

# Supportive Interventions for Caregivers of Individuals With Multiple Sclerosis: A Systematic Review

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## ABSTRACT

**BACKGROUND:** Caregivers of individuals with multiple sclerosis (MS) are key members of the treatment team. Their needs and challenges should be met as interventions can be effective in improving not only their own health, well-being, and quality of life but also that of those they care for. The aim of this systematic review was to investigate supportive interventions for caregivers of individuals with MS.

**METHODS:** We conducted a database search of PubMed, Google Scholar, Science Direct, Scopus, and the Cochrane Library from 2000 to 2021. English-language studies that examined interventions administered directly to caregivers of individuals with MS and evaluated various outcomes were included. The Downs and Black checklist was used to assess the methodological quality of included studies.

**RESULTS:** Twenty of 367 relevant papers fit the eligibility criteria outlined in the methods of this study and were subsequently selected for this review. Of the included studies, there was a notable variance in key characteristics such as methods, outcome measures, sample size, and procedures. Supportive interventions, psychoeducational group interventions, and behavioral-adaptive therapies were the 3 main categories of interventions reviewed; however, each study had a significant correlation between the intervention and outcomes.

**CONCLUSIONS:** Despite the small sample size in this study, this review showed that various intervention models that target caregivers of individuals with MS have been successful.

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Individuals with multiple sclerosis (MS) are faced with a range of debilitating symptoms, such as movement disorders, fatigue, sleep disorders, and mood swings.<sup>1</sup> The progressive nature of this chronic disease requires increasing care over their life span; however, availability of care is simultaneously hindered by an increase in the global prevalence of MS.<sup>2</sup> Although estimating the number of individuals with MS requiring care today is difficult, studies show that 46% to 58% of individuals with MS receive informal care from primary caregivers.<sup>3</sup> Studies also have shown that many individuals with MS require full-time care from primary caregivers,<sup>4</sup> who are usually family members and are not financially compensated for their role.<sup>5,6</sup> Family caregivers assist in basic activities of daily living, instrumental activities of daily living, and providing social-psycho-emotional care. Factors as basic as lack of time and factors as complicated as insufficient education on disease etiology, symptoms, and prognoses, as well as a lack of caregiving best practices, contribute to limitations in providing care that adequately meets the needs of the individual with MS.<sup>7,8</sup>

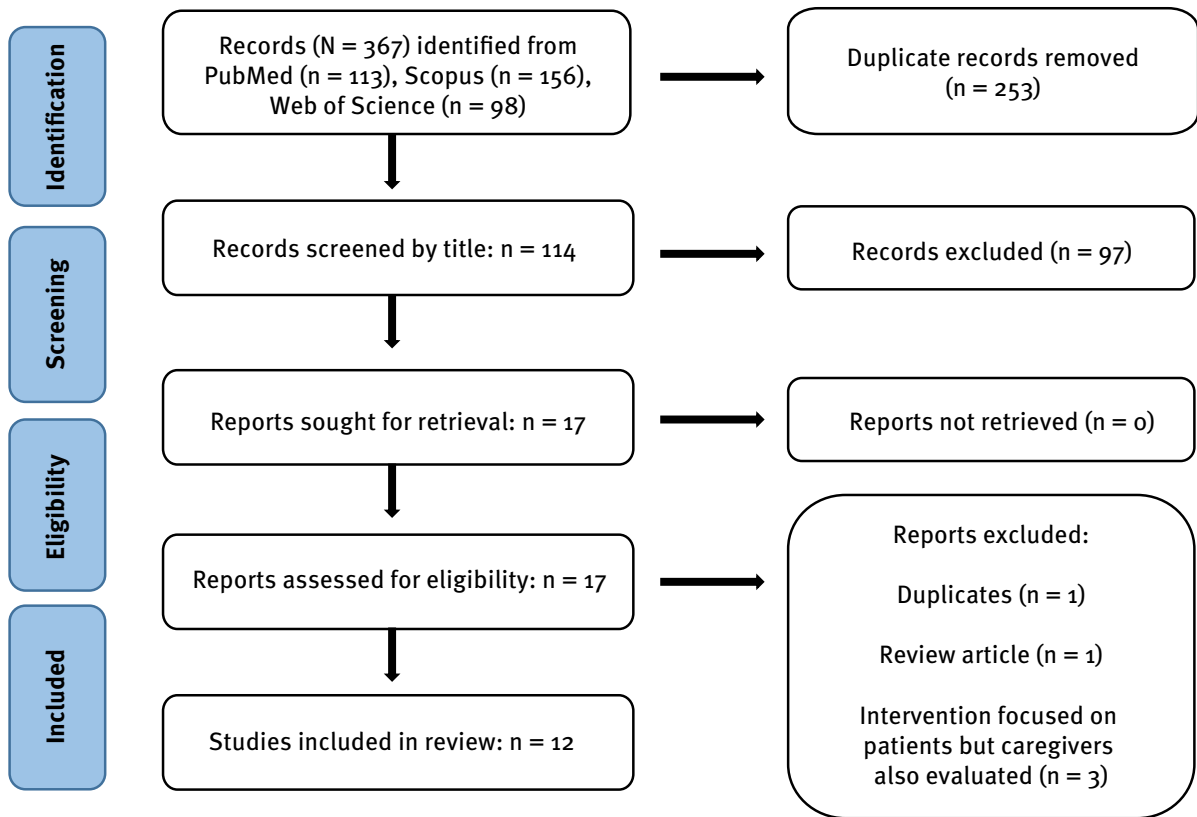
In addition to the lack of wage-based work, primary caregivers of individuals with MS experience significant burdens, including psychological reactions such as depression, anxiety, and anger.<sup>7,8</sup> Previous studies show that the unpredictable course and progressive nature of MS can negatively affect the quality of life and health of caregivers.<sup>9-12</sup> Therefore, managing their needs and challenges can be effective in raising their levels of health, well-being, and quality of life as well as those of their families, including the individual with MS.

