Examining the roles of self-compassion and resilience on health-related quality of life for individuals with Multiple Sclerosis

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ABSTRACT

Background: There are over 400,000 individuals living with Multiple Sclerosis (MS) in the U.S. These individuals experience unpredictable relapses of disabling conditions and poorer quality of life than the general population. Recent literature suggests self-compassion and resilience may improve wellness in this population.
Objective: The purpose of this study was to examine the roles of self-compassion and resilience on perceived health-related quality of life for individuals with Multiple Sclerosis (MS) using mediation analysis.
Methods: Two hundred fifty-nine adults with MS from MS advocacy, support, exercise, and education groups around the United States participated in the study. Participants' self-compassion, health-related quality of life (HRQoL), and resilience were assessed using self-report measures. A simple mediation analysis was conducted to examine the relationships between the independent variable, self-compassion, the depended variable, HRQoL, and the mediating variable, resilience.
Results: Results showed a significant direct effect between self-compassion and health-related quality of life ($\beta = 0.49$, $p < 0.0001$, CI = 0.37—0.61), as well as an indirect relationship through resilience ($\beta = 0.18$ $p < 0.0001$, CI: 0.17, 0.47).
Conclusion: These results contribute to the theoretical knowledge of how self-compassion influences HRQoL in this population. For individuals with MS, engaging in self-compassion may provide a strategy to cope with debilitating conditions and reframe perceptions of their health. Additionally, increasing resilience may help individuals overcome stressful and traumatic events and experience quality of life with disability. Self-compassion and resilience are both modifiable constructs that can be targeted by programs seeking to improve overall wellness.

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Introduction

Multiple Sclerosis (MS) is an autoimmune condition that affects the central nervous system. The prevalence of MS is 149.2 per 100,000 in the US, impacting the lives of over 400,000 individuals.[1] MS is characterized by periods of exacerbations of symptoms that may involve balance and mobility impairments, affect vision, speech, hearing or cognition, as well as cause extreme fatigue, spasticity, and paresis.[1] As individuals experience relapses of the condition and face greater disability, they have increased difficulty engaging in activities of living, which decreases functional independence and reduces their quality of life.[2—4]

Health-related quality of life (HRQoL), which is one's perception of their overall wellbeing as it relates to health, has been an indicator of wellness and widely studied among populations with chronic disease, trauma, and disability.[5,6] Individuals with MS have reported significantly lower HRQoL than the general population, perhaps because of their associated conditions and accumulation of disabling symptoms.[7] Health professionals are challenged to find ways to improve health and wellness in this population.[8] Engaging in self-compassion is one approach that has the potential to improve HRQoL for individuals with MS.

Self-compassion is defined as the desire to ease one's own suffering through offering self-kindness, and nonjudgmental

understanding.[9] Through these actions, individuals can comfort themselves in times of distress, acknowledge their pain or struggle, and know that they are not isolated in their experiences. Cultivating self-compassion can be beneficial when dealing with difficult life events, such as chronic disease, and when feelings of inadequacy arise, such as engaging in physical activity with a disability.[9,10] Research has revealed a positive association between self-compassion and the emotional components of quality of life, and that self-compassion predicts disease-specific quality of life.[11] In addition, self-compassion was reported to be a "robust" predictor of quality of life in a sample of individuals experiencing moderate to severe depression or anxiety. Being self-compassionate may increase the ability of people with MS to take a mindful attitude toward their condition, therefore being more accepting of their experience while still engaging in meaningful daily activities. Since individuals with MS face extraordinary fatigue and acute attacks, they may endure greater psychological challenges and negative affect (due to "suffering") than the general population. Therefore, self-compassion may play an important role in psychological health and the perception of one's HRQoL.

