

Mapping Resilience: Structural Equation Modeling of Psychological Resilience in Multiple Sclerosis Care Partners

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ABSTRACT

BACKGROUND: Care partners are essential supports to individuals with multiple sclerosis (MS). Both negative and positive outcomes associated with the caregiving role have been reported. Psychological resilience may be an important factor influencing the MS caregiving experience, but an MS-specific model of care partner resilience has yet to be established. This study sought to explore an explicit model of MS care partner resilience.

METHODS: Cross-sectional data from 471 Canadian MS care partners were collected via an online survey. Confirmatory factor analysis (CFA) and structural equation modeling (SEM) were used to test measures within a hypothesized model of resilience. Resilience was measured using the 25-item Connor-Davidson Resilience Scale.

RESULTS: Following CFA, the hypothesized model was simplified due to the poor fit of several variables. The final model yielded a moderate SEM fit ($\chi^2 = 6030.95$, $P < .01$). Being a woman was associated with greater caregiving tasks ($\beta = 0.53$, $P < .001$) and poorer spiritual health ($\beta = -0.35$, $P < .001$). Spiritual health, but not caregiving tasks, had a positive impact on both positive ($\beta = 0.48$, $P < .01$) and negative coping ($\beta = 0.49$, $P = .01$). Quality of life and resilience did not have relationships with other variables in the model. However, quality of life had a positive, unidirectional influence on resilience ($\beta = 0.83$, $P < .01$).

CONCLUSIONS: Our findings indicate that spiritual health is an important predictor of coping and should be further explored in MS care partners. Quality of life may act as a precursor to resilience within MS care partners. Further research and exploration into MS care partner resilience is warranted to confirm this exploratory model.

Int J MS Care. 2023;25(6):245-251. doi:10.7224/1537-2073.2023-078

Multiple sclerosis (MS) causes progressive physical and cognitive disability, which can make daily tasks difficult for individuals living with the disease.¹ Friends and family members of individuals with MS, herein referred to as care partners, provide over three-quarters of MS care, and are key resources helping individuals with MS live safely and independently within the community.² While care partners are essential, the added stress associated with providing care can manifest negative caregiving outcomes.³ In some cases, MS care partners report reduced perceived health and quality of life due to their role and demonstrate higher levels of stress, depression, and anxiety than the general public.^{3,4} The MS caregiving experience, however, is not ubiquitously negative; care partners also report benefits to caregiving, including enhanced relationships, feelings of mastery, and confidence.⁵ Currently, the mechanisms driving positive and negative caregiving outcomes in MS care partners are poorly understood.

Psychological resilience may be an important factor when considering caregiving outcomes. Resilience is broadly defined as a process of adapting to stress or trauma, or being able to “bounce back” from adversity.⁶ In the caregiving context, resilience is more aptly defined as the ability to maintain good psychological well-being amid rigorous care demands.⁷ Resilience has been positively associated with quality of life and well-being among care partners of individuals with a chronic illness.⁸ In the literature specific to care partners, resilience has been characterized as both a state and a trait, with conceptualizations that are often ambiguous and incongruent among various studies.⁹ Only recently has resilience in an MS-specific caregiving context been examined and defined as a cycle of responses to the evolving stressors of the caregiving role made to maintain caregiver well-being.¹⁰

Factors that may promote or diminish resilience have been previously explored in various caregiving populations.

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Note: Supplementary material for this article is available online at IJMSC.org.

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At the individual level, characteristics like younger age,¹¹ male sex,¹² and high spirituality¹³ have been positively associated with resilience among caregivers of individuals with stroke and dementia. Much of the influence of these variables may be mediated by the effects of social support and coping.⁷ Among MS care partners, social support has been associated with better mental health-related quality of life¹⁴ and has been found to be a significant predictor of care partner resilience.¹⁵ Coping is a core mediator of adjustment in the caregiving role.¹⁶ High levels of resilience among dementia caregivers have been associated with the use of active, problem-based coping and refraining from the use of avoidance-based coping strategies.^{7,8}

Notably, MS care partners represent a unique subset due to the specific characteristics of the disease itself. The early age of onset, variable disease course, symptomatic heterogeneity, and uncertainty in progression pose distinct challenges to both individuals with MS and their care partners.⁵ The challenges faced by MS care partners are likely different from those reflected in most caregiving literature, which is predominantly focused on caregivers of older and dementia populations. Therefore, investigation of MS care partners as a potentially distinct population is both warranted and necessary.