Although a few previous studies have shown that the use of MS-appropriate educational and therapeutic strategies can help reduce caregiver burden and increase their self-efficacy,<sup>10,13-17</sup> limited studies have been conducted on specific interventions for caregivers of individuals with MS.<sup>18</sup> To our knowledge, there is no published systematic review. Therefore, the aim of this study was to systematically

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**FIGURE 1.** Preferred Reporting Items for Systematic Reviews and Meta-Analyses 2020 Diagram

review the results of intervention programs for caregivers of individuals with MS. Using a systematic approach and identifying effective interventions could help clinicians support these individuals.

## METHODS

The present study was conducted by following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses<sup>19</sup> guidelines; the research question was determined based on a Population, Intervention, Comparison, Outcomes, and Study design.

### Search Strategy

The study began with a search of the PubMed, Cochrane Library, Web of Science, and Scopus databases using Medical Subject Heading keywords (TABLE S1, available online at IJMSc.org). Because caregiver interventions can have educational and supportive goals as well as MS-specific care goals, the search included many different intervention terms to find all possible studies.

### Inclusion and Exclusion Criteria

The search was limited to English-language studies published in 2020, 2021, and 2022 that examined interventions administered directly to caregivers of individuals with MS involving health promotion-related programs focusing on education, counseling, psychology, or emotions, or a

combination of these focuses. Studies that examined a joint therapeutic intervention for the patient and the caregiver were included only if the intervention had a direct effect on the caregiver and this effect was explicitly evaluated. Conversely, studies on interventions aimed at individuals with MS but with caregiver outcomes measured were excluded from the review.

### Screening and Study Selection

Two authors (F.H. and M.B.) began independent searches simultaneously using common keywords. Duplicates were removed before screening papers based on the inclusion and exclusion criteria. All studies were reviewed based on title and abstract. A full-text review of the selected studies was then conducted independently by both reviewers and compared to verify agreement in included studies. Disagreements were resolved through discussion and consultation with the remaining authors until a collective agreement could be reached. FIGURE 1 shows the search and screening process.

### Data Extraction

To extract data from qualified studies, the reviewing authors examined each study separately. Data extracted from the studies included the first author's name, year of

publication, study design and objectives, number of participants in each group, number of sessions and duration of intervention, evaluated variables, and intervention type and outcome.

### Quality Assessment

All studies were evaluated using the Downs and Black checklist<sup>20</sup> for quality of reporting (10 questions), external validity (3 questions), internal validity (ie, bias and confounding; 13 questions), and statistical power (1 question). The studies were classified into 4 levels of quality based on their scores: excellent (26-28), good (20-25), fair (15-19), and poor ( $\leq 14$ ).<sup>19</sup> The reviewing authors separately evaluated the studies and then examined the overall risk of bias in a joint session.

### Data Synthesis

Data synthesis was organized by intervention method, effectiveness, and type. Due to the heterogeneity of the included studies, meta-analysis was not possible.