Resilience may be one mechanism through which self-compassion promotes improved perceptions of HRQoL. Studies have demonstrated that resilience is influenced by engagement in self-compassion,[6,12,13] as well as positively related to quality of life.[14] Resilience has been conceptualized as the capacity to persist or bounce back through positive adaptation in times of stress or adversity.[15,16] Several studies[12,17] have reported a positive relationship between resilience and quality of life for individuals with MS; however, individuals with MS have reported lower levels of resilience compared to the general population and other acquired disability groups.[12,14] A recent qualitative study explored barriers and facilitators to resilience among individuals with MS.[12] Participants described several facilitators that supported resilience, which included psychological adaptation and social connection. Psychological adaptation included awareness of challenges (mindfulness), acceptance, and self-compassion, while social connectedness included support from peers with MS as well as family and friends. Silverman[12] supports the importance of mindfulness, social connectedness, and self-compassion as promoters of resilience in this population.

While there has been support for the notion of self-compassion and resilience promoting quality of life, there is a need to understand the mechanisms by which these effects occur for individuals with MS. Therefore, the purpose of this study was to examine the roles of self-compassion and resilience on health-related quality of life. Our specific aim was to discern the mechanisms by which self-compassion contributes to overall wellness for individuals with MS. It was hypothesized that for individuals with MS, self-compassion would directly influence HRQoL, and indirectly influence HRQoL through resilience.

Methods

Participants

Two hundred and fifty-nine individuals with MS participated in the study. Inclusion criteria were 1) between the ages of 18—65, and (2) having a medical diagnosis of MS. Participants may have had a medical diagnosis of any of the four types of MS (i.e. relapse-remitting, primary-progressive, secondary-progressive, and progressive-relapsing).

Participants were predominantly white (90.31%) females (84.17%) with a mean age of 48.55 (SD = 10.47) years. The average BMI was 28.32 (SD = 7.93; range: 17.13—70.31), and 59.64% (n = 143) of individuals reported being in the overweight or obese

categories. Seventy-three percent of participants reported having a relapse-remitting MS course, and 18.22% were secondary-progressive. Time since last acute attack was reported at greater than twelve months for 53.85% of individuals, followed by less than 3 months for 23.67% of individuals. Thirty-eight percent of participants were employed for wages, and 35.27% reported being unable to work due to their MS. Forty-eight percent of participants had a diagnosis of MS for 10 years or less (n = 123), 31.50% had MS for 11—20 years (n = 80), and 20.08% had MS for between 21 and 49 years (n = 51). The majority of participants reported their health status as good, very good, or excellent (65.05%). Table 1 presents demographic information for this study.

Measures

Participants completed a survey that included three questionnaires and demographic information for a total of 60 questions: Revised Connor-Davidson Resilience Scale[18,19] (CD-RISC10), Self-Compassion Scale[20] (SCS), and the Function Neutral Health-Related Quality of Life Short Form[5] (FuNHRQOL-SF). The demographic questionnaire included items on current health status, and information about MS status (MS type, date of diagnosis, time since last relapse).

The SCS measured individuals' self-compassion on a 5-point Likert-type scale ranging from 1 (almost never) to 5 (almost always). This 26-item scale has three paired subscales: (1) self-kindness vs. judgment, (2) mindfulness vs. over-attachment, and (3) common humanity vs. isolation. Previous research[20] demonstrated test-retest reliability (r = 0.80-0.93), and in our sample the internal consistency coefficient was α = 0.93. The measure includes questions such as, "When I'm going through a very hard time, I give myself the caring and tenderness I need" and "I'm disapproving and judgmental about my own flaws and inadequacies." Items from judgment, over-attachment, and isolation were reverse coded, and each of the three subscale means were averaged to get a total mean for self-compassion. A higher total score represented a higher level of self-compassion.

A revised CD-RISC10 was used to measure individuals' resilience, or ability to cope with stress.[18,19] The CD-RISC10 is a self-report measure comprised of 10 items and responses are given on a 5-point Likert scale. Sample items include "I tend to bounce back after illness or hardship" and "I am able to adapt to change." The total mean score was used to identify individuals' perception of their resilience, with a higher score associated with higher resilience. The measure demonstrated good internal consistency (α = 0.85) in a previous study,[19] and in this study sample (α = 0.86).

