

Healthier Living with MS: The Key Role of Self-Efficacy and Emotion Regulation

Abstract

Objectives: Understanding distress and quality of life (QOL) is important in improving the lives of people with multiple sclerosis (MS), and investigating their antecedents is very important. The present study aimed to examine the role of multiple sclerosis self-efficacy and difficulties in emotion regulation in predicting distress and QOL in people with MS. Also, this study compared types of MS (RRMS, PPMS, and SPMS) in terms of MS self-efficacy, difficulties in emotion regulation, distress, and QOL.

Methods: This study included 122 people with three types of MS (RRMS=33, PPMS=62, and SPMS=25). Data were collected by the use of four scales: Quality of Life (QOL), Psychological Distress (DASS), Difficulties in Emotion Regulation (DERS), and Multiple Sclerosis Self-Efficacy (MSSE). Pearson's correlation, path analysis, MANOVA, and Tukey's post hoc test were used for data analysis.

Results: Findings indicated MS self-efficacy had negative and significant effects on difficulties in emotion regulation and distress and had a positive and significant effect on QOL. Difficulties in emotion regulation had a negative and significant effect on QOL and a positive and significant effect on distress. Also, the indirect effect (through difficulties in emotion regulation) of MS self-efficacy on distress and QOL was significant. In addition, the comparisons showed that differences between RRMS and SPMS in terms of MS self-efficacy and distress were significant.

Conclusions: Self-efficacy and emotion regulation are key components in improving the life (reducing distress and increasing QOL) of people with MS, although it depends to some extent on the type of MS disease.

Keywords: Multiple sclerosis, Self-efficacy, Difficulties in emotion regulation, Distress, Quality of life

1. Introduction

A satisfying life requires both reducing negative emotions and increasing positive experiences and sufficient quality of life (QOL). But multiple sclerosis (MS), as an autoimmune disease, is one of the most common chronic neurological conditions (Prakash et al., 2019) that disables the nervous system and reduces the QOL (Arnett, 2003). Because of its unpredictable, chronic, and life-changing nature MS causes a high level of distress in people, especially in the early stages of the disease (Janssens et al., 2003). In fact, many people with MS have negative psychological experiences including anxiety, depression, and stress (Giordano et al., 2011; Antony et al., 1998; Boeschoten et al., 2017; Mrabet et al., 2022), at frequencies and severities above those of the general population (Pham et al., 2018). A study on a sample of patients with MS in Iran showed that 44.8% had moderate stress, 47.1% had moderate depression, and 39.1% had moderate anxiety (Karimi et al., 2020).

An important contribution to distress and QOL of people with MS is made by symptoms and emotions related to their disease. Symptoms experienced by people with MS range from mild to moderate or severe (Confavreux et al., 2000), and the pattern of these symptoms can be very variable, including cognitive, visual, motor, bladder function, fatigue, and pain problems (Brownlee et al., 2017). According to social cognition theory, self-efficacy plays an important role in dealing with MS and the unpleasant symptoms and emotions associated with it. People with MS strive to maintain their independence despite increasing disease-related disability, and one of the main factors influencing independence is self-efficacy (Jongen et al., 2014). MS self-efficacy refers to maintaining one's function in the presence of this disease and controlling MS disease from the patient's perspective (Chiu et al., 2015). Evidence shows that self-efficacy in people with MS is related to more physical activity, fewer symptoms (Motl et al., 2006),

increased self-esteem and subsequent functioning (Barnwell and Kavanagh, 1997), and health-related QOL (Motl et al., 2013).