## RESULTS

### Study Identification and Selection

Using keywords, 367 articles were identified across the 5 databases. After removal of 253 duplicate articles, 114 articles were reviewed and screened. After title and abstract evaluation, another 97 articles were removed for not meeting the inclusion criteria. The remaining 17 articles underwent a full-text review, after which 5 were deleted because they did not meet the inclusion criteria. Finally, 12 studies were included in the present systematic review (Figure 1).

### Quality Assessment

Based on the Downs and Black checklist, 7 articles had average scores of 20 to 25 and were classified as "good" and 5 articles had average scores of 15 to 19 and were classified as "fair" (TABLE S2).

### Study Design

Of the studies included in this systematic review, 2 were controlled clinical trials<sup>17,21</sup> and 10 were pre-post test, quasi-experimental studies.<sup>10,13-16,22-26</sup> Of the quasi-experimental studies, 6 had a control group<sup>10,15,16,22,23,25</sup> and 4 did not.<sup>13,14,24,26</sup> Eight studies used follow-up procedures: 2 had 1-month follow-ups,<sup>10,16</sup> 4 had 3-month follow-ups,<sup>14,15,24,25</sup> and the remaining 2 had both 3- and 6-month follow-ups (TABLE S3).<sup>17,26</sup>

### Participants

The studies varied in sample size, from a minimum of 12 people to a maximum of 120 people. In total, 479 caregivers were studied, 272 of whom received specific research interventions. Moreover, 130 individuals with MS were studied in some of the reviewed studies, among which 85 received a research-related intervention.

A total of 8 studies focused solely on interventions for caregivers of individuals with MS<sup>10,13,15-17,22,25,26</sup>; 4 studies conducted interventions on both groups (individuals with MS and caregivers),<sup>14,21,23,24</sup> with primary outcomes assessed for both caregivers and individuals with MS. Most studies outlined specific inclusion and exclusion criteria with respect to age and the presence of chronic mental, cognitive, or physical problems and diseases. In 9 studies, it was explicitly stated that family caregivers or relatives who did not receive wages were eligible for the study.<sup>10,13,15-17,21,22,24,25</sup> In other studies, it was not clear whether unpaid caregivers were included. Only 3 studies reported inclusion criteria that specified the history of care in terms of duration and/or hours per day.<sup>13,22,25</sup>

Age was considered 1 of the criteria for caregiver inclusion in 8 studies; in 1 study, caregiver and patient participants in the intervention had to be older than 45 years<sup>13</sup>; the other studies stipulated that participants must be between 18 and 70 years old.<sup>10,14,16,17,21,22,25</sup> Although age was not explicitly considered as an inclusion criterion, 1 study investigated children between 9 and 14 years old who had a parent with MS.<sup>24</sup>

An Expanded Disability Status Scale score was an inclusion criterion in 3 studies. Rakhshan et al<sup>21</sup> required an Expanded Disability Status Scale score between 2 and 3; the range in the study by Pahlavanzadeh et al<sup>10</sup> was 3 to 9.5 and in the study by Mohseni Takalu et al<sup>22</sup> was 4.5 and higher. Another study specified that the individuals with MS were ambulatory.<sup>26</sup> Excluding Mohseni Takalu et al, it was not possible to specify the degree of disability of the individuals with MS.

Three studies used specific intake questionnaire scores as criteria for inclusion: a moderate to high score on the Depression, Anxiety and Stress Scale-21 items<sup>22</sup> questionnaire; the absence of cognitive problems as assessed by the Perceived Deficits Questionnaire<sup>14</sup>; and a Zarit Burden Interview score of at least 21.<sup>17</sup>

Dissatisfaction or unwillingness to continue participation in the intervention, the onset of specific diseases with the capacity to affect the caregiving process, and worsening MS prognoses in individuals with MS were common exclusion criteria. In 3 studies, it was clearly stated that participants were excluded from continuing if they missed 1 or more intervention sessions.<sup>10,21,25</sup>

### Outcome Measures

Using various postintervention questionnaires, most studies focused on assessing negative outcomes of caregiving, such as care burden severity or acquired mental illness in caregivers. In 5 studies, the degree of caregivers' care burden was quantified<sup>10,14,16,17,26</sup>; 4 of those studies used the Zarit Burden Interview.<sup>10,14,17,26</sup>

The second most common outcome assessed was the level of depression, anxiety, and stress. In 4 studies, the effect of the interventions was assessed with some combination of the Generalized Anxiety Disorders Scale; the



Given the numerous challenges in caring for individuals with multiple sclerosis, appropriate interventions for caregivers must be designed and implemented.

