

Review

Significance and potential of self-management research for HTLV-1 associated myelopathy: review of self-management for people with multiple sclerosis

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Abstract

Objective and Methods: A total of 21 published studies on self-management for people with multiple sclerosis (MS) were reviewed to explore the significance and potential of self-management for people with HTLV-1 associated myelopathy (HAM). These studies were classified based on three concepts: self-management regimen and preferences, context of self-management, and outcomes of self-management.

Results: Self-management regimens for people with MS include medical, role, and emotional management. Moreover, self-management regimens are closely associated with the context of self-management, emphasizing the importance of investigating contextual factors and regimens concurrently. Quality of life (QOL) has been evaluated as an outcome of self-management, and self-management has been shown to have both positive and negative effects on the QOL of people with MS. However, insufficient studies focus on self-management regimens and patient preferences; further investigation is necessary to develop effective self-management interventions that reflect the often unique nature of the disease for each individual. The characteristics of HAM are also unique to individual patients. Therefore, investigation of people with HAM in particular is required.

Conclusion: This literature review examined the significance of investigating self-management for people with HAM.

Key words: self-management, multiple sclerosis, HTLV-1 associated myelopathy

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Introduction

“Living with illness” is a focal issue for patients, families, and healthcare professionals, following the shift from acute to chronic health conditions. With increasing life expectancy comes the occurrence of chronic conditions among individuals; in other words, “living with illness” is a problem faced by nearly every human in his or her lifetime. Chronic conditions are described as health problems that persist over time and require some degree of healthcare management¹. People with chronic conditions must learn how to manage their illness and its effects long-term, and they must incorporate this management into their everyday lives. They must partner actively with healthcare professionals in managing their chronic conditions².

Management of chronic conditions is found to be difficult, however, for people with neurological disorders that have no cure and an unpredictable prognosis, such as multiple sclerosis (MS) and Parkinson’s disease. Accordingly, it is difficult for patients to identify effects and symptoms they can manage over the course of their illness. People with HTLV-1 associated myelopathy (HAM) in particular often encounter difficulty in managing their chronic condition. HAM is a spinal spastic paraparesis caused by infection with human T-lymphotropic virus type 1. There are approximately 3,000 cases of HAM in Japan. Common symptoms include gait disorder due to chronic spastic paraparesis, weakness of the lower limbs, bladder function disturbance, constipation, and sensory symptoms such as tingling, pins and needles, and burning³. Because there is no cure, people with severe HAM must consider modifying not only their daily behaviors but also their entire way of life. In a previous study⁴, a phenomenological method was used to investigate the experience of people with HAM. Results showed that people with HAM had often been living with their illness for a significant period before their diagnosis,

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and remained in a state of uncertainty after their diagnosis due to lack of knowledge about the disease. Throughout the progression of symptoms, they experienced a “feeling of loss of self-control” over their body, their disease, and their future. However, many attempted to manage the problems caused by HAM. In conclusion, it is important to provide support and opportunity for people with HAM to manage their chronic condition, thereby helping them find positive meaning in their illness and improving their quality of life (QOL). A better understanding of self-management would also provide nurses with information about how to best assist people with HAM.

Self-management is defined as “learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition”⁵. It has gained importance in management of chronic conditions. Self-management science has developed, in part, due to the insufficiency of the acute care model to meet the needs of people with chronic conditions⁶, and research has already described and evaluated self-management interventions in various areas^{6–8}. The Stanford Patient Education Research Center has developed and evaluated self-management programs for people with chronic conditions such as arthritis and HIV/AIDS⁹, which proved to be effective; participants exhibited significantly improved self-management behaviors¹⁰. Previous studies have shown that a self-management approach is effective in supporting not only lifestyle-related diseases, such as hypertension, cardiovascular diseases, and type 2 diabetes, but also progressive neurological disorders such as MS, which is similar in presentation to HAM.

The most common neurological disorder studied in the context of self-management is MS¹¹. Rae-Grant *et al.* identified 39 articles in a systematic review of self-management programs in individuals with MS and other neurological conditions¹². MS is one of the most common chronic progressive diseases of the central nervous system, with the most common symptoms including fatigue, numbness, gait problems, bladder and bowel dysfunction, vision problems, sexual dysfunction, cognitive function changes, and emotional changes¹³. Some characteristics of MS, such as symptoms, uncertainty of course, and progressive disability, are similar to those of HAM. Common issues for people with MS included uncertainty regarding the course, symptoms, and prognosis of their disease and a reduced sense of control¹⁴, consistent with the findings of previous research on the experiences of people with HAM. Patients with HAM may increase their sense of control over their chronic illness through self-management. Furthermore, independent engagement in managing chronic conditions may lead patients to reestablish and/or maintain control over their lives and sustain their QOL^{15–17}. As patients realize that self-

management processes can positively affect their chronic conditions, they may be better able to live with their illness, resulting in enhanced QOL.

For these reasons, studies of self-management in people with MS are very informative for patients with HAM, which shares many symptoms common to neurological disorders. Although a systematic review of self-management intervention for people with MS has already been done¹², the present study conducted an integrative review to determine the current knowledge in self-management science for people with MS, focusing specifically on three concepts: self-management regimens and patient preferences, the context of self-management, and outcomes of self-management. This study aimed to explore the significance and potential of self-management for people with HAM by reviewing published studies of self-management for people with MS.