Current MS care partner literature broadly focuses on associations with negative caregiving outcomes, like burden and distress.¹⁷ Little is known about resilience in the MS caregiving context, including what influences it and how it may sustain care partner well-being. The current study aims to expand our understanding of resilience in MS care partners and clarify ambiguities in existing resilience literature. Specifically, this study explores an explicit model of resilience among MS care partners related to care partner quality of life, stressors, and resources.

METHODS

Design

This study uses cross-sectional data from the third time point of a longitudinal study of resilience among MS care partners. Information on the initial study protocol and baseline data has been reported by Cardwell et al.¹⁵ The study protocol was approved by the University of Ottawa Science and Health Sciences Research Ethics Board [H-02-20-5338]. All participants provided informed consent.

Participants

Participants in the present sample included MS care partners living in Canada enrolled in a longitudinal study of care partner resilience.¹⁵ Eligible care partners were 18 years of age or older; currently providing physical, emotional, or informational assistance to a person living with MS; a resident of Canada; and willing to complete an annual online survey in English for a 3-year period. Care partners were excluded if they reported difficulty with memory, calculation, or reasoning that significantly interfered with their daily functioning. Four hundred

seventy-five participants who completed the previous 2 time points of data collection were invited to complete a third and final data collection point (ie, year 3 of the annual questionnaire). Participation was via an online survey using an institutional SurveyMonkey (Momentive) platform between June 2022 and August 2022. The survey took an estimated 30 minutes to complete, and respondents received up to \$10 in the form of an online gift card as compensation for their participation.

Model Development

The theoretical model proposed herein was influenced by the ecological resilience model that recognizes influences on resilience at personal, interpersonal, and societal levels.⁶ The organization of variables within the model was informed by a qualitative meta-synthesis of caregiving and quality-of-life studies in MS,⁵ which outlined a process whereby stressors (eg, caregiving demand, sociodemographic factors) are modified by care partner resources (eg, social support, coping resources, motivations) to manifest care partner well-being and quality of life. Justification for relationships between variables was drawn from existing caregiving literature and prioritized MS-specific findings when possible (see supplementary materials). A conservative approach was maintained, while hypothesizing relationships between variables to minimize the number of constraints on the model. This approach ensured an underidentified model that reduced the potential for spurious associations and statistical bias.

Measures

Care Partner Stressors

Sociodemographic characteristics of participants were collected, including age, gender, education level, race, marital status, income (as a category), and employment. Care partners' relationships with their care recipients and care partner-reported Patient Determined Disease Steps (PDDS)¹⁸ scores were also collected. The Caregiving Task Inventory for MS (CTIMS) was used to characterize the caregiving tasks performed by participants.¹⁹ The CTIMS is a 26-item, MS-specific questionnaire that evaluates how often a care partner must assist their care recipient with specific tasks, ranging between 1: *no help* and 5: *lots of help*. The scale contains 4 subscales: activities of daily life, instrumental care, psycho-emotional care, and sociopractical care. Higher scores indicate that more care is being provided, with total scores ranging between 26 and 130.¹⁹

Care Partner Resources

The Spiritual Health and Life-Orientation Measure (SHALOM) was used to assess participants' spiritual health and well-being.²⁰ This measure consists of 20 statements across personal, interpersonal, environmental, and transcendental spirituality subscales. Scores for each question range between 1: *very low* and 5: *very*



Spiritual health may play a role in coping among multiple sclerosis (MS) care partners and should be considered when assessing care partner well-being.

In the present sample, MS care partner resilience and quality of life were not associated with positive or negative coping strategies.