Use of supportive intervention programs has a positive effect on reducing caregiver burden and psychological problems.

More studies are needed to determine what kind of intervention is most effective. ■

Patient Health Questionnaire; the Hospital Anxiety and Depression Scale; the Depression, Anxiety and Stress Scale-21 items questionnaire; the Beck Anxiety Inventory; the Beck Depression Inventory; or the 14-item Perceived Stress Scale.<sup>14,16,22,26</sup>

Although no studies used the same tool, 2 studies examined the effect of interventions on the level of caregiver self-efficacy.<sup>13,15</sup> The first study used the Caregiver Problem-Solving Self-Efficacy Scale both to measure the effect of the intervention on the level of caregivers' self-efficacy and to investigate caregivers' strategies and abilities to monitor and improve their personal health.<sup>13</sup> The second study used the Self-Efficacy Questionnaire of Caregivers to assess self-efficacy in the fields of nutrition, medications, appropriate therapeutic exercise, caregiver-patient relationship, and ability to obtain information.<sup>15</sup>

In addition to the aforementioned primary outcomes, 2 studies focused on caregiver life satisfaction,<sup>14,24</sup> 2 on caregiver quality of life,<sup>17,23</sup> 2 on caregiver flexibility when facing challenges,<sup>14,17</sup> and 2 on caregiver MS knowledge. Each outcome listed was examined with different tools.<sup>14,24</sup> Health literacy, level of hope, self-concept, readiness to care for individuals with MS, self-perceived meaningfulness of life, level of patient support, positive and negative emotions, as well as physical and psychological effects of MS on the caregiver were secondary outcomes that were examined by different tools before and after the interventions in the reviewed studies.

### **Intervention Type and Effect**

In 11 studies in this review, the intervention was performed on adult caregivers (>18 years). The 12th study focused on children aged 9 to 14 years who had a parent with MS.

The minimum course of intervention in the studies was 6 days, and the maximum was 3 months.<sup>21,24</sup> Nine studies had group intervention sessions; 3 studies had individual intervention sessions.<sup>14,17,26</sup> Most studies had weekly intervention sessions that varied from 45 minutes to 2 hours in duration. In 9 studies, the intervention was conducted in-person and face-to-face<sup>10,13,15,21-26</sup>; 3 studies had online programs.<sup>14,16,17</sup> There were 3 main types of studies: supportive interventions, psychoeducational group interventions, and behavioral-adaptive therapies.

### **Supportive Interventions**

The studies of this type took a more holistic approach, encompassing multiple caregiver needs. The interventions focused on training-based support and on providing information to caregivers to improve their self-efficacy. Of the 4 studies in this category, 2 were group support<sup>15,21</sup> and 2 were individual support.<sup>17,26</sup>

The aim of the study by Jafari et al<sup>15</sup> was to empower caregivers to improve health literacy, guided by the Family-Centered Empowerment Model. The intervention concentrated on improving the level of caregiver self-efficacy, self-control, and self-esteem by providing information about MS and challenges related to caring for an individual with MS. The intervention improved caregiver self-efficacy and health literacy in caregivers compared with a control group that did not receive the intervention.<sup>15</sup>

The study by Rakhshan et al<sup>21</sup> was based on the Collaborative Care Model, so both individuals with MS and their caregivers were part of a group intervention to increase hope. Participants received the necessary training on caregiving strategies, what to expect from routine medical examinations, the nature and progression of MS, and the role of hope and its effect on one's life. Postintervention evaluations showed that the level of hope in the intervention group increased significantly compared with the control group.<sup>21</sup>

The intervention in the study by Martindale-Adams<sup>26</sup> was based on the Stress Process Model, with a focus on caregivers acquiring information and learning skills that would help them withstand and cope with situational challenges. The results of this study showed significant changes in caregivers' depression scores before and after the intervention.<sup>26</sup>

Potter et al<sup>17</sup> compared the effects of an acceptance and commitment therapy self-help book. The control group received "usual care." One intervention group received only the self-help book. The other intervention group received the book and weekly telephone calls to improve their understanding of the content and facilitate real-world implementation. All assessments were made by telephone or online. The caregivers who received both text-based resources and weekly telephone support had significant and lasting effects in reducing postintervention care burdens.<sup>17</sup>