Methods

Existing research was explored through two electronic databases, PubMed and CINAHL, using MS and self-management or self-care as search criteria, with the following terms added: regimen, preference, context, outcome, and QOL. A self-management regimen is the method for managing a chronic condition, and patient preferences lead to a better understanding of patient perspectives. The context of self-management presumably includes factors relevant to the self-management regimen. QOL was added because it is assumed to be the final outcome of self-management.

Articles that met the criteria for review were identified and classified according to the concepts of self-management regimens and patient preferences, the context of self-management, and outcomes of self-management outlined in a matrix table for review. Each article was systematically read and synthesized.

Results

Twenty-one research articles were identified and classified according to the concepts of self-management regimens and patient preferences, the context of self-management, and outcomes of self-management.

Self-Management Regimens and Preferences of People with MS

Self-management regimens and preferences were identified from six studies (Table 1) that described various disease-specific problems and difficulties as well as management regimens for people with MS.

Self-management regimens

Self-management regimens were identified in four studies that described patient experiences^{18–21} and one that described the development and psychometric analysis of the Multiple Sclerosis Self-Management Scale²². Because self-management encompasses a large number of topics, the present study classified self-management according to the three following tasks, described by Lorig and Holman¹⁰.

Medical management

Medical management describes managing health problems through modified behaviors, such as taking medications, adhering to exercise and diet plans, going to the doctor, and using medical devices^{10, 23}. To assume responsibility for management of their disease, it is important for people with MS to understand the disease and know how it affects them as individuals^{18, 20, 22}. Malcomson *et al.* reported that keeping up to date with the latest research on MS increased patients' knowledge and empowerment²⁰. Furthermore, people with MS must know their own limitations, because patient experiences of different symptoms are unique to each individual²⁰. Understanding and familiarity with one's own case of MS is considered the first step in the self-management regimen, and relates to how patients ultimately participate in their treatment.

Active participation in treatment is important in medical management. Taking medication based on an understanding of its effects is the primary regimen, and medication adherence is expected from patients as part of their daily routines^{21, 22}. Disease-modifying drugs, such as immunomodulating drugs and immunosuppressant drugs, are known treatments for MS²⁴ and are most effective when started early and taken on a generally long-term basis; some cases require self-injection of drugs. Therefore, adherence to treatment is an important regimen in management of MS symptoms. Participation in conventional therapies, such as physiotherapy, speech therapy, and counseling, is another medical regimen that people with MS must consider²¹.

Patients should not only actively participate in their treatment, but also strive to maintain their own health status^{20–22}. The most important health maintenance behavior is exercise, such as stretching, swimming, walking, and yoga. Rehabilitation is another treatment for people with MS. Patients reportedly recognized that appropriate exercise was beneficial both for maintaining their physical status and for coping with emotional issues²⁰. When engaging in exercise, people with MS must incorporate rest so as to minimize fatigue^{20, 21}. They must know their symptoms and capabilities to ensure they have enough energy to get through the day; regular rest is an essential part of their regimen. Dietary supplements, such as vitamins, minerals, and oils, are also

essential to maintain health²¹.

A cooperative relationship between patients and healthcare providers facilitates active participation when people with MS take control of their own health condition. However, some negative experiences were reported by people with MS; studies showed that some healthcare professionals paid attention only to patients' physical signs and symptoms and did not address other concerns, such as psychosocial issues and potential lifestyle changes^{18, 20}. Building trusting relationships between patients and healthcare professionals is a fundamental task in medical management.

Role management

Role management describes maintaining, changing, and creating new meaningful behaviors and life roles to allow people with MS to carry out normal activities^{10, 23}. MS symptoms have adverse effects on patients' daily activities. Specifically, activities of daily living (ADL) and mobility are major issues for patients with MS²¹. Patients must be creative in developing new ways to maintain independence in ADL, and many employ assistive devices, such as wheelchairs, to maximize their mobility.

Symptoms and behavior modification also affect patients' social lives. People with MS tend to adjust their social lives based on their conditions to maintain and develop their social networks^{20, 21}. Malcomson *et al.* reported that fatigue or urinary urgency or frequency required patients to meticulously plan their daily schedules²⁰. Several patients also made changes to their employment circumstances or left work due to mobility issues and the impact of fatigue. People with MS hoped to maintain their social lives as much as possible and to foster a sense of purpose by contributing to society. Such regimens relate to social life adjustments.

When patients assume role management, strong support from their family and friends is indispensable^{20, 22}. Patients also were reported to value the opportunity to meet with others who have MS, which allowed them to share experiences and advise each other. Serious decision-making is a precursor to changing and creating new meaningful behaviors and life roles. Therefore, seeking and accepting support can be considered a meaningful regimen.

Emotional management

Emotional management concerns dealing with the emotional changes associated with a chronic condition, such as anger, fear, frustration, depression, uncertainty about the future, and changed expectations and goals^{10, 23}. O'Hara *et al.* reported that coping, which involves the use of cognitive or behavioral strategies to handle stress, was the highest priority among people with MS²¹. Because people with MS experience uncertainty and unpredictability related to their

Table 1 Self-management regimens and preferences of people with multiple sclerosis