Self-efficacy in dealing with emotions can be understood from the perspective of emotion regulation. Emotion regulation refers to the processes that people use to influence when, how, and the intensity of the experience of emotions (Gross, 1998). There are various dimensions of emotion regulation (e.g., emotional clarity, non-acceptance of emotions, emotional awareness, etc.) (Gratz and Roemer, 2004., Sörman et al., 2021). Research has focused on the relationship between emotion regulation and mental and physical consequences related to health (Gross, 2013; McRae and Gross, 2020), and difficulties in emotion regulation have been considered a trans-diagnostic factor that helps to understand emotional disorders (Gay et al., 2017). In people with chronic medical conditions, emotion regulation is related to distress (Prentice et al., 2021), depressed mood, and partner-related stress (Messerli-Bürgy et al., 2012). Also, people with MS seem to experience a higher level of difficulty in emotion regulation and a lower level of QOL, and difficulties in emotion regulation are related to depression and anxiety (Prakash et al., 2019; Gay et al., 2017). Evidence shows that people with MS have more difficulties in emotion regulation compared to healthy controls (Phillips et al., 2014). The incidence of alexithymia - difficulty in identifying, labeling, and expressing emotions - is 62.5% in people with MS (Mrabet et al., 2022).

Overall, evidence suggests that self-efficacy in chronic conditions (such as MS self-efficacy), and regulation of disease-related unpleasant emotions are related to health and QOL and distress (such as depression), including patients with MS. But it is not clear what role difficulties in emotion regulation plays in the relationship between MS self-efficacy with distress and QOL. However, since MS self-efficacy refers to the belief of people with MS that they are able to positively influence some aspect of their condition and cope with their illness (Rigby et al., 2003), the current study was conducted with the hypothesis that the self-efficacy of people with MS about their disease affects their distress and QOL, by affecting their ability to deal with emotional experiences.

Moreover, many patients move from relapsing-remitting MS (RRMS) to secondary progressive MS (SPMS) over time, which can be considered as a disease continuum, thus SPMS is characterized by the longer duration of living with MS (Scalfari et al., 2014; Tremlett et al., 2008), the worsening neurological function (Lassmann et al., 2012), and the intensifying of disability and the weaker therapeutic response (Bruce et al., 2021). Intensifying these negative experiences during the disease is thought to bring more unpleasant psychological experiences and perceptions. Accordingly, the second hypothesis posited a difference among people with different types of MS (RRMS, primary progressive MS [PPMS], and SPMS; Klineova and Lublin, 2018) in terms of MS self-efficacy, difficulties in emotion regulation, distress, and QOL.

2. Methods

2.1. Design and Participants

This study used a cross-sectional design. First, the relationship between MS self-efficacy (independent variable), DEES (mediating variable), and distress and QOL (dependent variables) was tested. Second, three types of MS (RRMS, PPMS, and SPMS) were compared to determine their differences in terms of difficulties in emotion regulation, MS self-efficacy, distress, and QOL.

The research population was people with MS who received medical services from three private hospitals in Tehran from January to June 2022. The inclusion criteria included having an MS diagnosis, being aged 18 to 60 years, and being able to give informed consent to participate in the research. Exclusion criteria included receiving a psychiatric diagnosis prior to MS, and other medical comorbidities including cancer, pre-existing chronic pain, diabetes, dementia, gastrointestinal disease, renal disease, and cardiovascular disease (based on the medical documents and the chief nurse's information). The purpose of this research and the principles of research ethics were explained to the participants. Before starting to answer the

research questions, all participants provided an informed consent form. Then, the questionnaires were administered by the first and second researchers, via paper forms. The present study included 122 people with MS (RRMS=33, PPMS=62, and SPMS=25) between the ages of 20 and 57 (M= 36.74 years; SD = 8.85).

2.2. Measures

2.2.1. *Quality of Life (QOL)*

To measure the QOL, the World Health Organization Quality of Life (WHOQOL-BREF) Questionnaire was used. This questionnaire has 26 items and measures QOL in terms of physical health, psychological health, social relationships, and environmental health. The participants responded to the questions on a 5-point scale. A higher score indicates a higher QOL. In the Persian version, Nejat et al. (2006) reported the test-retest reliability of the subscales to be in the range of 0.75 to 0.84. Its differential validity in differentiating healthy people from people with chronic diseases was reported as acceptable.