### Group Psychoeducational Interventions

In 5 studies, the interventions were group based and centered on psychological training.<sup>10,13,22-24</sup> Finlayson et al<sup>13</sup> examined the impact of a novel program for caregivers older than 50 years, “MS Challenge Meetings.” Based on the Person-Environment-Occupation Model, the problem-solving training group’s goals were to improve and enhance caregivers’ self-efficacy, ability to prepare and manage care challenges, and ability to apply self-care strategies. Overall, the meetings improved caregivers’ adaptive responses such that they were better prepared to give care, provide more clinical assistance, and perceive their caregiving roles more positively.<sup>13</sup>

The intervention by Mohseni Takalu et al<sup>22</sup> was also program-based therapy and showed significant differences in reducing caregivers’ depression scores compared with the control group. Although pre- vs postintervention anxiety and stress differences were not meaningful between groups, the respective incidences were reduced in the intervention group compared with the control group.<sup>22</sup>

The intervention studied by Pahlavanzadeh et al<sup>10</sup> also did not have significant between-group differences, but the severity of the burden of care for caregivers who received psychoeducational training in the intervention group decreased compared with before the intervention.

The aim of the group therapy in the study by Azimian et al<sup>23</sup> was to improve the quality of life and increase self-perceived meaning in life. This hope-based treatment program was offered to both caregivers and patients, and the results were remarkable. Caregivers’ quality of life scores increased, and there were significant between-group differences in the meaning of life components.<sup>23</sup>

In the only study to focus on children who had parents with MS in our review, the intervention by Coles et al<sup>24</sup> focused on improving the level of adaptation, compatibility, family cohesion, and well-being. Held over 6 days at a camp location, the intervention had 8 group training sessions for children and their parents with MS to complete together as well as recreational activities. After the intervention, children reported significant reductions in stress levels and restrictions on activities, as well as an increase in social support and knowledge about MS.<sup>24</sup>

### Coping-Behavior Therapies

The interventions conducted in 3 studies were based on behavioral, cognitive, and adaptive approaches and strategies.<sup>14,16,25</sup> Participants in 1 study received both an individual and an online intervention program,<sup>14</sup> a second study administered a joint in-person group and online program,<sup>16</sup> and a third study administered a group face-to-face program.<sup>25</sup>

Using telehealth, Halstead et al<sup>14</sup> designed an online clinical training program, Resilience-Based Skills Program for People with Multiple Sclerosis and Their Caregivers. The program was six 45-minute sessions; 2 sessions were

attended by individuals with MS and their caregivers, while the remaining 4 training sessions were for caregivers only. The main content of the caregiver intervention program was positive adaptation strategies to MS, such as acceptance, resilience, and adaptation to face caregiving challenges. After the intervention, caregivers reported feeling more empowered and ready to care for individuals with MS. Moreover, caregivers’ levels of anxiety and depression decreased significantly, and their satisfaction of life increased significantly.<sup>14</sup>

The intervention in the study by Khazaeili et al<sup>16</sup> tested the effect of internet-based mindfulness training on reducing caregivers’ anxiety, depression, and care burden. The program was a combination of cognitive therapy based on mindfulness and stress reduction. Caregivers received training on facing obstacles and challenges, developing appropriate solutions, becoming aware of one’s thoughts, and focusing on the present. There was a significant difference in the anxiety, depression, and care burden scores after the intervention and follow-up compared with the control group.<sup>16</sup>

The group intervention in the study by Banitalebi et al<sup>25</sup> focused on improving caregivers’ self-management skills using the adaptive problem-solving approaches of courage, time management, and emotional self-regulation. The aim of this study was to improve caregivers’ self-concept; a significant difference was seen between the intervention and control groups.<sup>25</sup>

## DISCUSSION

The purpose of this review was to provide a better understanding of interventions for caregivers of individuals with MS. Findings from the present review showed that, to date, few interventions have been performed directly for caregivers as only 12 studies reported on the effective role of caregivers in the management of MS during the past 22 years. This finding indicates a lack of information about the lived experiences and well-being of caregivers and the individuals with MS they care for. The results of the reviewed studies indicate that caregiver-specific interventions significantly improved and enhanced various outcomes for both parties.