Authors	Purpose	Design/sample	Instruments/measures	Results
O'Hara, De Souza, & Ide (2000)	1. To assess the extent to which a community population of people with MS practice self-care to manage their condition 2. To identify common self-care practices 3. To establish whether a consensus exists regarding priorities in self-care	Design Qualitative research strategy Delphi survey Grounded theory approach Sample 136 people diagnosed with MS, as confirmed by general practitioners. Response rates: round 1 $N = 136$ (68%), round 2 $N = 131$ (96%), round 3 $N = 126$ (95%).	Round 1 Task: List up to 10 things you do for yourself because of your MS. Categories were elicited from the data by thematic content analysis in a grounded theory approach. Round 2 Task: Rank your top 10 priorities out of 17 key areas from round 1 Round 3 Task: Indicate whether or not you agree with the group rankings	Round 1 101 people reported using 10 or more self-care practices (74%) These were categorized into 17 areas for the main survey Round 2 Most categories within the top 10 in round 1 remained in the top 10 in round 2 Round 3 Priorities in self-care in round 3 were ranked as follows (mean rank): 1. Coping (1.5), 2. ADL (3.6), 3. Social life (3.7), 4. Rest (5.2), 5. Mobility (5.7), 6. Dietary supplements (6.5), 7. Medication (6.6), 8. Exercise (7.0), 9. Leisure (7.2), 10. Conventional therapy (8.2)
Courts, Buchanan, & Werslein (2004)	To investigate the lived experience of people with MS and to examine their needs from their own perspective	Design Qualitative research strategy Focus group interview; two focus groups held Sample 10 individuals affiliated with the Multiple Sclerosis Society (MSS)	Each focus group lasted approximately 1.5–2 h. Focus group audiotapes were transcribed verbatim and analyzed by the investigators to identify themes.	Four themes identified <i>Nobody's listening</i> Based on participants' feelings <i>Symptom devastation</i> Based on descriptions of the overwhelming presence of symptoms with accompanying lifestyle changes <i>Pick and choose</i> Described activities to maintain a sense of control over life, and the progression of denial <i>Fight your own fight</i> Described becoming a "self-advocate" and taking charge of lifestyle changes
Isaksson & Ahlström (2008)	To describe the methods used by patients with MS to manage chronic sorrow and to apply these management methods to the theoretical model of chronic sorrow	Design Qualitative research strategy Qualitative latent content analysis Sample 38 participants identified in the previous study (2005) as experiencing chronic sorrow	Interview aided by the Swedish version semi-structured, open-ended interview guide developed by the Nursing Consortium for Research on Chronic Sorrow (NCRCS), Swedish version. Qualitative latent content analysis. Theoretical model used to sort the narrative text.	Management of chronic sorrow in patients with MS <i>Ineffective internal management</i> Theme: Struggling with vulnerability <i>Ineffective external management</i> Theme: Deficient affirmation <i>Discomfort</i> Theme: Sorrow resulting from vulnerability <i>Effective internal management</i> Theme: Mastering with realistic awareness <i>Effective external management</i> Theme: Endorsing management <i>Increased comfort</i> Theme: Appreciation of life and trust in the future

Authors	Purpose	Design/sample	Instruments/measures	Results
Malcomson, Low-Strong, & Dunwoody (2008)	1. To explore personal accounts and experiences of individuals with MS who felt able to cope with the disease in day-to-day life 2. To use this information to advise others on coping techniques or strategies to maximize quality of life/well-being in day-to-day life	Design Qualitative research strategy Focus group interview; two focus groups held Thematic analysis Sample 13 individuals affiliated with the MS Society in Northern Ireland	Focus groups lasted 90 min each. Groups were video- and audiotaped and transcribed verbatim by researchers. Thematic analysis is "a method of identifying, analyzing, and reporting patterns (themes) within data"	Theme and subthemes <i>Something is wrong</i> Distress, uncertainty, and fear <i>Getting a diagnosis</i> Prolonged Unsupportive and unhelpful Feelings <i>Getting help</i> Lack of psychosocial support <i>Consequences to lifestyle</i> Interpersonal consequences Changing employment circumstances Major challenges <i>Getting on with day-to-day life</i> Proactivity Perspective Control via self-management <i>Advice for others with MS</i> Self-management and perspective <i>Advice for health professionals</i> Personal needs Guidance and information <i>"Expert" patients and peer support</i>
Hessen, Kasper, Segal, Köpke, & Mühlhauser (2004)	To describe possible prerequisite factors for patient participation in people with MS, such as patient role preferences, MS risk knowledge, perceived subjective knowledge level, and information interest	Design Descriptive correlational study (comparative descriptive design) Sample 100 randomly selected patients in each group: primary progressive (PP) and relapsing-remitting (RR) disease 169 patients with MS (out of 213; response rate 79%)	MS risk knowledge (MSK) questionnaire Perceived level of knowledge (PLK) Information interest questionnaire Role preference scale 12-item instrument used to obtain MS demographic data	Decisional role preferences Most patients ranked shared decision-making ($n = 65$) and informed choice style highest ($n = 60$); 79% of patients preferred active roles. Strongest correlation (Pearson's $r = 0.4$, $p = .05$) between MSK and role preference was found in the patient group with the shortest disease duration. PLK was also significantly correlated with different role preferences, supporting the link between autonomy and knowledge (ANOVA $F(4; 135) = 3.1$, $p = .018$). MSK and PLK Mean knowledge score was 6.4 (SD: 2.4), representing 34% of possible correct answers. Highest MSK score was seen in patients with a recent (maximum 1 year) MS diagnosis, followed by RR and PP patients (ANOVA $F(2; 166) = 15.9$, $p = .001$). The RR subgroup answered 38% of questions correctly compared with 27% in the PP group. Recently diagnosed patients had the highest MSK scores (ANOVA $F(3; 163) = 7.1$, $p = .000$). Information interest Major information interests were related to alleviation of symptoms and MRI. PP patients showed strong interest in treatment of gait disturbances and physiotherapy, followed by experimental therapies. Immunomodulatory therapies were among the minority of areas chosen in the whole cohort and in the subgroups. Patients with knowledge scores in the upper quartile rated the knowledge item "validity of studies" among the top three. In the three other patient groups, this item was not mentioned among the top 10.