2.2.2. *Distress*

To measure distress, the short form of depression, anxiety, and stress scale (DASS) was used (Lovibond and Lovibond, 1995). This form has 21 items and answers to each of them are given in a range of 4 points from 0 (never) to 3 (always). In the Persian version, Samani and Jokar (2007) reported the Cronbach coefficient of the subscales as 0.75 to 0.87, and its differential validity was significant in differentiating students with and without unpleasant experiences.

2.2.3. *Difficulties in Emotion Regulation (DERS)*

DERS was developed by Gratz and Roemer (2004). This 36-item scale evaluates the difficulties of regulating emotions during tension and distress. Participants rated each item on a scale of 1 (never) to 5 (always). Khanzadeh et al. (2012) reported the criterion validity of the Persian version to be significant, and Cronbach's alpha of the components was reported in the range of 0.80 to 0.89.

2.2.4. *Multiple Sclerosis Self-Efficacy (MSSE)*

This scale was developed by Rigby et al. (2003). This tool has 14 items, each scored on a 6-point scale from 1 (completely disagree) to 6 (completely agree). This scale assesses independence and activity, personal control, and interests. Higher scores mean higher self-efficacy. In the Persian version of this scale, its validity was significant and the alpha coefficient of the whole scale was reported as 0.90 (Tanhaye et al., 2014).

2.3. Statistical analyses

Initially, data were collected from 122 participants, but 2 participants were excluded from the final analysis due to outlier data. All analyses were done using SPSS-28, apart from bootstrapping using AMOS-24. Skewness and kurtosis values were used to evaluate normality. Considering that George and Mallery (2010) suggest that the skewness and kurtosis of each variable in the range of ± 2 indicate the normality of its distribution, the data of the current research were deemed to have a normal distribution (skewness of the variables was in the range of -0.10 to 0.65 and their kurtosis was in the range of -0.95 to -0.20) (Table 1). Pearson's correlation test was used to evaluate the relationships between variables (sex, age, Disease duration, difficulties in emotion regulation, MS self-efficacy, distress, and QOL) (Meyers et al., 2006). Path analysis tests were used to test the direct and indirect effects (through difficulties in emotion regulation) of MS self-efficacy on distress and QOL. Also, the bootstrapping method with 5000 resamples was used to evaluate direct, indirect, and total effects. In order to compare the three subtypes of MS, the multiple analysis of variance (MANOVA) tests and Tukey's post hoc test was used (Meyers et al., 2006).

3. Results

In the research sample, 81 were women (67.5 %) and 39 were men (32.5 %). In terms of educational level, 27 people had a diploma (22.5 %), 67 people had a bachelor's degree (55.8 %), and 26 people had a master's/doctorate degree (21.7 %). In terms of marital status, 39 people were single (32.5 %), 70 people were married (58.3 %), and 11 people were divorced (9.2 %).

The relationship between MS Self-efficacy, Difficulties in Emotion Regulation, Distress, and QOL

Pearson's correlation test was used to evaluate the relationships between variables (Table 1). According to Table 1, age ($r=0.10$, $P>0.05$) and disease duration ($r= .07$, $P>0.05$) had no significant relationship with distress. Difficulties in emotion regulation had a significant positive relationship with distress ($r=0.71$, $P\leq 0.01$), and MSSE ($r=-0.64$, $P\leq 0.01$) had a significant negative relationship with distress. In addition, age had a significant negative relationship with QOL ($r=-0.18$, $P<0.05$), but the relationship between disease duration and QOL was not significant ($r=-0.13$, $P>0.05$). Also, the relationship between MS self-efficacy ($r=0.63$, $P<0.01$) and QOL was significantly positive, but the relationship between difficulties in emotion regulation ($r=-0.54$, $P<0.01$), and distress ($r=-0.54$, $P<0.01$), with QOL was significantly negative. The descriptive statistics values of variables and the correlation between them are reported in Table 1.