Most of the 12 studies in this review reported on interventions to reduce the burden of care, anxiety, and depression; however, the tools and outcomes measured between these studies were often heterogeneous, making comparison difficult. On the other hand, this may indicate the complex role of those who care for individuals with MS. Despite the limitations of data synthesis due to study heterogeneity, the collective evidence and assessed outcomes depict an overall beneficial effect of interventions on improving a dynamic array of care-based challenges.<sup>27</sup> Although MS caregiver interventions are limited, the effectiveness of the interventions reviewed in the present study can be described due to the relatively close nature of caregiving in other populations, based on extensive caregiver interventions

from other populations. A systematic review by Marim et al<sup>28</sup> confirmed that education and support programs for caregivers of patients with dementia were more effective than usual care in reducing caregiver burden. Other systematic reviews on caregivers of individuals with cancer or who had had a stroke also showed the effectiveness of caregiver interventions; Cheng et al<sup>29</sup> found that psychoeducational interventions were effective on caregiver anxiety, depression, quality of life, burden, and self-efficacy, and Panzeri et al<sup>30</sup> showed that psychological interventions were useful in reducing caregivers' anxious and depressive symptoms.

The studies in this review are divided into 3 general categories based on intervention type; however, the limited sample size of each study in each category makes it difficult to compare or contrast methodological advantages within or between categories. The category that yielded the most positive effect was psychoeducational interventions, perhaps attributable to the group structure and the direct application to explicit caregiver needs. Supportive interventions were not coordinated to a specific need and covered a wider array of care-based challenges; the perceived advantage of this approach to the chronicity, unpredictability, and progression of MS is that it holistically addresses the multiple dimensions and aspects of caregivers' needs.<sup>31</sup> All interventions provided pertinent information about MS, associated symptoms, and management strategies to achieve patient compliance and, thus, improvement. Research on caregivers of other populations has also shown that supportive interventions can also effectively reduce caregivers' burdens.<sup>32,33</sup>

It is difficult to compare the effectiveness of interventions that differ in their target audience (ie, group or individual programs) and mode of delivery (ie, in-person or remote) due to the small number of studies. Group interventions had constraints, juggling a specific number of sessions in a limited period, as well as a more formal or structured setting to accommodate all participants. The content of these sessions was usually based on the collective problems and challenges of participating caregivers. In the individual interventions, the space is more flexible (ie, less structured and formal) as it focuses on the needs of the specific caregiver at that time and the timeline of sessions can be more easily tailored to those needs, which improves participant compliance.<sup>14,17,26</sup> The caveat is that results of individual interventions are inherently less generalizable. This review does not compare included studies that use remotely delivered interventions due to the small sample size, but studies conducted on caregivers of other patient populations, such as people with dementia, depict meaningful improvements in caregivers' adaptive skills and stress levels through the use of similar remotely delivered interventions.<sup>28</sup> Söylemez et al<sup>34</sup> conducted a systematic review and meta-analysis of telehealth applications on self-efficacy levels of family caregivers of individuals with dementia. No effects were observed for caregiver burden, stress,

depression, or quality of life, but an improved self-efficacy level was reported.<sup>34</sup>

The holistic consideration of outcomes and interventions is a strength of this review. We tried to examine the most common implications for all interventions for caregivers of individuals with MS. Another strength is the use of an integrated, accurate, and extensive resource search strategy. It was realistically comparative with a detailed analysis of the structures for the intervention types and corresponding outcomes measured.

One of the limitations we encountered in this study was small sample size. This limitation necessarily dictated the process of presenting the results: to maintain a meaningful volume of information in each category, fewer categories had to be used. Similarly, the resulting outcome measures and observations had to be presented in logical and appropriate groupings. Due to the heterogeneity of the studies, a meta-analysis was not done. Also, studies on joint interventions for caregivers and individuals with MS were evaluated. Despite the potential for improving interventions for caregivers of individuals with MS, more substantive research is needed to evaluate the specific interventions more accurately.

## CONCLUSIONS

Despite the numerous challenges, the need to design and develop appropriate interventions for caregivers is crucial to the well-being of both caregivers and individuals with MS. In a systematic scoping review, Rajachandrakumar and Finlayson<sup>18</sup> echoed a similar need to develop and evaluate interventions for caregivers of individuals with MS and suggested that these interventions could be extracted from programs for caregivers of those with other chronic diseases.

The results of this review elucidated that interventions can improve and enhance various aspects of the lives of people who care for individuals with MS. Overall, the results of the postintervention assessments showed significant progress in improved facilitation of caregivers' needs. The most positive outcome of these interventions was the reduction in care burden and in caregivers' psychological problems. These positive results justify future research and the need to refine available interventions to achieve further positive outcomes for caregivers of individuals with MS. ■

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