Authors	Purpose	Design/sample	Instruments/measures	Results
Bishop & Frain (2007)	To describe the development and psychometric analysis of the Multiple Sclerosis Self-Management Scale (MSSM)	<p>Design Item generation and scale development</p> <p>Pilot testing and revision</p> <p>Sample 266 individuals with MS: random sampling from the mailing lists of three chapters of the National MS Society in the Southeastern United States</p>	<p>Questions concerning demographic and MS-related information</p> <p>Multiple Sclerosis Impact Scale (MSIS-29)</p> <p>Delighted-Terrible Scale (DTS; an overall QOL scale)</p> <p>Multiple Sclerosis Self-Management Scale (MSSM)</p>	<p>Factor Analysis One of the 39 items was loaded $\leq .30$ on all factors and was dropped. The final MSSM included 38 items.</p> <p>Cronbach's $\alpha = 0.86$</p> <p>Mean of overall MSSM scale: 157.72 (SD: 16.46).</p> <p>Replicability supported by similarities in means among sexes and across educational backgrounds and race.</p> <p>Seven factors identified: Factor 1, treatment adherence (7 items) Factor 2, care provider-patient relationship (5 items) Factor 3, emotional health and social support/resources (8 items) Factor 4, health and symptom awareness (4 items) Factor 5, MS knowledge and information (5 items) Factor 6, health maintenance behavior (5 items) Factor 7, communication about symptoms or changes (5 items)</p> <p>Construct validity assessed by correlation with QOL and MSIS-29: Moderately positive correlation between MSSM and DTS ($r = 0.45, p = .000$) Moderately negative correlation between MSSM and both the psychological health impact scale ($r = -0.39, p = .000$) and the physical health impact scale ($r = -0.28, p = .000$)</p>

illness after diagnosis, the authors' findings are consistent with the common trajectory of MS patients' experiences. People with MS must cope with the stress associated with MS symptoms and everyday life using methods such as relaxation, aromatherapy, and low-impact exercise, like yoga and swimming²⁰.

Because MS is a personally intrusive condition and requires patients to rethink their life goals and plans, people with MS experience a range of feelings, such as distress, fear, frustration, worthlessness, and reduced self-esteem, both before and after diagnosis²⁰. Patients have attempted to manage their feelings by staying aware of them, being open and honest, and having the confidence to seek help. As described by Isaksson and Ahlström, some people with MS were able to find ways to effectively manage chronic sorrow¹⁹. Internal management methods involved distraction for comfort, acceptance and adjustment, "can-do" attitudes, positive and constructive thinking, creation of hope, and personal care. External management methods included care and encouragement from family, respectful acknowledgment from friends, and confirmation from healthcare personnel. In contrast, Courts *et al.* reported denial as a defense mechanism for controlling the emotional impact of MS's intrusion into patients' daily lives¹⁸.

Patient preferences

Patients' preferences reflect their wishes regarding self-management. Only one article was identified that related to MS patient preferences in terms of self-management. Hesen *et al.* explored patients' decisional role preferences, knowledge of risks, and interest in information, as well as the relationships among these factors²⁵. Seventy-nine percent of patients preferred to take an active role in areas such as informed choices and shared decision-making in the course of treatment. People with MS showed interest in obtaining information related to alleviation of symptoms and MRI to determine symptom progression, followed by knowledge of relapses, including knowledge of steroids and eastern complementary medicine.

Context of Self-Management for People with MS

Although some self-management contexts for people with MS are discussed in the section on self-management regimens and preferences, the present study tried to identify them by adding five articles (Table 2). Each aspect of context was classified among three contextual factors—condition-specific factors, physical and social environments, and individual and family characteristics—which are described by the Individual and Family Self-Management Theory²⁶.

Condition-specific factors

Condition-specific factors are physiological, structural, or functional characteristics of the condition and its treatment or prevention that impact the number, type, and importance of behaviors needed to manage it²⁶. As mentioned in the section on self-management regimens, the characteristics of MS, such as its devastating symptoms, affect patients' self-management¹⁸. Features such as a protracted diagnostic process were related to healthcare communication²⁷. Biomarkers such as fatigue affected the significance of self-care decisions for people with MS²⁸. Moreover, the type of MS was associated with self-efficacy²⁹. Because it is difficult for others to understand the variety of personal differences and the sometimes invisible symptoms experienced by people with MS, symptoms unique to each patient affect their self-management regimens.

Physical and social environments

Environmental factors can be physical or social, including access to healthcare, transitions in healthcare providers or settings, transportation, neighborhood, work, school, culture, and social capital, and can either enhance life or present barriers²⁶. As stated in the section on role management, physical factors, such as the availability of mobility aids and certain employment circumstances, affected self-management in people with MS with respect to social life^{20, 21}. Likewise, others' lack of knowledge about MS was related to ineffective management of chronic sorrow¹⁹, and self-management was further affected by social relationships³⁰ and interactions within the social context²⁸. Interpersonal encounters stigmatized people with MS via one of two processes, either ignoring or overemphasizing the illness, in social relationships³⁰. Stigma within a social network led to a sense of "feeling more ill" in patients, and may interfere with their active engagement in managing their own care. Paterson *et al.* found that MS influenced social interactions for patients, determining the significance of their decisions. For example, the visibility of MS symptoms often exposed people with MS to public scrutiny, causing them to avoid moving in public settings for fear of being regarded as "handicapped"²⁸.