The FNHRQOL-SF was used to measure individuals' HRQoL.[5] This 13-item measure has five dimensions: physical, mental, and social health, as well as life satisfaction and environment. Participants answer questions in these five domains with a 7-point Likert-type scale ranging from 1 (never or almost never) to 7 (always or almost always). In other measures of HRQoL health is not divorced from function. These measurement tools create a bias against individuals with disability who may have less functional ability, but not necessarily poorer health. Thus, the FNHRQOL measure is unique because it removes bias against individuals with disabilities in the HRQoL domain, thereby measuring HRQoL distinct from function and with regard to the process of adapting to disability.[5] This measure includes questions such as, "Were you satisfied with your daily life in general?" "Did your life have purpose?," and "Did you get where you needed to go?" Three items were reverse coded, and the total mean score was used to obtain perceived HRQoL, with a higher score associated with a higher perceived HRQoL. The short form demonstrated good internal consistency in this study (α = 0.91).

Table 1
Demographics of participants.

Demographics	Percent	Frequency (n)
Sex (n = 259)		
Male	15.77%	41
Female	84.23%	218
Race (n = 258)		
White	90.31%	233
Black	1.55%	4
Native American	1.55%	4
Latino	3.88%	10
Not Listed	0.78%	2
Did not wish to disclose	1.94%	5
MS Type (n = 258)		
Relapse-remitting	73.26%	189
Secondary-progressive	18.22%	47
Primary-progressive	7.36%	19
Progressive-Relapsing	1.16%	3
Time since last acute attack (n = 247)		
Less than 3 months	22.67%	56
3 to 6 months	10.12%	25
7 to 9 months	4.86%	12
10 to 12 months	8.50%	21
Greater than 12 months	53.85%	133
Health Status (n = 258)		
Poor	5.81%	15
Fair	28.68%	74
Good	36.43%	94
Very good	24.03%	62
Excellent	5.04%	13
Employment (n = 258)		
Employed for wages	38.37%	99
Self-employed	3.88%	10
Out of work greater than 12 months	6.20%	16
Out of work less than 12 months	1.55%	4
Homemaker	5.81%	15
Student	1.16%	3
Retired	7.75%	20
Unable to work	35.27%	91
BMI (n = 248)		
<18.5	2.02%	5
18.5—24.9	40.32%	100
25.0—29.9	26.02%	67
≥30.0	30.65%	76

Note: Differences in *n* resulted when participants did not respond to certain demographic questions. Multiple Sclerosis (MS); Body Mass Index (BMI).

Procedures

This study employed a convenience sample of individuals with MS. Participants were recruited from the National MS Society's local chapters and support groups, and from other MS advocacy groups and exercise programs through email, printed flyers, social media advertisements, and in-person survey distribution.

Recruitment occurred over four months. For the email recruitment, an initial contact email was sent out to 21 individuals with (1) a description on the study, (2) a link to complete the online questionnaire, and (3) a deadline to complete the questionnaire. After 10 days, a second reminder email was sent out with the link to the questionnaire. A final follow-up email and thank you was sent out 10 days after the second contact.

Additionally, a member of the research team attended MS events in the area (i.e. informational events and conferences) to distribute flyers and printed surveys with postage paid return envelopes, and collect email addresses of individuals interested in participating. Approximately 90 printed survey packets were distributed to individuals attending MS events and clinics and 12 were returned. Printed flyers with a description of the study, a link to complete the survey, and contact information of the research team were also distributed to social support groups and exercise programs.

Online advertisements were posted through social media outlets (Facebook), posted to MS advocacy webpages, and distributed through e-blasts and e-newsletters. The National MS Society, the Multiple Sclerosis Foundation, and the Multiple Sclerosis Association of America all assisted with advertising the research study through their webpages and list servers. For the online social media recruitment, advertisements were posted with a brief description of the study and target population, a link to complete the survey, and information to contact the research team. Advertisements were reposted every 10 days for three recruitment attempts. A University Institutional Review Board approved all study activities, and informed consent was obtained from all participants.

