50)
Monthly income (million Rials)	0	2(10)
	<30	10(50)
	30-70	6(30)
	70-100	1(5)
	>100	1(5)
Type of disease	Recovering/relapsing	12(60)
	Primary progressive	3(15)
	Secondary progressive	5(25)
Degree of disability	Mild	10(50)
	Medium	4(20)
	Trouble walking	2(10)
	Long-term use of crutches and wheelchairs	3(15)
	Recent use of crutches	1(5)

Table 3. Changes in variables of self-management and health-related quality of life score of ms patients after the intervention (calculated by repeated measures ANOVA)

	Variables	Mean±SD			F Statistic	P	Effect Size
		Pre-test	Post-test	Follow-up			
Self-management	MSSM-R	85.18±00.85	91.17±85.67	92.16±55.30	12.293	<0.001	0.39
	Healthcare provider relationship and communication	22.5±6.32	24.10±5.47	23.61±6.01	1.709	0.195	0.08
	Treatment adherence /barriers	25.10±6.25	26.5±50.26	27.15±4.73	4.114	0.024	0.17
	Social/family support	9.45±3.03	10.10±3.18	10.25±2.55	7.23	0.113	0.10
	MS knowledge and information	15.00±4.92	16.75±3.99	17.00±3.71	8.118	<0.001	0.29
	Health maintenance behavior	12.95±4.08	14.40±3.25	14.55±3.57	6.586	0.004	0.25
Health-related quality of life	SF-36	50.25±17.64	54.60±18.11	57.05±18.99	3.257	0.049	0.14
	General health	51.75±17.18	55.00±16.27	58.00±16.43	1.060	0.332	0.05
	Physical functioning	55.00±33.56	56.50±29.96	64.50±25.89	1.899	0.164	0.09
	Role physical	38.75±39.29	47.50±38.81	41.25±36.52	0.949	0.396	0.04
	Role emotional	33.3±40.49	29.95±37.33	45.05±42.32	1.909	0.162	0.09
	Bodily pain	62.65±26.80	63.85±24.65	62.85±24.05	0.062	0.940	0.00
	Social functioning	57.70±22.96	59.60±31.20	62.75±26.57	0.445	0.595	0.02
	Vitality	53.00±25.04	59.00±12.93	61.00±15.18	1.280	0.280	0.07
	Mental health	49.00±24.24	64.60±14.81	61.20±19.64	4.462	0.018	0.19

MSSM-R: The multiple sclerosis self-management scale–revised; SF-36: The short form health survey.

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Discussion

This study aims to determine the feasibility of telephone-delivered self-management intervention in patients with MS. The importance of our results is the significant impact of our intervention in increasing the total self-management score of MS patients. Our study's results align with those of other studies, such as the double-blind study conducted by Bombardier et al. According to their study, motivational telephone interviews for 30 minutes a day for 6 months significantly increased the lifestyle indices (including physical and mental health improvements, etc.) [27].

According to the present study's results, there was no significant positive or negative relationship between the healthcare provider relationship and communication in the pre-test, post-test and follow-up stages. In Deibel et al.'s study, MS participants felt that having more information and a strong relationship with healthcare professionals as tools of self-management skills are needed to address their physical and psychosocial challenges [28].

Regarding treatment adherence/barriers, the mean scores of the post-test and follow-up increased significantly in relation to the pre-test. This means that our intervention significantly increases patients' treatment adherence. Our study's results align with the study of Graziano et al. In their study, 82 patients with MS were investigated, and interventions were conducted in behavioral therapy sessions. Finally, after 6 months, treatment adherence was observed in these patients, demonstrating that psychotherapy sessions effectively increased treatment adherence/barrier [29].

No significant difference was observed in the average score of the social/family support area in our examined patients after the intervention. One of the reasons for this difference can be considered the poor socioeconomic status of patients and their families. However, Baharian et al.'s study showed that social support is related to self-management in MS patients. This concept should be

Table 4. Pairwise comparisons of variables which changes significantly between the pretest and follow-up

Variables			Mean Difference	Standard Error	Significance Level	95% CI for Difference	
						Lower	Upper
Total score	Pre-test	Post-test	-6.85	1.45	<0.001	-10.67	-3.03
		Follow-up	-7.55	1.83	0.002	-12.35	-2.74
	Post-test	Follow-up	-0.70	1.73	0.999	-5.26	3.86
Treatment adherence/barriers	Pre-test	Post-test	-1.40	0.67	0.155	-3.17	0.37
		Follow-up	-2.05	0.87	0.089	-4.33	0.23
	Post-test	Follow-up	-0.65	0.62	0.925	-2.28	0.98
MS knowledge and information	Pre-test	Post-test	-1.75	0.61	0.032	-3.37	-0.12
		Follow-up	-2.00	0.60	0.011	-3.59	-0.40
	Post-test	Follow-up	-0.25	0.35	0.999	-1.18	0.68
Health maintenance behavior	Pre-test	Post-test	-1.45	0.35	0.002	-3.37	-0.52
		Follow-up	-1.60	0.55	0.027	-3.04	-0.15
	Post-test	Follow-up	-0.15	0.53	0.999	-1.55	1.25
Total score	Pre-test	Post-test	-4.35	2.09	0.154	-9.84	1.14
		Follow-up	-6.80	3.20	0.142	-15.21	1.61
	Post-test	Follow-up	-2.45	2.68	0.999	-9.49	4.59
Mental health	Pre-test	Post-test	-15.6	5.31	0.026	29.56	-1.63
		Follow-up	-12.2	6.77	0.262	29.97	1.57
	Post-test	Follow-up	-3.4	4.04	0.999	-7.21	14.01