Quality of life may be predictive of resilience in MS care partners. ■

high. Higher scores indicate better spiritual well-being, with total scores ranging between 20 and 100.²⁰ The Coping with MS Caregiving Inventory (CMSCI) assessed the styles of coping used by participants in their caregiving roles. The 34-item questionnaire contains 5 subscales measuring reliance on problem- and emotion-focused coping strategies including avoidance, practical assistance, supportive engagement, criticism/coercion, and positive reframing. Items are scored on a 5-point scale between 1: *never* and 5: *very often*. Higher scores indicate more frequent use of coping methods, with total scores ranging between 34 and 170.²¹ The 12-item Interpersonal Support Evaluation List (ISEL-12) evaluated the perceived level of social support available to care partners. The scale is divided into 3 subscales measuring appraisal, belonging, and tangible support. Items are rated on a 4-point scale between 1: *definitely false* and 4: *definitely true*. Higher scores indicate greater perceived social support, with total scores ranging between 12 and 48.²² The 27-item Benefit Finding in Multiple Sclerosis Caregiving Scale (BFiMSCS) was used to assess the degree to which care partners attribute positive outcomes or benefits to their caregiver role. Statements identifying areas of spiritual, interpersonal, and personal growth are rated on a 3-point scale ranging between 1: *not at all* and 3: *a great deal*. Higher scores indicate greater perceived benefit of the caregiving role, with total scores ranging between 27 and 81.²³

Care Partner Well-Being

The Caregiver Health-Related Quality of Life in Multiple Sclerosis (CAREQOL-MS) scale assessed care partner health-related quality of life. The CAREQOL-MS contains 24 items divided into 5 subscales: physical burden and global health, social impact, emotional impact, need for help, and emotional reaction.

Each item is scored between 1: *never* and 5: *always*. Higher scores indicate better quality of life, with total scores ranging between 24 and 120.²⁴ The 25-item Connor-Davidson Resilience Scale (CD-RISC 25) was used to measure resilience among care partners. Topics addressed by the scale include personal competence, tolerance of negative affect, positive acceptance of change, control, and spirituality. The measure contains 25 items; each is scored between 0: *not true at all* and 4: *true nearly all of the time*, with higher scores indicating higher levels of resilience and total scores ranging between 0 and 100.²⁵

Data Analysis

All data were first inspected for missing values and outliers. Kolmogorov-Smirnov tests were used to test normality of the variables to be used in subsequent factor analysis. Descriptive statistics were calculated to summarize the sample characteristics. Pearson's correlation coefficients were calculated to characterize relationships between variables. All preliminary data analyses were conducted using SPSS version 28.0 (IBM SPSS Statistics).

Assessing Measure Fit

Confirmatory factor analysis was used to test the fit of scales included in the hypothesized model. Established subscales for each measure were tested as single factors before being loaded collectively onto a single latent variable. Testing the fit of each measure in this stepwise fashion ensured that the latent variables included in the structural equation modeling (SEM) model were statistically sound. All analyses were completed using a maximum likelihood with a robust standard error (MLR) estimator. The following indexes were used to assess model fit: χ^2 values, root mean square error of approximation (RMSEA), comparative fit index (CFI), Tucker-Lewis index (TLI), standard root square mean residual (SRMR), and the loadings of individual items within each factor. Good fit was defined as: RMSEA value below 0.06; CFI and TLI values above 0.9; SRMR value below 0.08; and significant factor loadings ($P < .05$).²⁶

Assessing Model Fit

If variables produced a satisfactory factored solution, they were entered into the hypothesized structural equation model (FIGURE S1). Due to the complexity of the proposed model, variables were entered using a stepwise approach. The initial model that was tested included only latent variables to ensure convergence. Observed variables were then added. Finally, education and age were added as moderating variables. Modeling analyses were conducted using MPlus version 8.9 (Muthén & Muthén).

RESULTS

Of the 471 care partners from across Canada, 50.5% were women and reported a mean age of 40.0 years ($SD = 7.2$). A summary of the sample demographics is provided in

TABLE 1. Participants reported a mean resilience score of 58.8 (SD = 8.2), and a mean quality of life score of 79.0 (SD = 8.6). Summary statistics of all other scales used in the structural analyses are presented in **TABLE S1**.

Assessing Measure Fit

Confirmatory factor analysis yielded a good fit for spiritual health ($\chi^2 = 468.67$, RMSEA = 0.06, CFI = 0.90, TLI = 0.89, SRMR = 0.05) and caregiving task scales ($\chi^2 = 785.94$, RMSEA = 0.07, CFI = 0.90, TLI = 0.89, SRMR = 0.05). The loadings of all items in each scale were consistently positive and significant ($P < .001$).

