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Shared decision-making in multiple sclerosis physical symptomatic care: a systematic review

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Abstract

Background: Multiple sclerosis (MS) is a chronic autoimmune inflammatory, demyelinating, and neurodegenerative disease affecting young adults. People with MS are highly interested in engaging in physical symptom management and decision-making but are often not actively engaged in symptom management discussions. Research examining the benefit of shared decision-making in the management of physical MS symptoms is sparse.

Objectives: This study aimed to identify and synthesize the evidence on the use of shared decision-making in physical MS symptom management.

Design: This study is a systematic review of published evidence on the use of shared decision-making in physical MS symptom management.

Data sources and methods: MEDLINE, CINAHL, EMBASE, and CENTRAL databases were searched in April 2021, June 2022, and April 2, 2023, for primary, peer-reviewed studies of shared decision-making in the management of MS physical symptoms. Citations were screened, data extracted, and study quality assessed according to Cochrane guidelines for systematic reviews, including risk of bias assessment. Statistical synthesis of the included study results was not appropriate; results were summarized in a nonstatistical manner using the vote-counting method to estimate beneficial versus harmful effects.

Results: Of 679 citations, 15 studies met the inclusion criteria. Six studies addressed shared decision-making in the management of pain, spasms, neurogenic bladder, fatigue, gait disorder, and/or balance issues, and nine studies addressed physical symptoms in general. One study was a randomized controlled trial; most studies were observational studies. All study results and study author conclusions indicated that shared decision-making is important to the effective management of physical MS symptoms. No study results suggested that shared decision-making was harmful or delayed the management of physical MS symptoms.

Conclusion: Reported results consistently indicate that shared decision-making is important in effective MS symptomatic care. Further rigorous randomized controlled trials are warranted to investigate the effectiveness of shared decision-making associated with MS physical symptomatic care.

Registration: PROSPERO: CRD42023396270

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A patient living with
multiple sclerosis since
2003

Plain language summary

Shared decision-making among people with Multiple Sclerosis (MS) and their healthcare providers in the management of the physical symptoms of MS.

Shared decision-making is suggested to be a key mechanism in promoting optimal symptomatic care related to Multiple Sclerosis (MS). Shared decision-making is mostly

done and studied in relation to choosing therapies that may slow disease progression but not usually for symptomatic care. There are a few studies highlighting the effect of utilizing shared decision-making in symptomatic care of MS.

We performed this study to identify all the published data about using shared decision-making in symptomatic care in MS to answer the research question: *What is the evidence on shared decision-making in managing physical MS symptoms?*

We performed a systematic search for all the related published study results in four large literature databases. We found 15 studies on the use of shared decision-making in the management of MS-related symptoms. We synthesized the study results relating to the use of shared decision-making in symptomatic care of MS. The studies used several different designs and included a wide range of study rigor and quality.

The results of our systematic review are:

- All the studies were consistent in their conclusions that shared decision-making is important for effective MS-related symptom management.
- Several studies found that symptomatic care is of the highest priority to people with MS, but not often a priority to their health care providers.
- The use of a shared decision-making model can promote discussion of symptoms in clinical consultations and align the goals of people with MS and their health care providers.
- Education of people with MS regarding their symptoms and available treatments will promote effective shared decision-making discussions.

The available evidence supports that the use of shared decision-making is beneficial to the management of physical symptoms of MS. Further studies using a randomized controlled study design are required to establish the degree of benefit of utilizing shared decision-making associated with MS symptomatic care.

Keywords: balance, fatigue, gait disorders, MS, neurogenic bladder, pain, SDM, spasms

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Introduction

Shared decision-making has gained increasing attention in the care of people with multiple sclerosis (MS) and in the field of health care in general.^{1–5} In health care, shared decision-making is the process by which health care providers (HCPs) and patients work together to make health care decisions that align with patients' goals, preferences, and values.⁶ Compared with people who have other chronic disorders, people with MS are significantly more interested in being actively engaged in decisions regarding their treatments.⁷

Physical (motor and sensory) symptoms that can accompany MS include mobility (gait) limitations, balance issues, spasticity/spasms, weakness,

bowel/bladder dysfunction, sexual dysfunction, sensory loss, fatigue, and pain.^{8,9} The experience of these symptoms is highly variable and differs significantly among people with MS.^{8,10} This variability makes it challenging to effectively manage these symptoms.^{9,11} People with MS often manage emerging symptoms on their own until they have the opportunity to discuss them with their HCPs.¹²

The current MS symptomatic treatment guidelines do not include shared decision-making and are centered on the 'Identification, Causation, Alleviation, and Prevention of complications' (ICAP) model for symptom management.¹³ Treatment focuses on symptomatic assessment and management with minimal shared decision-making or patient input.

Clinicians and MS experts identify, assess the cause, prioritize, and treat the symptoms.

Shared decision-making is a complex entity that guides MS treatment as well as symptomatic care, lifestyle considerations, and environmental factors.⁶ In our experience, studies of the shared decision-making model in MS care are often associated with disease-modifying treatments. Research investigating the utilization of shared decision-making specifically in the management of physical symptoms of MS has been sparse, representing a knowledge gap in the field.^{8,10} Moreover, the benefit of utilization of shared decision-making in MS care overall has been challenged, recently sparking a formal debate on the subject led by the MS in the 21st Century Steering Group.¹⁴

Arguments presented in this debate *against* utilizing shared decision-making recognized the years of study required by HCPs to effectively treat people with MS.¹⁴ It is a seemingly impossible task to relay that education to people with MS within the restricted consultation time.¹⁴ Nevertheless, this may be what is required to support balanced and informed shared decision-making.¹⁴ Fortunately, much information is readily available via the Internet, and this information can trigger valuable discussion between patients and HCPs. Unfortunately, information gathered by people with MS from the Internet outside a clinical consultation meeting is rarely without bias and can often cloud judgment rather than provide clarity.¹⁴ Arguments *in favor* of the utilization of shared decision-making in the care of patients with MS included the idea that increased patient engagement increases treatment adherence and improves outcomes.¹⁴ In addition, improved patient engagement enhances the patient–HCP relationship resulting in more effective treatment, the primary objective of HCPs. The authors summarizing the debate concluded that the level of patient engagement in shared decision-making should be driven by the patient and must be determined by the HCP for each patient.¹⁴ In addition, it is important that patients be provided with timely, accurate, and understandable information.¹⁴