applied in clinical practice when targeting and designing education, support, and care for MS patients. This notion can be used when designing education, support, and care for patients with MS in clinical practice [30].

Our study's mean score of patients' MSKI increased significantly from the pre-test to the post-test and follow-up. In this respect, our study aligns with many previous studies, including the study of Plow et al. [13] and Bombardier et al. [27]. This outcome illustrates the lack of patients' knowledge about their illness and the benefit of a healthcare provider's education and information provision to patients.

The present study's mean score of health-maintaining behaviors increased positively and significantly from the pre-test to the post-test and follow-up. The results of Plow et al.'s study are consistent with the results of our research. According to the results of this study, after training by the therapist for 6 months, performing sports activities in patients as a HMB has had a positive and significant effect [13]. In addition, Bombardier et al. concluded in their study that there was an inverse and significant relationship between motivational interviews and reducing alcohol consumption in patients [27].

In the present study, the mean score of the total quality of life showed a positive and significant increase. These results align with the studies of Bombardier et al. and Finlayson et al. According to the results mentioned in the study of Finlayson et al. there is a significant relationship between motivational interviewing and controlling the level of fatigue and patients' quality of life [1, 31]. In the study by Proctor et al. telephone-based psychotherapy positively improves depression, fatigue, quality of life, MS symptoms, physical activity, and medication

adherence in the short-term [32]. Also, in a study by Moss-Morris et al. Internet-based cognitive behavioral therapy self-management is a promising, acceptable and cost-effective approach for treating MS fatigue and improving broader outcomes such as distress [33].

According to the results of our study, the average score in the physical performance area did not increase significantly. This issue is inconsistent with the results of past studies. The study conducted by Plow et al. demonstrated that group conference calls followed by appropriate phone calls have a small statistically significant effect on promoting physical activity and reducing fatigue in MS patients [13]. The reason for this difference could be the small sample size of the present study compared to other studies [23, 34] and perhaps the length of the questions in the questionnaire was associated with the decrease in accuracy of answering the questions by the patients. As fatigue is a non-specific symptom and affects various dimensions of patients' daily lives, it should be addressed through a comprehensive approach that targets both patient behaviors and their emotional and mental attitudes toward fatigue. However, the clinical correlation of treatment effects, specifically the relationship with patients' daily functioning, has been unclear and likely requires longer-term interventions exceeding 6 months. According to the results of this investigation, the average score of the bodily pain subscale increased in the post-test group compared to the pre-test, but it decreased in the follow-up. Overall, these changes were not significant. This study is comparable to Ehde et al.'s in lowering the average score of bodily pain [35]. The average range of vitality scores among patients in this study has increased over time. However, this increase was not significant. It is in line with many studies, such as the study of Ehde et al. and Graziano et al. In both mentioned above studies, cognitive-behavioral therapy caused a significant reduction in depression scores [29, 35]. Also, the results of our study indicate a positive and significant increase in the mental health score. This result aligns with other studies, such as Ehde et al.'s and Turner et al.'s studies [35, 36].

Conclusion

In this study, telephone-delivered self-management intervention in patients with MS has positive effectiveness in many areas under investigation. The mean score in self-management, treatment adherence/barriers, knowledge and information about the disease, HMBs, quality of life, vitality and mental health increased significantly in the follow-up compared to the pre-test. Therefore, this intervention can be used to improve the quality of life of these patients. The follow-up of patients during and after the treatment period is of particular importance.

Study limitations

Despite the registration of many patients with MS in the Rasht MS Association, only a small number of patients are connected with this association. So, the weak point of our study is its small sample size. Therefore, it is recommended that further studies be conducted on a broader scale and with a larger sample size.

Ethical Considerations

Compliance with ethical guidelines

The research was approved by the Research Ethics Committee of the Guilan University of Medical Sciences (Code: IR.GUMS.REC.1399.508).

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Authors contributions

Conceptualization: Mozaffar Hosseininezhad and Sajjad Saadat; Methodology: Sajjad Saadat and Roghaye Zare; Investigation: Fatemeh Younesi Rostami, Masoumeh Qanbary Joopish and Alia Saberi; Writing the original draft: Ali Bonyad; Writing, review and editing: Alia Saberi; Supervision: Mozaffar Hosseininezhad, Sajjad Saadat and Alia Saberi.

Conflict of interest

The authors declared no conflict of interest.

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