Healthcare professionals were reported to play an important role in MS patients' social environments^{27, 31}, given that patients seek their advice and support³¹. However, patients reported cases of ineffective communication with healthcare professionals, such as lack of respect or engagement and highly adversarial interactions²⁷. Such attitudes taken by healthcare professionals may discourage effective self-management.

Table 2 Context of self-management for people with multiple sclerosis

Authors	Purpose	Design/sample	Instruments/measures	Results
Paterson, Thorne, & Russell (2002) **"Chronic illness" refers to type 2 diabetes, HIV/AIDS, or MS	To investigate the nature of self-care decision-making in chronic illness to develop a comparative analysis of disease and identify patient criteria to evaluate self-care decision-making across diseases	Design Qualitative research strategy Sample 21 English-speaking individuals over the age of 18 who received treatment for either type 2 diabetes, HIV/AIDS, or MS for a period of at least 3 years (7 individuals in each disease category)	Multiple data-collection methods used: 1. A modified "think-aloud" technique 2. Audiotaped formal interviews 3. Final focus group Data collection and analysis were conducted concurrently using a constant comparative analytic approach. Initial analytic framework was built on the authors' previous research.	Self-care decision making in chronic illness has both general and disease-specific features <i>Timeliness</i> Affected number of everyday decisions and perceived prognosis <i>Interaction within a social context</i> Patients' disease influenced their social interactions, and their social interactions determined the meaning and significance of their decisions <i>Biomarkers</i> Physiological indicators and symptoms typically associated with the disease <i>Healthy practices</i> Considered an aspect of self-care decision-making by all participants <i>Information</i> The quantity and nature of information available about the disease and its management influenced the meaning and significance of self-care decision-making, particularly decisions about consulting others and adhering to prescribed regimens
Thorne, Harris, Mahoney, Con, & McGuinness (2004) **"Chronic illness" refers to end-stage renal disease (ESRD), non-insulin-dependent diabetes mellitus (NIDDM), MS, and fibromyalgia (FM)	To examine commonalities and variations across theoretically selected disease categories to develop initial conclusions about the general field of healthcare communication in chronic illness	Design Qualitative research strategy Grounded theory Sample 38 individuals representing four chronic conditions recruited from various local clinics and healthcare practices (12 with MS, 10 with FM, 7 with ESRD, and 8 with NIDDM)	Data collection Face-to-face interviews and focus groups: Eight participants involved in focus group discussion Eight healthcare professionals experienced in care of people with chronic illness involved in interviews during a final research phase.	Common communication themes Patients indicated the importance of healthcare communication at three distinct levels <i>Courtesy</i> Pertained to the general tone of interactions related to scheduling, everyday politeness, remembering names, and feeling welcome within the clinic or office <i>Respect</i> Pertained to individual consultations between patients and healthcare practitioners <i>Engagement</i> An extension of courtesy and respect
Grytten & Måseide (2006)	1. To investigate how people with MS experience attitudes toward MS and how they act on stigma in personal relationships 2. To explore the situational significance of stigma by elaborating on social relationships in networks and how people manage the experience of stigma within the social networks of everyday life	Design Qualitative research design Grounded theory approach Sample 14 informants: five recruited by physicians, five by the local MS, and four by a support group	Unstructured interviews with flexible and open-ended questions The constant-comparison method originating from the grounded-theory method of Glaser and Strauss	<i>Stigma and the experience of being ignored</i> Invisible symptoms and inability to communicate the presence of the disease cause ignoring: polite inattention toward the illness. <i>Networks and the dilemma of acknowledgment</i> Networks may overemphasize acknowledgement of MS and run the risk of negotiating yet another conflicting meaning; well-intentioned acts by those in close relationships with MS patients might represent a dilemma. <i>Coping systems and construction of MS</i> Individuals with MS established social relationships with relatives and other people with MS to obtain moral support and affirmation in approaching social contexts. Coping systems are especially relevant when people with MS face new situations that threaten their identity. <i>Development of a coping system</i> Coping systems are created to counteract social isolation and negotiate acknowledgment of MS resulting from stigma.