While information is important, information alone is not enough for full patient engagement. A study of engagement of people with MS in physical

activity showed that information provision is not a primary driver of physical activity levels.¹⁵ Rather, focus on patient–therapist discovery of individual capability and successful methods of behavioral regulation is more likely to promote increased physical activity, and thereby improve management of mobility, gait, balance, weakness, and spasticity symptoms.¹⁵ People with MS have difficulty talking about some physical symptoms with their HCPs, specifically mobility limitations, spasms, bladder/bowel dysfunction, and sexual dysfunction^{10,16}; therefore, it is essential to the success of shared decision-making that both the patient and the HCP be skilled in the best-suited communication approach¹⁰ and interact at a deeper level than just information transfer.^{15,17}

There is an unmet need for a review of published evidence and the subsequent development of evidence-based recommendations regarding the use of shared decision-making in MS physical symptom management. To address these needs, a systematic review of published literature was conducted in accordance with Cochrane guidelines^{18,19} to answer the following research question: *What is the evidence on shared decision-making in managing physical MS symptoms?*

Methods

Search and screen strategy

Four large literature databases, MEDLINE, EMBASE, CINAHL, and CENTRAL, via four different search engines (PubMed, ProQuest, EBSCOhost, and Ovid, respectively), were searched electronically in April 2021 (pilot search), June 2022 (pilot search), and finally February 4, 2023 (formal search), for peer-reviewed, primary studies of shared decision-making and physical symptom management in people with MS. The search strategy was designed to capture a broad range of study types to provide a comprehensive review of available results. Terms used were ‘multiple sclerosis’ AND ‘shared decision’ OR ‘shared clinical decision’ OR ‘decision aid’ OR ‘informed decision’ OR ‘decision support’ OR ‘clinical decisions’ OR ‘decision-making’ OR ‘engagement’. No limits on publication date or language were imposed. The full search strings designed for each database are presented in Supplemental File 1. The quality of the search string was tested in a PubMed search

of MEDLINE and successfully captured all 13 previously known related articles used as a positive control sample. The reference sections of appropriate recent reviews were also searched manually. Symptom management studies associated with an acute MS relapse were excluded, because these are treated with corticosteroids and involve an acute decision-making process. Our emphasis in this systematic review was on physical symptoms, because cognitive and emotional manifestations of MS may impact shared decision-making in MS and the ability to engage in meaningful discussions. Inclusion criteria were peer-reviewed, primary studies of all designs (both qualitative and quantitative); consideration of shared decision-making; and consideration of management of physical symptoms associated with MS. Exclusion criteria were non-peer-review, nonprimary study reports; conference proceedings, editorials, reviews, systematic reviews, meta-analyses, animal studies, theses, treatment guidelines, and study protocols; no people with MS included; no clinical decision-making by people with MS and clinicians considered; physical symptoms of MS not considered; or study of acute MS relapse.

Duplicate citations and articles of exclusionary types were removed in a primary screen performed by a single author (JK). A second screen of titles and abstracts was performed by two authors independently (ABZ and JK), with discrepancies resolved upon discussion. A final screen based on independent reading of the full text (ABZ and JK) eliminated any further irrelevant articles.

Data extraction, study quality assessment, and synthesis

Data were extracted manually from the full text of each included study into a custom excel worksheet (ABZ and JK). Study attributes extracted included: study purpose, study design, symptom of study, location and setting of study, study funding, study year, study/control population, sample size, years since MS diagnosis, study instruments utilized, statistics utilized, follow-up period, relevant results, relevant study conclusions, and study authors' recommendations. The risk of bias and methodological quality of each study were assessed individually using tools (e.g.

Critical Appraisal Skills Program Qualitative Checklist 2018, Joanna Briggs Institute Checklist for Case Reports, Joanna Briggs Institute Checklist for Case Series, Revised Cochrane risk-of-bias tool for randomized trials 2.0) in accordance with the study design type as recommended by Ma *et al.*²⁰ Two authors (ABZ and JK) independently assessed the risk of bias in randomized controlled trials. A broad range of study types and designs was included. All study results and conclusions were summarized in a nonstatistical manner using the vote-counting method to estimate the effect (beneficial or harmful) of shared decision-making in MS symptom management.¹⁹ This review protocol was registered with PROSPERO: CRD42023396270.

Recommendations and certainty ratings

Recommendations regarding the utilization of shared decision-making in the management of physical symptoms of MS were formulated. The certainty of the evidence for each recommendation was rated based on the quality and applicability of the body of evidence related to each in accordance with Grading of Recommendations, Assessment, Development and Evaluations (GRADE) certainty ratings.²¹ The study designs, quality of the studies, consistency of results, and the applicability of the study populations to the population of interest are considered as part of the determination of the certainty ratings.