Table 1. Descriptive Statistics and Correlations in People with MS

	M (SD)	Skew	Kurt	DD	DERS	MSSE	Distress	QOL
Age	36.74 (8.85)	.33	-.47	.42**	.14	-.29**	.10	-.18*
DD	68.06 (62.19)	.65	-.95	-	.05	-.16	.07	-.13
DERS	43.56 (12.88)	.17	-.43		-	-.59**	.71**	-.54**
MSSE	49.50 (9.16)	-.10	-.45			-	-.64**	.63**
Distress	21.66 (11.21)	.35	-.47				-	-.54**
QOL	289.26 (72.80)	.24	-.20					-

DD= Disease Duration, MSSE= MS self-efficacy, DERS= difficulties in emotion regulation, QOL= quality of life

Direct and indirect effects on Distress and QOL

A path analysis test was performed. The results of the test of the initial conceptual model showed that this model does not have a good fit. According to Meyers et al. (2006), to modify the model, the path of distress to QOL, which was non-significant, was deleted, and the modified model was tested again. Its results showed that the modified model has a good fit (CMIN/DF=1.36, GFI=.99, AGFI=.94, NFI=.99, RFI=.96, CFI=.99, RMSEA= .055). The results of the modified model can be seen in Figure 1.

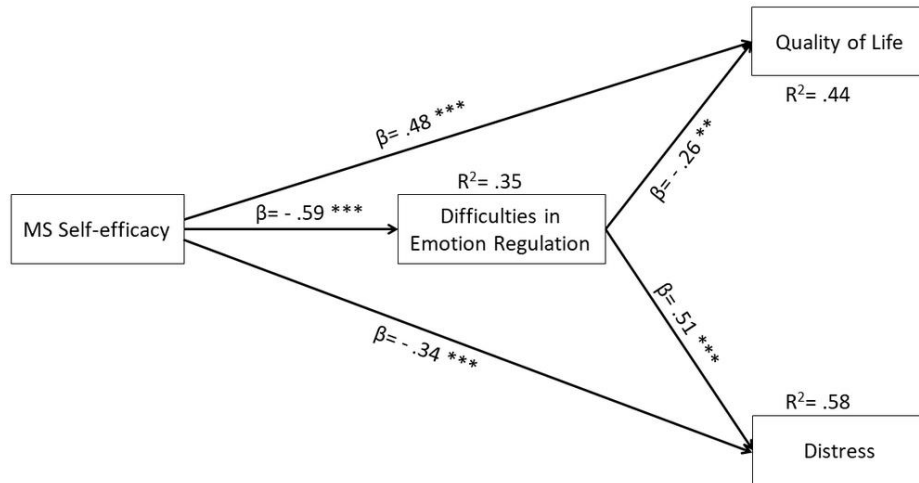


Fig. 1. Final model including the direct, indirect, and total effects. All coefficients were significant. ** $p \leq 0.01$ * $p \leq 0.001$**

According to Figure 1, MS self-efficacy had negative and significant effects on difficulties in emotion regulation ($\beta = -.59$, $P \leq .0001$) and distress ($\beta = -.34$, $P \leq .0001$), but its effect on QOL was positive and significant ($\beta = .48$, $P \leq .0001$). Also, the effect of difficulties in emotion regulation was negative and significant on QOL ($\beta = -.26$, $P \leq .001$), and positive and significant on distress ($\beta = .51$, $P \leq .0001$). But distress had no significant effect on QOL ($P > .05$). Moreover, the indirect effect of MS self-efficacy on distress (through difficulties in emotion regulation) was -0.30 ($P \leq .001$), and its total effect was -0.64 ($P \leq .001$). Also, the indirect effect of MS self-efficacy on QOL (through difficulties in emotion regulation) was 0.15 ($P \leq .001$), and its total effect was 0.63 ($P \leq .001$).

The differences between types of MS

MANOVA and Tukey tests were used. Box's test was not significant ($F = 1.20$, $P > 0.05$), and the assumption of the equality of covariance matrices of the dependent variables among the groups was confirmed. Also, the results of Levene's test were not significant for any of the dependent variables ($P > 0.05$). Therefore, the assumption of the same variance error of the groups was confirmed. The results of MANOVA can be seen in Table 2.