Authors	Purpose	Design/sample	Instruments/measures	Results
Fraser & Polito (2008)	To examine whether there was a difference in self-attendance between men and women with RRMS and progressive MS	<p>Design Comparative descriptive design</p> <p>Sample Convenience sample of 556 individuals with RRME and progressive forms of MS who completed the MSSE and demographic questionnaire</p>	Multiple Sclerosis Self-Efficacy Scale (MSSE): Contains 18 items rated on a scale of 10–100 regarding how certain individuals are that they will be able to perform specific behaviors Demographic questionnaire	<p>Women scored significantly higher on the MSSE function subscale ($M = 734$) than men ($M = 667$; $t = 3.4$, $p = 0.002$)</p> <p>Women scored higher on the MSSE control subscale ($M = 595$) than men, but not significantly ($M = 556$; $t = 1.5$, $p = 0.14$)</p> <p>Men with RRMS scored significantly higher on the MSSE control subscale ($M = 593$) than men with progressive MS ($M = 534$; $t = 2.02$, $p = 0.05$)</p> <p>Men with RRMS scored significantly higher on the MSSE function subscale ($M = 759$) than men with progressive MS ($M = 539$; $t = 6.2$, $p = 0.000$)</p> <p>Women with RRMS scored significantly higher on the MSSE control subscale ($M = 619$) than women with progressive MS ($M = 492$; $t = 5.4$, $p = 0.000$)</p> <p>Women with RRMS scored significantly higher on the MSSE function subscale ($M = 777$) than women with progressive MS ($M = 555$; $t = 11.2$, $p = 0.000$)</p>
Peters, Somers, Campbell, & Sharp (2003)	To ascertain variables independently associated with attendance at meetings and variables related to the level of perceived helpfulness among attendees	<p>Design Descriptive correlational design</p> <p>Sample Stratified random sample: 200 practices from eight randomly selected health boards or authorities invited to participate, two from each of four geographical areas. 67 agreed to participate, with similar participation rates across areas. As anticipated, an average of eight people with MS were registered with each practice</p>	<p>Cross-sectional survey using a postal questionnaire</p> <p>Explanatory variables</p> <ol style="list-style-type: none"> 1. Sociodemographic 2. Illness-related 3. Support-related 4. Self-management 5. Psychosocial 6. SF-36 social function score 	<p>Special meetings Only 136 (43%) had attended a meeting for people with MS. This proportion was higher among those with progressive MS (likelihood ratio $\chi^2 = 9.6$, $d.f. = 3$, $p = 0.02$). Of the 126 respondents, 20% found the meetings “not at all helpful”, 30% “slightly helpful”, 27% “moderately helpful”, and 24% “very helpful”.</p> <p>Variables associated with any attendance at special meetings <i>Univariate analyses</i> Nine of the 23 variables were statistically significant at the 5% level in single-variable logistic regression analyses <i>Multivariate analyses</i> The final model contained three variables: age group, contact with any health professional, and information factor Likelihood of attending roughly doubled between ages 45 and 64 years Among those who had contact with any health professional in the past 12 months, likelihood of attendance increased nearly sixfold For an increase of 1 in the information factor score, likelihood of attending decreased by approximately 30%</p> <p>Variables associated with the helpfulness of meetings <i>Univariate analyses</i> Four of the 23 variables were statistically significant at the 5% level in single-factor proportional odd regression models: an item relating to support ($p = 0.018$), self-management issues ($p < 0.0001$), the SF-36 mental health score ($p = 0.0016$), and the BDI score in four categories ($p = 0.0052$)</p> <p><i>Multivariate analyses</i> The last meeting attended was perceived as most helpful among those with mild depression (odds ratio = 1.91) and least helpful among those with more severe depression (odds ratio = 0.44). Lower levels of contentment regarding ability to access MS-related information were associated with reduced perceived helpfulness of the last meeting attended.</p>

Individual and family characteristics

Factors related to individuals and families may enhance or diminish self-management²⁶. Sociodemographic factors, such as age and sexuality, may also influence self-management^{29, 31}. Moreover, the ability and means to access MS-related information reportedly affected patients' attitudes toward attending meetings³¹. As mentioned in the section on medical management, understanding of MS and familiarity with the individual characteristics of one's own disease is reflected in self-management skills²⁰. Furthermore, family support for people with MS influences self-management. In an overlap with social environment factors, lack of acknowledgment or overemphasis of MS by family members created a sense of stigma among patients³⁰. Appropriate recognition of MS within the family was an effective contextual factor supporting self-management in people with MS.

Outcomes of Self-Management

Ten articles were selected for inclusion in this review to identify the outcomes of self-management on people with MS (Table 3), of which four described self-management regimens and outcomes and the other six self-management intervention programs and evaluated outcomes. Two of the six interventions focused on overall self-management. One was not disease specific³²; another focused specifically on MS³³. Two studies used the same wellness intervention program^{17, 34}. Another intervention focused on physical activities³⁵, and the final intervention focused on management of cognitive symptoms³⁶. Based on these studies, two types of outcome were described, discussed separately in this review: the effects of self-management intervention, and the final consequences of self-management.

Effects of self-management intervention

Three studies reported the effects of self-efficacy on people with MS with respect to self-management interventions. Two of the three showed positive effects of self-efficacy on self-management; they demonstrated a trend toward improvement in MS self-efficacy³² and improvement in self-efficacy for health practice¹⁷ as a result of self-management intervention. Systematic programs and continuous support based on self-management programs may increase patients' confidence to participate in self-management regimens. In contrast, Plow *et al.* reported that self-efficacy and expectation of physical activity frequency decreased significantly, whereas self-identity improved³⁴. They concluded that self-management interventions might cause changes in psychological constructs, such as self-efficacy, self-identity, and expectations.

Similarly, researchers have reported improvement in

health-promoting behaviors¹⁷ and increase in patients' understanding of MS³⁵. Shevil and Finlayson reported that the cognitive self-management intervention program had a positive impact on management of cognitive symptoms by increasing knowledge and awareness of cognitive changes, having positive social and emotional impacts, and changing perceptions regarding cognitive changes³⁶.

Outcomes of self-management regimens

In five studies, QOL improvement was measured as an outcome of self-management in people with MS. This is the ultimate goal for both patients and healthcare professionals. In a study by Stuifbergen *et al.*, improvements in selected dimensions of QOL, such as bodily pain and mental health, were observed as a result of the wellness intervention program¹⁷. According to Bishop *et al.*, self-management is strongly associated with perceived control, and both perceived control and self-management mediate the relationship between impact of MS and subjective QOL^{14, 37}. However, as described by Hartley, the ACTIVE (Advice, Coping mechanisms, Training, Information, Value your health, and Exercise) program, which involved information sessions, supervised exercise sessions in a hospital and a leisure center, contributed significantly to improved QOL in MS patients with mild to moderate impairment³⁵. Shaw *et al.* reported that symptom relief among people with clean intermittent self-catheterization had a positive effect on QOL³⁸. In contrast, practical difficulties, urinary tract infections, and psychological and cultural contexts were reported to have a negative effect on QOL.