A model loading the 5 coping subscales onto a single secondary factor did not converge; therefore, the model was split into a positive coping subscale ($\chi^2 = 117.024$, RMSEA = 0.06, CFI = 0.91, TLI = 0.88, SRMR = 0.05) of subscales associated with a productive coping technique and positive caregiving outcomes.²¹ This variable included positive reframing and supportive engagement subscales. A negative coping subscale ($\chi^2 = 432.12$, RMSEA = 0.08, CFI = 0.78, TLI = 0.74, SRMR = 0.07) of subscales associated with an unproductive coping technique and negative caregiving outcomes included avoidance and criticism/coercion subscales. The practical assistance subscale was removed due to poor fit when added to the positive coping model. Given the low disability level of care for recipients in the current sample, the relevance of items within the practical assistance subscale (ie, purchasing adaptive items, using respite care) was considered potentially low, supporting its removal from coping factors. Based on modification indexes provided by the MPlus software, correlational relationships between highly correlated single items in the same subscale were considered for theoretical plausibility by the authors. A single correlation was added between items 1 (*I talk through issues with _____ in an attempt to solve problems*) and 7 (*I accept that this is how it is*) on the supportive engagement subscale. Two additional correlations were added in the avoidance subscale between items 21 (*I try to improve our financial situation*) and 22 (*I try to snap _____ out of it*), and between items 19 (*I keep my problems to myself*) and 33 (*I drink or smoke more*) to modestly improve fit.

For both the benefit finding and social support scales, convergence failed due to a lack of variance in item scores and poor correlations within items. After several attempts at multi- and single-factor solutions, both scales were removed from the model.

Resilience converged onto a single factor with a poor fit ($\chi^2 = 1124.638$, RMSEA = 0.08, CFI = 0.60, TLI = 0.57, SRMR = 0.09). Following several attempts to improve fit using multifactor solutions and correlations between items, we decided to include resilience in the model as an observed variable using sum scores for each participant. Likewise, the 5 subscales of quality of life converged with a poor fit ($\chi^2 = 830.72$, RMSEA = 0.10, CFI = 0.67, TLI = 0.63, SRMR = 0.09). Thus, the summed scores of the total scale were

TABLE 1. Summary of Participant Demographics

Variable	Participants (N = 471)
Age, mean (SD)	40.0 (7.2)
Gender, n (%)	
Man	233 (49.5)
Woman	238 (50.5)
Race, n (%)*	
White	293 (53.1)
Black	162 (29.3)
Latin American	18 (3.3)
Educational attainment, n (%)	
High school/GED	26 (4.7)
College/CEGEP	358 (65.1)
Technical or trade school	43 (7.8)
Bachelor's degree	37 (6.7)
Master's degree	4 (0.7)
Doctoral degree	3 (0.5)
Employment, n (%)	
Full-time	438 (79.6)
Part-time	2 (0.4)
Unemployed	31 (5.6)
Household income, n (%)	
\$20,000-\$49,999	262 (55.7)
\$50,000-\$99,999	199 (42.1)
\$100,000-\$149,999	6 (1.3)
\$150,000 or more	4 (0.9)
PDDS of care-recipient, median (IQR)	3 (3)
Relation to care-recipient, n (%)	
Spouse/common-law	261 (55.4)
Parent	206 (43.7)
Child	3 (0.6)
Sibling	1 (0.2)
Cohabitation with care-recipient, n (%)	
Yes	468 (99.4)
No	3 (0.6)

PDDS, Patient Determined Disease Steps

*Participants could select multiple responses.

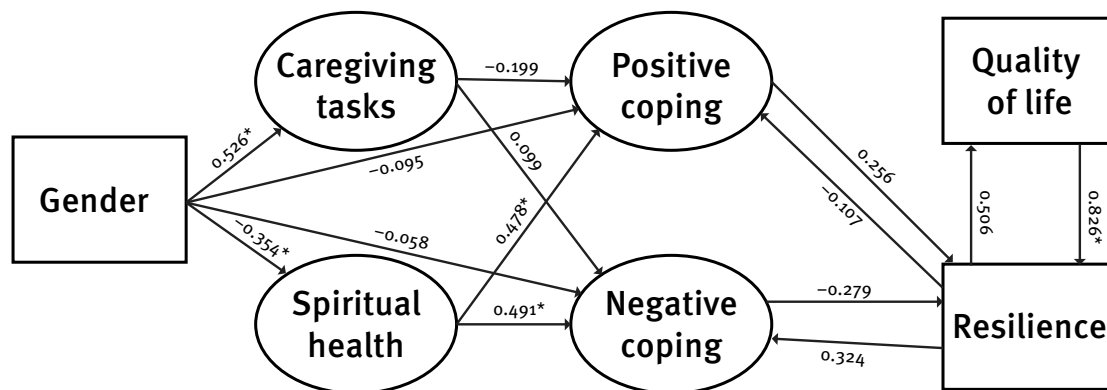
used as an observed variable in lieu of a factored solution. A square-root transformation was applied to both variables to improve their distributional properties and transform the variance to a scale more comparable to the other variables within the model.