Data analyses

A total of 339 participants were recruited. Sixteen participants were not within the 18—65 age range and one participant did not have a medical diagnosis of MS. Bennett[21] and Rubright, Nandakumar, and Glutting[22] recommend excluding participants with greater than 10% missing data from the analyses, as large amounts of missing data can impact the validity of results. Therefore, after participants not meeting inclusion criteria were removed, participants who had more than 10% missing data (n = 63) were also removed. This resulted in 259 participants being retained for the final model testing analysis. The final participants were comprised of 3.1% (8) from printed survey packets, 7.7% (20) from email recruitment, 54.4% (141) from social media advertisement, and 34.7% (90) from flyer distribution.

Demographic data (age, sex, race/ethnicity, BMI, overall health status, time since last acute attack, and duration and type of MS) were analyzed for descriptive statistics, including means and standard deviations. Normality was checked through tests of skewness and kurtosis, and results showed that data were not normally distributed (skewness: −0.42, p < 0.006; kurtosis = 3.36, p < 0.2). Therefore, to obtain a more accurate representation of the relationships among variables, the bootstrap resampling method was used with 1000 random resamples and 95% bias-corrected confidence intervals.[23,24] Correlation analyses were first conducted to identify the interrelationships among the model variables.

A path analysis was conducted to address the hypothesis that for individuals with MS self-compassion would directly influence HRQoL and indirectly influence HRQoL via resilience. Path analysis allows for the specification of the relationships among variables, and the calculation of indirect effects. The independent variable was self-compassion, the dependent variable was HRQoL, and the mediating variable was resilience. In the mediation analysis, the direct effect is noted as c' and the indirect effects are the product of "a" and "b". In the indirect effect, "a" is the path from the independent variable to the mediating variable, and "b" is the path from the mediating variable to the dependent variable. Total effect (c) is the sum of the direct and indirect effects (ab + c' = c).

Model fit was assessed using the Chi-square (χ^2) test, comparative fit index (CFI), Tucker-Lewis fit index (TFI), root mean square error of approximation (RMSEA), and the standardized root mean square residual (SRMR). While acknowledging fit indices are depended on sample size, Hu and Bentler[25] recommend a cutoff value close to 0.95 for fit indices (CFI and TFI). They also recommended a cutoff of 0.09 for SRMR when used in combination with RMSEA > 0.06.[25] For RMSEA, values less than 0.05 indicate a close fit, values in the range of 0.05—0.08 indicate a fair fit, values in the range of 0.08—0.10 indicate a mediocre fit, and values greater than 0.10 indicate a poor fit.[26,27]

Table 2
Correlation of model variables and descriptive statistics.

Variable	1	2	3	Mean	SD
1.Resilience	—	0.59*	0.60*	3.60	0.64
2.Self-Compassion		—	0.65*	3.32	0.76
3.Health-Related Quality of Life				4.89	1.24

Note: *$p < 0.0001$; coefficient α shown on diagonals.

Results

The results of the correlation analyses indicated that self-compassion was significantly and positively associated with HRQoL ($r = 0.65$, $p < 0.0001$) and resilience ($r = 0.59$, $p < 0.0001$). Resilience was significantly and positively associated with HRQoL ($r = 0.60$, $p < 0.0001$). Descriptive statistics and the correlations of model variables are presented in Table 2.

The goodness-of-fit statistics were: $\chi2(4) = 15.50$, $p = 0.004$; CFI = 0.99; TLI = 0.97; RMSEA = 0.10; and, SRMR = 0.02. In the mediation model, self-compassion and resilience explained approximately 51% of the variance in HRQoL and self-compassion explained 40% of the variance in resilience. The results of the mediation analysis indicated that self-compassion not only has a direct effect on HRQOL ($\beta = 0.49$, $p < 0.0001$, CI = 0.37−0.61), but also an indirect effect on HRQOL through resilience ($\beta = 0.18$, $p < 0.0001$, CI: 0.17, 0.47). The total effects of self-compassion on HRQoL were significant ($c = 0.67$, $p < 0.0001$). Results for the tested model are depicted in Fig. 1 and Table 3.