Results

Search and screen results

The initial electronic searches yielded 675 citations, and manual search of reference lists yielded four additional citations. After duplicate removal and the first and second screen, the full texts of 102 articles were assessed in a third screen (Figure 1). A total of 15 studies (16 articles; Table 1) met the criteria for inclusion in the systematic review, including one randomized controlled trial, 12 observational/cohort studies, and two case studies/case series. The management of symptoms of pain, spasms, neurogenic bladder, fatigue, gait disorder, and/or balance issues was investigated in six of these studies.^{22–28} Nine studies discussed physical symptoms in general.^{2,5,10,17,29–33}

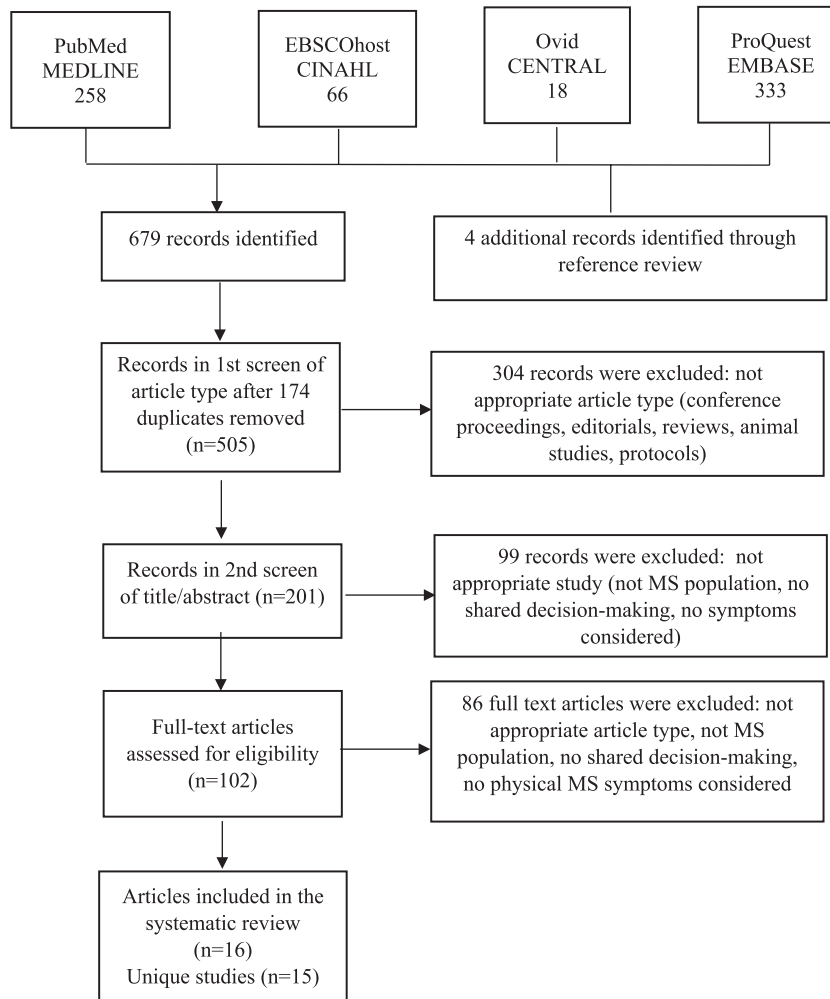


Figure 1. Citation disposition PRISMA flow diagram.

Systematic review analysis

No two studies reported results from the same instrument, questionnaire, or survey; thus, reported results were not appropriate for statistical integration (e.g. meta-analysis). Only two studies considered shared decision-making as an intervention variable: one did not report an effect size or numerical data to calculate an effect size and the other presented the observational conclusions of the use of shared decision-making in the management of physical symptoms of MS descriptively and narratively. The remaining 13 studies evaluated the data qualitatively and not quantitatively; therefore, effect sizes were not reported nor calculable for these studies.

We used the vote-counting method based on the reported conclusions of the study authors to

estimate the effect (beneficial or harmful) of shared decision-making in MS symptom management.¹⁹ Study details, risk of bias assessments where appropriate, benefit/harm vote, and study method quality assessments are presented for each included study in Table 1.

Shared decision-making as an intervention for pain and spasms

Pain and spasms are often invisible symptoms, which require neurological assessment and examination. Two studies, Col *et al.*²² Fitzpatrick and Cook,²⁵ investigated the effects of promoting shared decision-making as an intervention in the management of chronic pain and spasms. Col *et al.*²² performed a randomized controlled trial ($n = 38$) investigating the benefits of a new online

Table 1. Included articles study details.

| First Author | Year | Symptoms | Design | Population (N) | Population with MS | Study Author conclusions (Vote: beneficial or harmful) | Study method quality rating from very low to high (tool used) |
|---|------------|------------------|------------------------------|-----------------------------------|---|---|--|
| Col <i>et al.</i> ²² | 2020 | Pain | Randomized controlled trial | Chronic pain/MS patients (22) | English-speaking adults with access to the internet in a network of MS patients with chronic pain ^a | Shared decision-making tool increases successful pain management (beneficial) | Moderate. High quality because RCT and low risk of bias, reduced because not powered to determine statistical significance of the benefit in management of pain (RoB) |
| Col <i>et al.</i> ² | 2018 | General physical | Qualitative/ tool validation | MS patients (135) | Nonpregnant, English-speaking, with internet access, aged 21 to 75 years, mean 12.66 years since diagnosis, USA | Preference tool promotes shared decision-making and symptom management (beneficial) | High. Clear goal, design, results. Good MS sample. Rigorous analysis (CASP) |
| Col <i>et al.</i> ¹⁷ | 2018 | General physical | Qualitative/ observational | MS patients/ HCPs (71) | 47 non-pregnant, English-speaking, any type of MS (mean 12.41 years since diagnosis), age 21–75 years, USA | High importance of symptom management to MS patients (beneficial) | High. Clear goal, design, and results. Good MS sample. Rigorous analysis, but could have normalized for comparison (CASP) |
| Fitzpatrick and Cook ²⁵ | 2011 | Spasms, pain | Case study, intervention | MS patient | 59-year-old male, 9-year diagnosis, Ireland | Successful informed shared decision-making managing spasms and pain (beneficial) | High. Clear goal, design, and results. Good adherence to case-report standards (JBI CCR) |
| Heesen <i>et al.</i> ^{26,27} | 2004, 2007 | Gait, fatigue | Qualitative/ observational | MS patients (169) | 75 primary progressive, 75 relapse remitting, and 19 with MS < 1 year, mean duration 7.7 years, mean age 44 years, 106/63 female/male | Highest interest in managing gait disorder and fatigue, and preference for shared decision-making and informed choice, among MS patients (beneficial) | Moderate. Clear goal, design, and results. Good MS sample. Rigorous analysis. Some concerns of risk of researcher bias (CASP) |
| Held Bradford <i>et al.</i> ²⁴ | 2018 | Gait, balance | Case series | MS patients/ therapists (7 pairs) | Adults, 6 female, 6 had relapsing-remitting MS, 5 used either a cane or a walker, from Midwest USA | Increased shared decision-making important to maximize gait and balance (beneficial) | High. Clear goal, design, and results. Good adherence to case-series standards (JBI CCS) |
| Lippa <i>et al.</i> ²⁹ | 2017 | General physical | Qualitative/ observational | HCPs/MS patients (18) | 16 adults, 3 men, 13 women, Midwest USA, wide mix of education and years since MS diagnosis | Patients are already engaged in decision-making regarding physical symptoms. Shared decision-making (including the HCP) is essential to effective symptom management (beneficial) | Moderate. Clear goal, design, and results. Little analysis. Good MS patient sample (CASP) |
| Oreja-Guevara <i>et al.</i> ³⁰ | 2019 | General physical | Qualitative/ observational | HCPs/MS patients (27) | 12 adults, mix of gender, age, and stages of disease: primary progressive and relapsing-remitting MS, Europe and USA | Shared decision-making tool developed to increase effective symptom management (beneficial) | High. Clear goal, design, and results. Had balanced patient/HCP representation (CASP) |