Improved sleep and decreased fatigue³³, improved physical activity³⁴, improved physical status and depression³², and significant improvement in walking speed were also reported³⁵. Simmons *et al.* found an association between management of MS symptoms in the workplace and loss of employment and perceived risk of losing current employment for people with MS³⁹.

Discussion

This study aimed to explore the significance and potential of self-management for people with HAM based on the results of research on self-management for people with MS, focusing specifically on three concepts: self-management regimens and patient preferences, the context of self-management, and outcomes of self-management.

First, various aspects of self-management regimens for people with MS were reported, such as medical management, role management, and emotional management. Medical management included acquiring and keeping up to date with information related to MS and treatment, understand-

ing MS and being familiar with one's individual disease, understanding and adhering to a course of treatment, practicing health maintenance, knowing one's own capabilities in daily life, and building good relationships with healthcare professionals. Role management involved creating new ways to maintain independence, using aids, adjusting one's social life, and maintaining and developing one's social networks. Emotional management included coping with stress and managing negative feelings.

The characteristics of MS, such as a spectrum of symptoms, an uncertain course, progressive disability, and lack of cure, require patients to actively engage in self-management regimens. Regretfully, few studies have focused on the contents of self-management regimens for people with MS, leaving a gap in the literature related to self-management of MS. However, because MS patient care is already generalized and there is some degree of self-management intervention¹²⁾, further study or recognition of this gap by researchers may not be necessary. Of course, standard care and self-management interventions could be based on evidence from studies and past practices. However, self-management interventions cannot advance without a continuously updated understanding of patient perspectives due to the diversity of MS symptoms and uniqueness of patient experiences. Thus, it is important to enquire further into the self-management regimens and preferences of patients with MS to affirm the philosophy that self-management is "patient-centered." The characteristics of HAM are similarly unique to individual patients. Therefore, investigation of people with HAM will be needed to establish a standard of care for them in particular. Detailed investigation into self-management regimens from the patient perspective is important to develop effective self-management interventions that reflect the often unique nature of the disease for each individual. According to Lorig and Holman, although many concerns are shared across different diseases, behaviors, and populations, needs always differ between groups and even individuals¹⁰⁾. Therefore, assessment of the specific needs of people with HAM is a priority. Accordingly, this reaffirms the necessity of studying the qualitative aspects of regimens and patient preferences for people with HAM.

In this literature review, some contexts of self-management were identified based on three dimensions. Condition-specific factors illustrated the features of MS, such as a protracted diagnostic process, devastating symptoms, uncertain prognosis, progressive disability, and limited medical interventions. It is difficult to understand the experiences of people with HAM due to their complex backgrounds; the number of patients is small, there is no cure, the disease is infectious, and it can manifest in a variety of possible symptoms. Healthcare professionals who aspire to provide

effective self-management support should understand these features of the disease and the lived experiences of people with HAM.

Physical and social environmental contexts included the impact of physical conditions in social life, social relationships, and social interactions. Social environments influenced the psychological aspects of MS, as well as its significance and meaning. Environmental factors can be facilitative but also obstructive in the self-management of people with MS; thus, further research must investigate how different contexts mediate self-management. In particular, MS patients often felt stigmatized by interpersonal encounters. This presents the possibility that HAM patients may also experience stigmatization in social interactions. HAM is not as socially recognized and is apt to be misunderstood because its symptoms vary by individual. Moreover, HAM is an infectious disease that carries a lingering stigma toward viral infection, because it is in the same family as HIV and HBV. For these reasons, people with HAM may not feel comfortable disclosing their disease to others or consulting others about their chronic condition. It would be meaningful to focus on stigmas in future studies, because stigma may affect patients' active engagement in self-management.

Individual characteristics included demographic factors, recognition of MS-related information, and familiarity with one's individual case of MS. Family characteristics included capacity to support people with MS; however, limited literature exists on family characteristics. Family has a continuous effect on patients' self-management regimens. Further investigation of patient-family relationships, family functioning, and the effects of these factors on patients' self-management practices is necessary. Previous studies have found that family interactions and relationships affect HAM patients' decision-making. Therefore, there is a need for research exploring the meaning of family with respect to self-management in people with HAM.

Self-management interventions not only directly affect self-management regimens but also indirectly affect some contextual factors, such as self-efficacy and increased knowledge and understanding of MS. Some studies demonstrate the efficacy of self-management interventions for people with MS. Self-management also leads to some positive outcomes for people with MS regarding specific symptoms, physical status, and psychosocial consequences. With respect to QOL, the outcomes of self-management can be both positive and negative. Given the varying symptoms of MS and its impact on patients, QOL was investigated from both quantitative and qualitative approaches. This study suggests a need to explore in detail the meaning of self-management for QOL in people with HAM.