Table 2. The results of the MANOVA test comparing three types of MS

Dependent Variable	F	df	Sig	Partial Eta Squared
MSSE	4.22	2	.017	.07
DERS	.99	2	.374	.02
Distress	4.38	2	.015	.07
QOL	2.91	2	.059	.05

According to Table 2, the difference between types of MS was significant in terms of MS self-efficacy and distress. The Tukey test was used for multiple comparisons. The results of this test showed that the mean MS self-efficacy of RRMS ($M = 52.88$, $SD = 9.83$) was significantly higher than SPMS ($M = 46.12$, $SD = 8.46$) ($P < 0.05$), but there was no significant difference between RRMS and PPMS ($P > 0.05$) and between PPMS and SPMS ($P > 0.05$). There was no significant difference between groups in terms of the difficulties in emotion regulation ($P > 0.05$). The mean distress of RRMS ($M = 17.13$, $SD = 10.44$) was

significantly lower than SPMS (M=25.12, SD=12.04) ($P<0.05$). Also, the difference between RRMS and PPMS in terms of distress was almost significant, and the mean distress of group RRMS (M=17.13, SD=10.44) was lower than PPMS (M=22.67, SD=10.66) ($P=.052$). There is no significant p between PPMS and SPMS ($P>0.05$). In addition, there was no significant difference between groups in terms of the mean of QOL ($P>0.05$) (Table 3).

Table 3. The results of multiple comparisons based on Tukey's test

Dependent Variable	Groups	Mean Difference	Std. E	Sig.
MSSE	RRMS - PPMS	3.81	1.92	.122
	RRMS - SPMS	6.75*	2.37	.014
	PPMS - SPMS	2.95	2.11	.347
DERS	RRMS - PPMS	-3.25	2.77	.473
	RRMS - SPMS	-4.38	3.41	.407
	PPMS - SPMS	-1.13	3.05	.927
Distress	RRMS - PPMS	-5.54	2.35	.052
	RRMS - SPMS	-7.99*	2.89	.018
	PPMS - SPMS	-2.45	2.58	.611
QOL	RRMS - PPMS	8.61	15.44	.843
	RRMS - SPMS	43.41	19.00	.062
	PPMS - SPMS	34.80	16.98	.105

4. Discussion

The present study investigated the direct and indirect relationship (through difficulties in emotion regulation) of MS self-efficacy with distress and QOL. Also, this study has evaluated the difference in each of these variables among people with MS types.

The results showed that MS self-efficacy has a significant direct effect on reducing distress and increasing QOL. These results are consistent with previous research findings that show that self-efficacy in patients with MS is related to physical and psychological health and QOL (Barnwell and Kavanagh, 1997; Motl et al., 2006; Motl et al., 2013; Young et al., 2022), and has significant effects on independence (Jongen et al., 2014), these effects occur in different trajectories (Young et al., 2022). In fact, when patients with MS have higher self-efficacy, they have higher functional independence, have a stronger perceived personal control and confidence in social situations, and believe they can pursue their interests (Rigby et al., 2003). Thus, they feel less helpless and powerless against their disease and its symptoms and are more likely to be able to pursue their goals and daily schedule and pursue what is meaningful or pleasurable to them. As a result, it is likely that they will experience fewer negative emotions (decreased distress) and more positive experiences (increased QOL).

Another finding of the present study was that difficulties in emotion regulation can significantly mediate the effect of MS self-efficacy on distress and QOL. In fact, the results showed that MS self-efficacy can lead to a decrease in distress and an increase in QOL through the decrease of difficulties in emotion regulation. Considering that people with higher self-efficacy believe that they can apply a certain behavior to a problem, and through it achieve a certain result (Rigby et al., 2003; Vaughan-Johnston and Jacobson, 2020), they can have the same belief about their emotions as a "target" for self-efficacy beliefs.