Assessing Model Fit

The basic model containing only latent variables with acceptable factor loadings (ie, caregiving tasks, spiritual health, positive and negative coping) converged with a moderate fit. The addition of observed variables (ie, resilience and quality of life) to the model did not largely affect fit indexes. When age was added to the model as a moderating variable, the fit worsened so age was removed from the model. When education was added as a moderator, convergence was lost, so education was also removed from the model.

The final model (**FIGURE 1**) demonstrated a moderate fit, as indicated by fit indexes ($\chi^2 = 6030.95$, $P < .01$, RMSEA =

FIGURE 1. Final Model of Resilience in Multiple Sclerosis Care Partners



Note: Path coefficients are shown.
 *Denotes significant pathways ($P < .05$).

0.05, CFI = 0.78, TLI = 0.77, SRMR = 0.15). The χ^2 value was significant and several fit indexes, including the CFI, TLI, and SRMR, did not meet but approached a priori standards for good fit.

Gender was identified as a significant variable within the model; being a woman was associated with greater caregiving tasks ($\beta = 0.53, P < .001$) and poorer spiritual health ($\beta = -0.35, P < .001$). Among the mediating variables, caregiving tasks demonstrated no relationship with positive coping ($\beta = -0.20, P = .09$) or negative coping ($\beta = 0.10, P = .59$). Conversely, spiritual health was significantly associated with greater positive ($\beta = 0.48, P < .01$) and negative ($\beta = 0.49, P = .01$) coping. Neither positive ($\beta = 0.26, P = .23$) nor negative coping ($\beta = -0.28, P = .09$) was associated with resilience.

The only significant association among outcome variables was a positive effect of quality of life on resilience ($\beta = 0.83, P < .01$). This association was not bidirectional ($\beta = 0.51, P = .29$). A model retaining only significant associations is presented in **FIGURE S2**.

DISCUSSION

We sought to explore an explicit model of resilience in MS care partners as it relates to their quality of life, stressors, and resources. The hypothesized model required several modifications due to the poor fit of confirmatory factor analyses. The final model provided a moderate fit and demonstrated significant relationships between care partner stressors and resources, and quality of life and resilience. While the model itself is exploratory and requires further research to confirm the significant relationships identified, our findings provide some insight into the potential factors promoting MS care partner quality of life and well-being.

The current sample (50.5% women, mean age = 40.0) is comparable to MS caregiving samples reported in the

literature,¹⁷ which tend to be middle-aged women. Care partners in the present study reported low levels of resilience (mean score = 58.8) relative to previous samples of the general public (mean score = 80.4).²⁵ Mean quality of life scores (79.0), however, are higher than those reported in previous samples of MS care partners (mean scores = 61.7, 59.0).^{24,27}

Spiritual health positively impacted the use of both positive and negative coping strategies. Spiritual health often serves as an early resource to cope with the demands of caregiving.²⁸ For care partners, spiritual or religious practices promote feelings of cohesion and support them in seeking help from friends or family members in times of heightened stress.¹³ These actions align with aspects of positive reframing and positive engagement strategies in the positive coping variable, including “I talk to others about the problem” and “I seek assistance from others.” Notably, this finding emphasizes the potential importance of social structures in coping processes. In addition, spirituality may contribute to meaning-making and feelings of comfort that promote active coping strategies, including positive reframing.²⁸

As a counterpoint to these positive effects, a study on stroke care partners reported that religion may be used as a temporary escape from the stress of caregiving and may have a negative impact on mental health and well-being.²⁹ The use of religion or spirituality as an escape mechanism may explain the present positive association between spiritual well-being and negative coping, as the avoidance subscale addresses the use of escape mechanisms among care partners. Although our findings highlight the importance of spiritual well-being as a care partner resource, wherein it may promote the use of positive coping strategies, the potential for avoidant behaviors must be mitigated. Additional investigation into the role of spiritual health is warranted to further explore its effect on coping and importance for MS care partner well-being.