(Continued)

Table 1. (Continued)

| First Author | Year | Symptoms | Design | Population (N) | Population with MS | Study Author conclusions (Vote: beneficial or harmful) | Study method quality rating from very low to high (tool used) |
|---|------|--------------------|------------------------------|------------------------------------|--|--|--|
| Paterson <i>et al.</i> ²⁸ | 2002 | Fatigue, gait | Qualitative/observational | Chronic illness/MS patients (21) | 7 adults with MS, mean 16.6 years since diagnosis, mean age 50.6 years | Recommend that HCP engage in shared decision-making to support patient self-care, especially applicable to fatigue management for MS patients (beneficial) | Low. Clear goal, design, and results. Small MS sample. No analysis. Some concerns of risk of researcher bias (CASP) |
| Pietrolongo <i>et al.</i> ³² | 2013 | General physical | Qualitative/observational | HCPs/ patients (98) | 63 MS/CIS patients, mean age 37.5 years, 89% first episode/ relapse remitting, 12% relapsing/ chronic progressive | Recommend training HCPs in shared decision-making skills for effective symptom management (beneficial) | High. Clear goal, design, and results. Rigorous analysis. Multi-regional sample (CASP) |
| Rieckmann <i>et al.</i> ⁵ | 2015 | General physical | Qualitative/observational | HCPs/MS patient ^b | 1 person with MS | Patient engagement and HCP/patient relationship critical to effective symptom management (beneficial) | Low. low-quality data collection and analysis, high risk of bias due to very low patient representation (CASP) |
| Rieckmann <i>et al.</i> ¹⁰ | 2018 | General physical | Qualitative/observational | HCPs/MS patients (25) | 11 adults, a mix of gender, age, and stages of disease: primary progressive and relapsing-remitting MS, Europe and USA | Management of physical symptoms is important to people with MS, and enabling shared decision-making and prioritization of symptom management by HCPs is required for effective symptom management (beneficial) | Moderate. Clear goal, design, and results. Good MS patient sample. Little analysis (CASP) |
| Tractenberg <i>et al.</i> ²³ | 2021 | Neurogenic bladder | Qualitative/ tool validation | Spinal injury/MS patient (93) | 1 adult | Scoring method useful to both patient and HCP shared decision-making is most valid for symptom management (beneficial) | Moderate. Clear goal, design, and results. Low MS patient representation (CASP) |
| Wicks <i>et al.</i> ³³ | 2010 | General physical | Qualitative/observational | Chronic illness/MS patients (1323) | 347 MS patients, 19% male, mean age 46 years | Tool increased informed shared decision-making and improved symptom management (beneficial) | High. Clear goal, design, and results. Good MS sample. Appropriate analysis (CASP) |
| Wilson <i>et al.</i> ³¹ | 2014 | General physical | Qualitative/observational | MS patients (291) | Adults with recurring relapsing MS, mean 8.1 years since diagnosis, mean 4.6 years since the last relapse | Highest preference is successful symptom management (beneficial) | High. Clear goal, design, and results. Rigorous analysis. Good MS sample (CASP) |

CASP, Critical Appraisal Skills Program Qualitative Checklist 2018; CIS, clinically isolated syndrome; HCPs, healthcare providers; JBI CCR, Joanna Briggs Institute Checklist for Case Reports; JBI CCS, Joanna Briggs Institute Checklist for Case Series; MS, multiple sclerosis; RCT, Randomized Controlled Trial; RoB, revised Cochrane risk-of-bias tool for randomized trials 2.0.

^aThe total number of people with MS in this study was not reported.

^bThe total number of people involved in this study was not reported.

tool (PainAPP). The main outcome of the study was management of chronic pain, collected via the survey statement 'It helped me manage my chronic pain'. and the Brief Pain Inventory. The study population was given access to the PainApp website designed specifically to promote and support shared decision-making in pain management in a real-world setting, while the control group was given access to a different pain-management website. The study results showed that pain management was improved using PainAPP to promote shared decision-making compared with the control website. This result was presented without numerical details; thus, an effect size was not calculable. In addition, people with chronic pain and HCPs were found to have different foci, thus decreasing effective patient-HCP communication. Patients felt that their HCP did not respect or trust them and spent consultation time overcoming this. In contrast, HCPs used the clinical consultation time to gather patient information. Thus, the discussions during the clinical consultation were not aligned and at cross-purposes. Col *et al.*²² concluded that patients preferred shared decision-making and partnership with their HCPs, and increased shared decision-making resulted in improved pain management.