Discussion

The purpose of this study was to contribute to the conceptual understanding of the nature of the relationships among self-compassion, resilience, and HRQoL for individuals with MS. Current literature has suggested that self-compassion and resilience are important factors that positively influence HRQoL. This study examined not only the direct relationship between self-compassion and HRQoL, but also whether self-compassion was indirectly associated with HRQoL. Findings revealed that self-compassion was directly related to HRQOL and indirectly related to HRQoL through resilience.

In this study, self-compassion had a significant direct effect on HRQoL, which was expected. Studies have shown support for self-compassion's direct influence on overall wellness in the general population.[28] One study examined the role of self-compassion as a moderator between physical health and subjective well-being in the elderly.[29] According to the authors, the results showed that in individuals with relatively good physical health, their perception of their subjective wellness was high regardless of their level of self-compassion. However, in participants with poorer physical health and disability, self-compassion was positively related to greater subjective wellness. Additionally, the individuals who were more self-compassionate were more willing to use assistive devices such as mobility aides and hearing aids. The results from this study suggest that when living with disability or chronic condition, self-compassion may play a critical role in bolstering one's perception of wellness or HRQoL, and willingness to seek support.[29]

The stated hypothesis was supported in that resilience partially mediated the relationship between self-compassion and HRQoL. The findings of this study are consistent with other recent literature linking self-compassion with resilience among individuals with chronic disease.[6,12,29] Self-compassion has been related to improving individuals' resilience and coping related to life stressors such as chronic pain and disability.[13,29] Furthermore, resilience has been shown to mediate the relationship between MS symptoms, such as fatigue and pain, and quality of life.[14] Self-compassion may provide a lens through which individuals perceive their condition and relate to themselves, thereby promoting resilience. This may happen as individuals who engage in self-compassion take a more balanced or mindful view of their condition and feel less isolated when debilitating symptoms arise, allowing individuals to reframe negative perceptions and improve their ability to rebound from exacerbations of symptoms or disabling events.

Based on the results of this study, it is reasonable to expect that engaging in self-compassion may provide a strategy to cope with debilitating conditions and reframe perceptions of personal health for individuals with MS. Additionally, increasing resilience may help individuals overcome stressful and traumatic events and experience quality of life with disability.[6] Resilience and self-compassion are both modifiable constructs that can be targeted
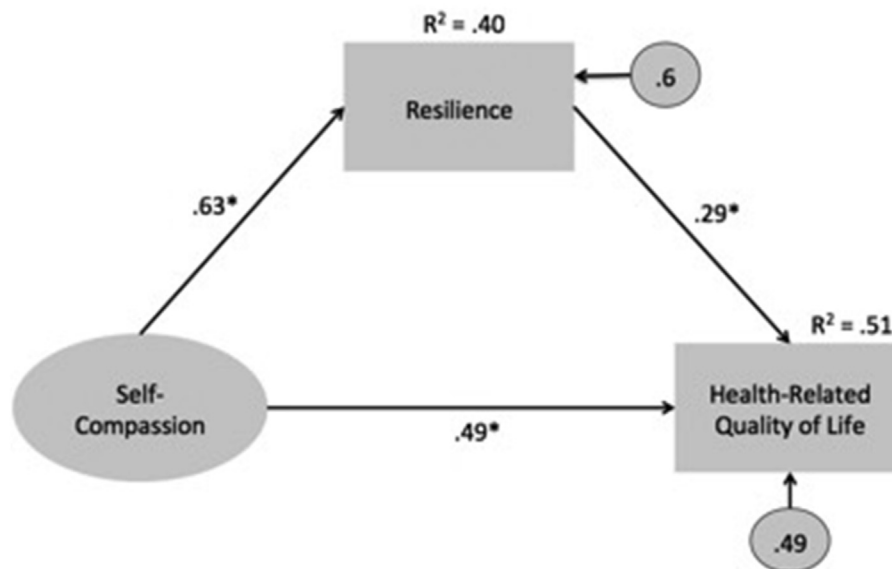

Fig. 1. *Mediation model of self-compassion and HRQoL*. NOTE: *p < 0.0001. Path coefficients were denoted above/next to the lines. Multiple square correlation shows variances explained by resilience and HRQoL and is denoted the above the variable.