In the context of MS disease, self-efficacy is an important determining factor for patients' effort and coping with unpleasant emotions caused by challenging and difficult situations related to the disease. The self-efficacy of people with MS in regulating emotions includes their sense of ownership and control over emotions and the understanding that emotions do not reflect objective facts but are personal and subjective experiences of events that people can manage, and pursue their values and interests. Therefore, those people with MS who have higher self-efficacy believe that they can be active and effective in dealing with their emotions, regulate and express them, and achieve their expected emotional outcomes. But those with low self-efficacy and reduced emotion regulation will experience increased vulnerability to negative emotions due to their illness. This likely prevents them from pursuing personal values, goals, and interests, and probably, from our analysis, can increase distress and decrease QOL. This finding that increasing difficulty in emotional regulation can lead to increased distress and reduced QOL is consistent with the results of some previous studies (Gianini et al., 2013; Messerli-Bürgey et al., 2012., Wierenga et al., 2017; Prakash et al., 2019; Leukel et al., 2022), which have shown that emotion regulation is related to health and wellbeing in chronic disease.

According to our results, although the distress was related to QOL, it did not have a significant effect on their QOL. This finding contradicts previous studies that have shown that distress in people with MS is associated with reduced QOL (e.g. Salehpoor et al., 2014; Gil-González et al., 2020). This finding can indicate that although distress is related to the QOL of people with MS, it is not significant when its impact on QOL is evaluated along with the effect of self-efficacy and emotion regulation. In other words, what determines the QOL of people with MS is not their distress, but their self-efficacy and emotional regulation in facing the symptoms of the disease, as well as their stress, depression, and anxiety (which refer to distress). Also, the finding is evidence that to improve health and QOL, instead of focusing only on psychopathology (such as trying to reduce distress), it is necessary to enhance positive components (here, increasing MS self-efficacy).

The comparison between groups showed that the mean MS self-efficacy of RRMS patients was significantly higher than SPMS patients. The mean distress in these two groups was reversed, that is, distress in SPMS was significantly higher than in RRMS. No significant difference was seen in other group comparisons. One reason for the difference between RRMS and SPMS in terms of MMSE and distress could be that RRMS patients usually experience a period of partial or total recovery after acute disease episodes (Klineova and Lublin, 2018), and these recovery periods can both induce a greater self-efficacy and reduce the intensity of unpleasant emotional symptoms. But for people with SPMS, their disease is worsening (Klineova and Lublin, 2018), which threatens their self-efficacy and aggravates their distress. In fact, the disability of both PPMS and SPMS patients is worsening. However, because SPMS patients experience an initial relapsing/remitting course prior to their SPMS diagnosis, before entering the progressive stage with an accrual of disability, they feel the loss of control more keenly, causing them to experience a more significant decrease in MS self-efficacy and a more significant increase in distress.

In sum, the findings of the present study support the effect of self-efficacy on the reduction of negative experiences (i.e., distress) and the increase in well-being (i.e., QOL). They also emphasize the mediating role of difficulties in emotion regulation in these relationships. This study provides evidence of differences between MS disease types in terms of self-efficacy and distress, which may be related to the severity of disease progression and severity of symptoms. Therefore, increasing MS self-efficacy and emotion regulation skills can be a useful mechanism to reduce distress and promote the QOL of patients with MS, via education and skills training in MS services (Brenner et al., 2022; Bijani et al., 2022; Lancaster et al., 2022).

However, the cross-sectional design of the present study is a limitation preventing conclusions about cause and effect. Therefore, longitudinal and interventional studies are needed to address the causal relationships between MS self-efficacy, distress, and QOL, and to evaluate difficulties in emotion regulation as a mediating mechanism. Another limitation is that the participants were patients of private

hospitals, as a result, they are above the average range of society in terms of finances and education. Therefore, it is suggested to conduct similar investigations on patients of public hospitals.

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Informed Consent. The implementation of this study has adhered to the Declaration of Helsinki. Also, Informed consent was obtained from all individual participants included in the study.

Conflict of Interest. The authors have no conflict of interest.

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