Fitzpatrick and Cook²⁵ reported the results of a case study of education as an intervention to promote informed shared decision-making regarding cannabis use to manage MS-related spasms and pain. The main outcome of the study was informed shared decision-making regarding management of pain and spasms, collected via informal feedback from the individual with MS. The individual with MS was provided extensive information and an intensive approach to education regarding available treatments. No control or baseline comparisons were made, and no effect sizes were reported or calculable. The result was the successful support of informed shared decision-making regarding management of MS-related pain and spasms. Although this approach was resource-intensive, the person with MS was actively engaged, receptive, satisfied, and thoroughly informed regarding cannabis use for symptom management. The resources used to provide the intensive education were deemed justifiable given the highly personalized health and life experience of persons with MS and was vital to the success of the intervention.²⁵

Neurogenic bladder and shared decision-making

Spastic or flaccid neurogenic bladder is highly prevalent in MS.⁹ Tractenberg *et al.*²³ developed a questionnaire [Urinary Symptom Questionnaire for People with Neurogenic Bladder (USQNB)] for the assessment of the various specific symptoms of neurogenic bladder, and performed a test trial ($n=93$) of the questionnaire. The main outcome of the study was the most effective and valid method of analyzing neurogenic bladder symptoms, collected via the USQNB questionnaire. The method of analysis of the results of the questionnaire that was usable by *both* the patient and the HCP in decision-making was the most effective and valid for the management of neurogenic bladder symptoms, compared with analysis methods that were only usable by the HCP. This analysis method generated patient profiles and burden estimates, without any numerical data or domain scores. Shared decision-making was not manipulated in this study, and effect sizes were not reported or calculable. The results of this study indicate that shared decision-making is beneficial in decisions regarding the management of symptoms of neurogenic bladder.²³

Gait, balance, and fatigue and shared decision-making

Fatigue and mobility issues are highly common in relapsing and progressive MS.⁹ Paterson *et al.*,²⁸ Heesen *et al.*,^{26,27} and Held Bradford *et al.*²⁴ reported results of studies of shared decision-making and management of gait, balance, and/or fatigue. Paterson *et al.*²⁸ was an early study investigating the decision-making process of people with MS ($n=7$) determined to be successful in symptom management via self-care decisions (also called autonomous decision-making).^{26,27} The main outcome of the study was the focus of symptom management decision-making compared among people with chronic illnesses, collected via audio diaries, interviews, and focus groups. For individuals with MS, fatigue management was the primary symptom requiring daily, immediate decision-making.²⁸ The worsening of gait disorders was also identified to require occasional self-care decisions.²⁸ The data were presented qualitatively; shared decision-making was not manipulated in this study, and no effect sizes

were reported or calculable. Based on their findings, the study authors recommended that HCPs engage in shared decision-making to support the self-care decisions of people with MS for the successful management of their symptoms.²⁸

Heesen *et al.*^{26,27} described the results of a study of people with MS ($n=169$) from an Outpatient Clinic at University Hospital in Hamburg, Germany. The main outcomes of the study were decisional role preferences and information interests, collected via focus groups and surveys. Most people with MS (79%) preferred active roles associated with their MS symptomatic care; shared decision-making was preferred most frequently (39%). The primary information interests were related to the alleviation of symptoms; treatment of gait disorder was the most frequently mentioned item of interest, and physiotherapy and treatment of fatigue were also among the 10 most frequently identified items.^{26,27} Shared decision-making was not manipulated in this study and effect sizes were not reported or calculable. The study authors concluded that it is essential that a shared decision-making process be available to individuals with MS.^{26,27}

The major outcome of the study by Held Bradford *et al.*²⁴ was the decisions of persons with MS and their physical therapists ($n=7$ matched pairs) to maximize gait and balance after physical therapy. This was investigated via survey, interview, and The Activities-Specific Balance Confidence Scale. While the physical therapists believed in the benefit of shared decision-making, application of it was inconsistent. The study authors recommended increasing shared decision-making skills to maximize gait and balance.²⁴ In addition, better understanding of how people with MS conceptualize and weigh risk may improve shared decision-making.²⁴ Shared decision-making was not manipulated in this study, and effect sizes were not reported or calculable. The study authors concluded that the development of a partnership promoting shared decision-making between persons with MS and their therapists was of great importance to maximize gait and balance.²⁴

General physical symptoms and shared decision-making

Different models, such as home monitoring, computerized models, and active patient engagement

and communication are a few approaches being applied to improve self-management in patients with MS.³⁴ Lippa *et al.*,²⁹ Wilson *et al.*,³¹ and Pietrolongo *et al.*³² described patients' preferences, engagement, and focus. These researchers found that management of physical symptoms is of high importance to people with MS, and improvement of HCPs skills in communication and shared decision-making is key to successful management of physical symptoms.

The main outcome of Wilson *et al.*³¹ was the preferences of individuals with MS ($n=291$) for the risk and benefit attributes of hypothetical disease-modifying treatments, collected via a survey. They found that symptom improvement was the highest-ranked preferred benefit (OR = 3.68, $p < 0.001$), even over prevention of disease progression for 10 years. Shared decision-making was not manipulated in this study, and effect sizes were not reported or calculable. The study authors concluded that determining patient preferences is a key step in shared decision-making.³¹

These data are consistent with the results of a study done by Pietrolongo *et al.*³² on the perceived involvement of people with MS in their first clinical consultation ($n=98$). The major outcome of the study was HCP shared decision-making skills in the context of MS care, collected via the Observed Patient Involvement in Shared Decision-Making questionnaire. This study found limited patient involvement abilities of MS HCPs during first consultations and highlighted the central nature of symptoms and symptom management among persons with MS.³² Shared decision-making was not manipulated in this study, and effect sizes were not reported or calculable. The study authors concluded that there exists a need to empower HCPs with better communication and shared decision-making skills to successfully manage physical symptoms.³²