Table 3
Path coefficients, variance, standard error, and confidence intervals.

Path	β	R^2	SE	BC CIs
Self-Compassion → HRQoL (c')	0.49*	—	0.06	0.37–0.61
Self-Compassion → Resilience (a)	0.63*	0.40	0.04	0.55–0.71
Resilience → HRQoL (b)	0.29*	—	0.06	0.17–0.41
Self-Compassion → HRQoL, mediated by Resilience (ab)		0.51	0.06	0.17–0.47

NOTE: *p < 0.0001. Variance explained (R^2), standardized regression coefficients (β), standard error (SE), and bias-corrected confidence intervals (CIs); Health-related quality of life (HRQoL).

by programs seeking to improve overall wellness. Future interventions could use strategies to foster social connection, such as peer support groups, and mindfulness practices to increase resilience through engagement in self-compassion. Support groups may help facilitate connection to others experiencing similar symptoms and help individuals feel less isolated when relapsing symptoms occur. A recent focus group study that evaluated participants' experiences with an intervention aiming to increase physical activity engagement and social support among a group of individuals with MS found that participants felt more connected and benefitted from the support of other participants, rather than from those who did not have MS.[30] Additionally, teaching individuals with MS mindfulness practices may enable them to keep a sense of perspective, combat negative thoughts and feelings, and promote flexibility and positive coping strategies when they are experiencing chronic fatigue or mobility impairments. These strategies may include mindfulness meditation, journaling, and stress management. Lastly, increasing resilience may be approached through teaching specific coping mechanisms and positive adaptations related to the uniquely unpredictable nature of MS conditions. These may include positive cognitive restructuring and problem solving, as suggested by Skinner and colleagues.[31] Community health workers and other health care providers can participate in community education on mindfulness-based therapies, and facilitate support groups that promote components of self-compassion. Additionally, they may include mindfulness-based practices in their counseling with patients.

While this study had encouraging results, readers should be cautious with extrapolating these findings to other groups of individuals with disability. Relationships should be tested among populations with chronic conditions and mobility impairments, such as Parkinson's, Amyotrophic Lateral Sclerosis (ALS), Muscular Dystrophy, Fibromyalgia, Rheumatoid Arthritis, and Spinal Cord Injury. This study was based on a convenience sample of individuals who participated in education and advocacy groups online and in person, as well as MS-specific support groups and exercise groups. The participants in this study may not have been reflective of the national population of individuals with MS across some demographic statistics as they were recruited from advocacy organizations and health education workshops. These participants may have been more motivated and confident in their ability to manage their condition, may experience more resilience, and have better perceptions of their health, and therefore may not entirely reflect the greater national MS population. Furthermore, results from other national datasets and longitudinal MS studies have documented the prevalence of MS in women is approximately three times higher than in men, with 87–95% of their sample being white.[32–34] Our study had a slightly higher distribution of females to males (approximately 4:1), and a similar racial and employment distribution. Additionally, this sample had more individuals with relapse-remitting MS (73.26%) than another study with a large longitudinal sample (57.9%).[33] Because the majority of individuals were recruited online through social media advertisements and flyers, it was not possible to calculate the return rate for how many

individuals viewed the online survey and how many participated. Additionally, the data in this study were cross-sectional, which limits the ability to determine causality.

The findings from this study have encouraging implications for populations with MS. Because individuals with MS face acute attacks, and often sudden worsening of symptoms and accumulation of disability, they endure greater psychological challenges and negative affect than the general population. Self-compassion and resilience are constructs that may help to re-shape how individuals with chronic conditions perceive their state of being and ability, as well as their HRQoL.

Conflict of interest statement

The authors have no conflicts of interest to declare. This manuscript has not been submitted to another journal.

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