The final model established a unidirectional relationship from quality of life to resilience. In the literature, resilience is often viewed as both a predictor of well-being and an outcome of caregiving.⁹ The relationship between quality of life and resilience in an MS-specific caregiving population has not previously been explored. The present model suggests that quality of life is not a result of but a precursor to resilience in care partners of individuals with MS who have low disability. Therefore, addressing factors affecting care partners' quality of life may be an important first step in promoting resilience. Additionally, the final model had no significant relationship between coping and resilience. This lack of association is surprising, as resilience has been closely associated with coping processes, both in definition and operationalization.⁸ This exploratory finding should be further investigated as it could have important implications as to how resilience is conceptualized and how it should be modified in future research.

Gender was a strong predictor of caregiving tasks. The gender disparity in care provision among caregivers has been well documented. Women more often take on caregiving roles and report greater caregiving intensity than men.³⁰ Our current findings suggest that this disparity is also present among MS care partners. Caregiving tasks, however, did not have a significant influence on coping in the final model. This finding is contrary to a previous study that demonstrated increased reliance on negative coping strategies in the presence of high care demands in activities of daily living.³¹ The same study also associated positive coping with heightened psycho-emotional care provision.³¹ The lack of a relationship between caregiving tasks and coping reported herein suggests that the caregiving role may not influence coping strategies to the degree previously reported. A reassessment of the impact of caregiving tasks on coping in MS care partners may be warranted to further investigate potential underlying factors. Benefit finding, which was removed from our final model, is a hypothesized mediator between caregiving tasks and coping.³¹ The inclusion of benefit finding in future research may be helpful to understand coping dynamics.

Overall, our findings suggest that characteristics of MS care partners themselves, not aspects of their caregiving role, may be more critical to coping and resilience processes. This is demonstrated by the significance of spiritual well-being and gender within coping pathways and the influence of quality of life on resilience. Supporting quality of life in all aspects of the caregiving role may have downstream benefits for building MS care partner resilience.

It is important to note that the findings of the present study are exploratory and are subject to several limitations. First, the fit of the final model is only moderate and does not meet all standards for establishing goodness of fit in SEM. Moreover, due to poor fit, the outcome variables of interest (ie, resilience and quality of life) were included in

the model as observed variables instead of as latent factors, which increases the potential for measurement error and reduces the precision of analyses. Thus, findings from the present study must be confirmed and expanded upon through future research.

Second, several measures used in the present analysis could not be included in the final model due to poor fit during confirmatory factor analysis. Issues with factor loading could be due to low variance in item responses within the scales analyzed, but the relevance of the measures used may also have been limited due to characteristics of the sample. Noncaregiver-specific scales, particularly the ISEL-12 that measures social support, may not resonate with MS care partners.

Third, issues with the fit of the scales could reflect the low disability status of care recipients. Care recipients had a care partner-reported median PDDS score of 3 (IQR = 3), indicating gait disability when without assistance. The low disability status of care recipients posed a particular issue for measuring coping: the practical assistance subscale is heavily focused on providing mobility assistance that may not be required by many of the care recipients in the current sample. Consideration should be given to creating and selecting measures for MS caregiving populations given the potential heterogeneity in the care needs and caregiving tasks that they manage. The unique progressive nature of MS should be accounted for in future measure development to consider potential differences in disability and caregiving support among individuals living with MS.

CONCLUSIONS

We proposed an exploratory model of resilience in MS care partners. The final model yielded a moderate fit and demonstrated significant relationships between care partner stressors and resources. Spiritual health had a positive effect on the use of both positive and negative coping strategies. While hypothesized relationships between care partner resources and resilience and quality of life were not significant, quality of life had a unidirectional influence on resilience. Our findings propose that promoting quality of life may have benefits for MS care partner resilience. Investigation into additional factors that may influence MS care partner resilience and quality of life across the spectrum of care support is warranted to expand upon and improve the fit of the current model. ■

DISCLOSURES: The authors have no conflicts of interest to disclose.

FINANCIAL AND MATERIAL SUPPORT: The present study was funded by a University of Ottawa Faculty of Health Sciences Development Grant.

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