Lippa *et al.*²⁹ examined in detail the elements and processes of medical decision-making *in situ* ($n=18$). The major outcome of the study was HCP decision-making in context when interacting with patients, collected via qualitative measures, field observations, and interviews; therefore, effect sizes were not calculable or reported. This study showed that medical decision-making is fundamentally distributed between physicians and patients, meaning that shared decision-making exists in the care of people with MS, whether it is

purposeful or not. This is consistent with the findings of Paterson *et al.*²⁸ Physicians and patients, however, can have very different ways of conceptualizing and evaluating the factors surrounding each decision, and thus, the process can be variably effective.²⁹ Symptoms were found to be key in the patient-defined and patient-dominated decisions because patients have critical experiential information regarding their symptoms. While many patient-dominated decisions were classified as 'treatment nonadherence', persons with MS were simply having to make decisions on their own, often because of the absence of alignment with their HCPs.²⁹ The study authors concluded that recognition by HCPs of the importance of shared decision-making is essential to the management of physical symptoms of MS.²⁹

Communication and goal-setting tools. Interactive, web-based, goal-oriented patient-focused programs may enhance self-management and communication, and promote an integrated interdisciplinary approach.³⁴ Rieckmann *et al.*,^{5,10} Oreja-Guevara *et al.*,³⁰ Col *et al.*,^{2,17} and Wicks *et al.*³³ described development, validation, and implementation studies of communication and goal-setting tools designed to improve effective shared decision-making in the management of physical MS symptoms.

The MS in the 21st Century Steering Group published three articles regarding shared decision-making and physical MS symptom management.^{5,10,30} The main outcome of Rieckmann *et al.*⁵ was the issues that influence the engagement of individuals with MS in their care, collected via critique and synthesis of identified patient engagement strategies. Some examples of these strategies were the promotion of shared decision-making by use of patient decision aids, health coaching, question prompts, self-management education, and support. The study authors identified the large impact that MS symptoms have on quality of life, including physical symptoms of gait and mobility impairments, sexual dysfunction, bladder/bowel dysfunction, fatigue, and pain.⁵ Shared decision-making was not manipulated in this study; no effect sizes were reported or calculable. The study authors concluded that patient engagement is required to effectively include symptom management in clinical consultation.⁵

The major outcome of Rieckmann *et al.*¹⁰ was the similarities and disparities in perception and prioritization between people with MS and HCPs

($n=25$), collected via joint open-forum workshops; therefore, effect sizes were not calculable or reported. They found that a greater importance was placed on management of hidden and invisible MS symptoms by people with MS compared with their HCPs.¹⁰ Physical symptoms that were included in the list of invisible symptoms were fatigue and sexual dysfunction. Differing priorities between patient and HCP resulted in cross-communication and the ineffective use of consultation time, which was already under severe constraints.¹⁰ The study authors concluded that prioritization of symptom management by HCPs is required for effective symptom management, and with improved communication and information people with MS will be able to take part in shared decision-making.

In Oreja-Guevara *et al.*,³⁰ the MS in the 21st Century Steering Group described the subsequent development of a communication tool to improve the standards of MS care. The main outcomes of the study were identification of issues in patient-HCP communication and development of solutions, via group discussions, surveys, and workshops. Shared decision-making was not manipulated in this study and effect sizes were not reported or calculable. The tool that was developed (myMS Priorities) focused on improving shared decision-making and current symptom experience, including mobility, spasticity, balance, pain, bladder/bowel dysfunction, fatigue, and sexual dysfunction.³⁰

Col *et al.*^{2,17} identified disparities between people with MS and HCP treatment goals and subsequently developed and evaluated a preference assessment tool (WhatMattersMS) designed to improve patient-HCP communication and promote shared decision-making. The main outcomes of Col *et al.*¹⁷ were the elicitation and prioritization of treatment goals from people with MS and HCPs, collected via nominal group technique meetings. The study results highlighted how the goals of people with MS often focus on the impact of specific symptoms, including bladder and bowel dysfunction, fatigue, and pain, on their quality of life, while HCPs' goals focused on slowing disease progression. Shared decision-making was not manipulated in this study; no effect sizes were reported or calculable. The study authors concluded that people with MS often need help understanding their treatment goals and making HCPs aware of these goals.

Subsequently, Col *et al.*² reported on the validation of the WhatMattersMS tool designed to address goal setting and aligning them between patients and HCPs. The main outcome of the study was whether the tool helps clarify the preferences of people with MS and their interest in sharing their preferences with HCPs, collected via a tool evaluation questionnaire. The second and third most important treatment goals (after brain health) as ranked by people with MS ($n=135$) were physical symptom management, including management of mobility and walking (second most important goal) and management of fatigue, bladder dysfunction, sensory dysfunction, pain, and balance issues (third most important goal).² Other shared decision-making elements assessed by this tool, included the preferred role in decision-making, stage of decision-making, and knowledge regarding MS.² Shared decision-making was not manipulated in this study; no effect sizes were reported or calculable. The study authors concluded that this tool effectively addressed the challenges faced with the utilization of shared decision-making in the management of physical MS symptoms.²

Wicks *et al.*³³ assessed the benefit of using an online patient-connection site, PatientsLikeMe, and sharing health information data online. The community consisted of people with several chronic conditions ($n=1323$), including MS ($n=347$). The main outcomes of the study were potential benefits of PatientsLikeMe for treatment decisions and symptom management, collected via a survey. A key element of the online portal that promoted shared decision-making was the generation of symptom management reports.³³ One-third (29%) indicated that they used the resulting report during health care visits, and 42% reported being moderately or a lot more involved in treatment decisions because of the online portal site. Notably, 66% of HCPs supported their patients' use of the site. In parallel, a majority (59%) found the site, PatientsLikeMe, helpful in the management of symptoms.³³ Shared decision-making was not manipulated in this study and the effect of promotion of shared decision-making on physical symptom management was not analyzed; no effect sizes were reported or calculable.

GRADE certainty rating

The studies included in this systematic review included a single randomized controlled trial that

investigated shared decision-making as an intervention. This study was judged to have low risk of bias, but was underpowered to show that the reported benefit due to the use of shared decision-making in pain management was statistically significant.²² Due to imprecision, the GRADE certainty rating for randomized controlled trial evidence was reduced from a high to moderate certainty rating.

The majority of the included studies were observational studies, and this study design corresponds with a low GRADE certainty rating; partly due to the high risk of bias that is inherent to this study design.²¹ Most participants in the studies were people with MS, making the study results directly applicable to people with MS, thus strengthening the certainty.²¹ Moreover, the included studies were overwhelmingly consistent in their conclusions that shared decision-making is important to the successful management of physical MS symptoms. All the studies (15 of 15) indicated the benefit of shared decision making, rather than harm, according to the vote-counting analysis (Table 1). Several studies identified shared decision-making as *critical* to effective management of physical MS symptoms. This consistency among study conclusions also strengthens the certainty of the body of evidence.²¹ Thus, the certainty rating of the observational studies evidence was raised from a low to moderate GRADE certainty rating.

Discussion

Fifteen studies were identified in the systematic review discussing shared decision-making in the management of physical symptoms of MS. The 15 studies included in this review were remarkably consistent in support of utilizing shared decision-making in the management of physical MS symptoms answering the question of the study; *What is the evidence on shared decision-making in managing physical MS symptoms?* All the studies (15 of 15) indicated the benefit of shared decision making, rather than harm, according to the vote-counting analysis. Most of the studies addressed physical symptoms in general, but some discussed specific physical symptoms: gait disorder, balance issues, fatigue, neurogenic bladder, pain, and spasms. Only one of the 15 studies was a randomized controlled trial assessing shared decision-making as an intervention,²² indicating that more research is needed to fully assess the effectiveness

of shared decision-making in the management of physical MS symptoms.

Management of physical symptoms was found to be of highest interest to people with MS, while this aspect of MS was not a high priority for HCPs, who placed more importance on slowing the progression of disease.¹⁷ The studies of gait, balance, and fatigue demonstrated that people with MS are able to understand the complexity of the disease and are not disturbed by balanced complex information, stressing the importance of partnership and shared decision-making.^{24,26–28} These studies demonstrate the strong preference of people with MS to be actively involved in shared decision-making for medical decisions in general, and particularly in the management of specific physical symptoms related to MS. Thus, management of MS-related gait disorder, balance issues, and fatigue benefit from greater information sharing and discussion of expectations, role preference, mutually meaningful goal setting, appropriate challenge, and action planning.^{24,26–28} These goals and roles are related to the concepts of shared decision-making, behavior change, and self-management.²⁸

Pain and spasm management information and communication tools equip people with MS with greater understanding of their condition, clearer treatment goals, and less interest in using opioids.^{22,25} Improving the lives of people with pain and spasms requires that patients understand their choices and the consequences of those choices.^{22,25} It also requires that HCPs understand their patients' goals and values, emphasizing the importance of open communication between patients and their HCPs.^{22,25} The results of the studies of neurogenic bladder, pain, and spasm management support the use of shared decision-making, through the use of tools and approaches that help clarify treatment goals, increasing active engagement of persons with MS, and improving patient–HCP communication.^{22,23,25} Patient treatment goals and symptom management that can be printed out as a report using online portals or apps, such as PatientsLikeMe or PainAPP, facilitate focused discussion between people with MS and their HCPs to maximize effective shared decision-making within limited clinical consultation time.^{22,33} Problems and solutions should be negotiated between people with MS and their HCPs, and shared expectations and goals of clinical care

should be created between people with MS and their HCPs.²⁹ Management of MS symptoms often involves comfort and functionality rather than medical necessity; therefore, the patient's values and experience have a large role in the decision-making process. To successfully manage symptoms, avoid misdiagnosis of symptoms, and increase treatment adherence, HCPs and people with MS must be in alignment, which can be achieved using shared decision-making.²⁹

The results of the studies from the MS in the 21st Century Steering Group suggest that healthcare organizations and policymakers need to analyze the ways in which their policies prevent patient engagement from succeeding.^{5,10,30} The consequences of patients not engaging are borne most heavily by the patients themselves and their families, in the form of emotional, physical, social, and financial costs. This also impacts heavily on healthcare systems and society with respect to wasted resources, suboptimal outcomes, and increases in health disparities.^{5,10,30} The relationship between the HCP and the person with MS makes a critical difference to a person's experience of MS.^{5,10,30} Fundamental to patient-centered care and patient engagement is a patient–HCP relationship that includes open lines of communication, HCP availability, and HCP willingness to work as a partner with patients.

Many of the studies identified in this review investigated the sources of the challenges faced by people with MS in management of their physical symptoms. For example, while symptom management is of primary importance to people with MS, it has not been the primary focus of HCPs, and thus discussions in clinical consultations have often been at odds. Moreover, discussion of some of physical symptoms is difficult for people with MS (e.g. sexual dysfunction, bladder and bowel dysfunction, mobility limitations, spasms). Furthermore, trustworthy, accurate, and accessible information sources for people with MS are necessary for successful shared decision-making. While this information has been available online, there has been a need to purposefully direct people with MS to reliable information sources, so that they are not required to sift through the uncurated information that exists online. In response to the identification of problems that people with MS face, there has been a widespread effort to meet these needs. For example, tools

that promote shared decision-making, such as myMS Priorities, PatientsLikeMe, What MattersMS, and PainAPP, increase effective communication, assess patient preferences, inform symptom management, and identify treatment goals. More reliable, accurate, and accessible MS information pathways have been established in conjunction with these tools and websites.

A challenge and a knowledge gap that have been identified in MS care include the need for specific educational areas of both people with MS and MS HCPs. For example, education of patients with all the up-to-date information on available treatments for physical symptom management including recent innovative therapies was considered worth the required intensive use of resources.²⁵ Symptom alleviation was suggested as a major topic for advanced courses of education of people with MS.^{26,27} It was suggested that both persons with MS and HCPs should be made aware of uncertainty in decision-making and the importance of enhancing shared decision-making skills.²⁴ HCPs were suggested to increase their understanding of how persons with MS conceptualize and weigh risk related to different gait and balance-enhancing behaviors, especially regarding mobility device use.²⁴ It was suggested that persons with MS should recognize the importance of self-management skills to maximize gait and balance, and the challenge and importance of redefining a sense of self, particularly for the use of compensatory measures such as mobility devices.²⁴ Education of HCPs in how to encourage patient engagement, understand changing patient sense of self, assess patient preferences, and shared decision-making communication skills will facilitate effective shared decision-making discussions within the clinical consultation timeframe. As training in these skills is incorporated into medical education,³² shared decision-making-based discussion will be more easily a part of the clinical consultation, starting with the initial clinical consultation bringing patients immediately into their preferred role in treatment decisions.

Clinical recommendations and implications for clinical practice

Clinical recommendations based on this evidence, each with a weak recommendation in favor,²¹ are as follows:

1. Education and information sharing with people with MS related to identification, assessment, and management of physical symptoms guided by the HCPs.^{2,25–27,33}
2. Shared discussion of the goals of people with MS and HCPs.^{2,10,17,22,24,28–32}
3. Engagement and motivation of people with MS to participate in discussion of physical symptoms.^{5,29–32}
4. Shared decision-making with people with MS to develop a partnership in the management of physical symptoms of MS.^{22,23,24–29,32}

The model of ‘Identification, Causation, Alleviation, and Prevention of complications’ (ICAP)¹³ can be adapted to be used in symptom management in clinical practice with the addition of the shared decision-making process. The revised model called ICAPS (S = shared decision-making) may direct symptomatic care in MS (Figure 2). Shared decision-making is a dynamic process between people with MS and their HCPs, which leads to enhanced partnership, effective physical symptom management, and improved quality of life.

Study limitations

The largest possible source of risk of bias in the inclusion of studies in a systematic review is the risk of publication bias.¹⁹ The authors of this systematic review did not seek out unpublished study results. Nevertheless, the publication of included study results does not appear to be largely influenced by funding sources or study author conflicts of interest, and there is no detectable systematic promotion of shared decision-making via funding pressure.¹⁹

The existence of a risk of publication language bias is acknowledged.¹⁹ Although the search for articles was not limited to the English language, all articles that met inclusion criteria were published in English. Therefore, the results of this analysis may be highly applicable to English-based clinical situations, but not applicable to other language-based clinical situations.

Risk of time-lag bias, citation bias, and selective reporting bias appear minimal in the included articles.¹⁹ Multiple publication bias was minimal.¹⁹ Location bias was minimized by searching several large literature databases.¹⁹ Subsequent

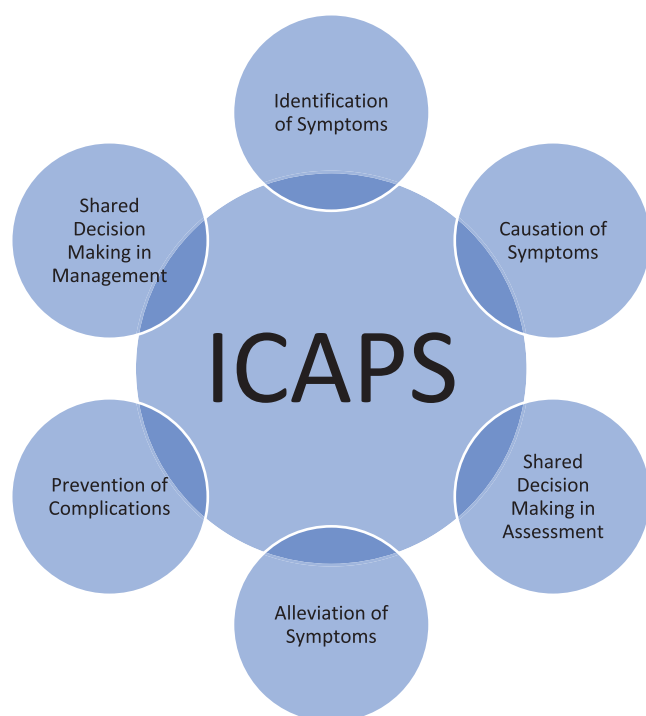


Figure 2. Identification, causation, alleviation, prevention of complications, and shared decision-making (ICAPS) model of symptomatic care in MS. The proposed ICAPS model is based on the ICAP model from Cohen.¹³

searches of Clinicaltrials.gov did not yield any studies or citations not already included.

While the literature search was designed to capture all articles published on this subject, there was a relatively small number of articles identified that met inclusion criteria. The majority of the citations found did not focus on shared decision-making and chronic MS-related physical symptom management. Although there are shared decision-making-based discussions about symptom management in clinical practice, clinical data is lacking, indicating the need for more research in this area.

One randomized control trial met the inclusion criteria for this systematic review. It is encouraging, therefore, that the search used in this systematic review identified the study protocols for three additional randomized controlled clinical trials (NCT04032431, NCT04233970, NCT04236544) that are currently in development to examine the benefit of shared decision-making in the treatment of MS. The results of these and future randomized controlled trials will

be important in the development of this field and the establishment of the specific benefits and effectiveness of shared decision-making in physical MS symptom management.

Conclusion

Based on the consistent conclusions reported in the studies identified in this systematic review, we suggest that shared decision-making is of fundamental benefit to the management of physical MS symptoms. Of primary importance, outside of a shared decision-making structured discussion, the subject of management of physical symptoms may not even arise, in part because clinical consultation time is often severely limited. Thus, management of physical MS symptoms is a critical example of the importance of shared decision-making in bringing clinical aspects of MS that are of high priority to the person with MS to the forefront of discussions with their HCPs.

Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Author contributions

Aliza Bitton Ben-Zacharia: Conceptualization; Data curation; Funding acquisition; Investigation; Project administration; Resources; Supervision; Validation; Visualization; Writing – review & editing.

Jong-Mi Lee: Conceptualization; Resources; Writing – review & editing.

Jennifer Kahle: Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Supervision; Validation; Visualization; Writing – original draft; Writing – review & editing.

Bonnie Lord: Conceptualization; Writing – review & editing.

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Competing interests

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Availability of data and materials

All data accessed in this systematic review are publicly available. Methods details are provided in Supplemental File 1.

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Supplemental material

Supplemental material for this article is available online.

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