Table 3 Outcomes of self-management for people with multiple sclerosis

Authors	Purpose	Design/sample	Instruments/measures	Results
Shaw, Logan, Webber, Broome, & Samuel (2008)	To describe the experience of people carrying out CISC and the impact on their quality of life	<p>Design Qualitative methodology</p> <p>Grounded theory approach</p> <p>Sample Sampling frame: all those registered with the continence services in Wales and regularly using self-catheterization 15 individuals agreed to take part in the study</p>	<p>Data collection Semi-structured interview</p> <p>Data analysis Grounded theory approach</p>	<p>Impact on quality of life <i>Positive impact</i> Related to alleviation of lower urinary tract symptoms leading to CISC therapy. Symptoms of urgency, frequency, and incontinence had a major impact on people's lives, and CISC greatly relieved the consequences of these symptoms.</p> <p><i>Negative impact</i> Impact on daily activities and social activities Physical impact Carrying out CISC Psychological impact</p> <p>Factors explaining variation in impacts on quality of life Six first-order categories identified:</p> <ol style="list-style-type: none"> 1. "Reasons for carrying out CISC" 2. "sex" 3. "Type of catheter" 4. "Frequency of carrying out CISC" 5. "Duration of CISC" 6. "Lifestyles"
Shevil & Finlayson (2009)	To evaluate a group-based, cognitive self-management intervention program developed specifically for people with MS	<p>Design Mixed-method study design: Qualitative (focus group) and quantitative (descriptive)</p> <p>Sample 31 individuals who met eligibility criteria and attended at least four intervention sessions</p>	<p>Intervention "Mind over matter: learning to manage cognitive symptoms in multiple sclerosis" Focus group interview Focus groups conducted during the second half of the fifth session in each cycle</p> <p>Program evaluation questionnaire Telephone-administered by a trained research assistant 6 to 10 days after the program ended</p> <p>Facilitator reflection notes Completed by the facilitator</p>	<p>Of the 35 participants, 22 attended all five sessions, suggesting that the program was interesting and met their needs. Most items received a mean rating above 6 or 7.</p> <p>Process evaluation categories and subthemes <i>Course content</i></p> <ol style="list-style-type: none"> 1. Increasing knowledge and awareness of cognitive changes 2. Problem solving through cognitive challenges 3. Practicing solutions and strategies 4. Emotional and social implications 5. Changing perceptions <p><i>Format and methods of delivery</i></p> <ol style="list-style-type: none"> 1. Repetition 2. Group-based intervention 3. Length 4. Handouts 5. Homework 6. Between-session calls 7. Facilitator 8. Location <p><i>Recommended changes</i></p> <ol style="list-style-type: none"> 1. Incorporation of caregivers 2. Additional content

Authors	Purpose	Design/sample	Instruments/measures	Results
Bishop, Shepard, & Stenohoff (2007)	To describe an evaluation of the disability centrality model among a sample of people with MS	<p>Design Descriptive correlational study</p> <p>Theoretical framework Bishop (2005) developed the Disability Centrality Model</p> <p>Sample 98 adults with MS on the mailing list of a chapter of the National MS Society located in the Southeastern United States</p>	<p>Instruments Delighted-Terrible Scale (DTS) Ladder of Adjustment Disability Centrality Scale (DCS) Self-Management Scale</p>	<p>Intervariable correlations All correlations were in the predicted direction</p> <p>Mediation analysis Domain satisfaction was regressed on domain impact ($p < 0.0001$). QOL was regressed on domain impact ($p = 0.002$). QOL was regressed on both domain impact and domain satisfaction. The relationship between domain satisfaction and QOL was significant ($p < 0.0001$), and the previously significant relationship between impact and QOL was no longer significant ($p = 0.774$). The Sobel test supported the mediating role of satisfaction in the relationship between impact and QOL ($p < 0.0001$).</p> <p>Domain control was regressed on domain impact ($p < 0.001$). QOL was regressed on domain impact as described in analysis 1. QOL was regressed on both domain impact and domain control. The relationship between domain control and QOL was significant ($p < 0.0001$), and the previously significant relationship between impact and QOL was no longer significant ($p = 0.540$). The Sobel test supported the mediating role of control in the relationship between impact and QOL ($p < 0.0001$).</p> <p>Moderation analysis The hypothesized moderating effect of importance was supported by the significant path from the interaction term to overall QOL ($p = 0.053$; $B = 0.656$) and the significant change in R^2 when the interaction term entered the regression equation.</p>
Bishop, Frain, & Tschopp (2008)	To explore the relationships between perceived control, self-management, and subjective quality of life (SQOL) among a sample of adults with MS	<p>Design Descriptive correlational design</p> <p>Conceptual framework Included the illness intrusiveness model and the disability centrality model</p> <p>Sample 157 adults with MS randomly selected from the mailing lists of two chapters of the National MS Society located in the Southeastern United States</p>	<p>Delighted-Terrible Scale (DTS) Disability Centrality Scale (DCS) Multiple Sclerosis Self-Efficacy Scale (MSSE) Multiple Sclerosis Impact Scale (MSIS-29)</p>	<p>Intervariable correlations Self-management, perceived control, the importance-satisfaction interaction term, and SQOL were all significantly positively correlated with each other and significantly negatively correlated with the two measures of MS impact</p> <p>Mediation analyses The direct effects model testing the subject impact of MS on SQOL demonstrated adequate fit, and the chi-square test statistic was significant, $p = 0.000$. The path coefficient from subjective MS to SQOL was significant and negative, $\beta = -0.38$, $t(4,155) = -5.09$, $p < 0.001$.</p> <p>The direct effects model testing the symptom impact score on SQOL demonstrated adequate fit, and the chi-square test statistic was significant, $p = 0.000$. The path coefficient from combined MSIS-29 scores to SQOL was significant and negative, $\beta = -0.64$, $t(4,155) = -9.973$, $p < 0.001$.</p> <p>The full model for subject impact provided a slightly improved fit, and the chi-square test statistic was still significant, $p = 0.000$. The path coefficient from subjective MS to SQOL was no longer significant, $\beta = -0.111$, $t(4,155) = -1.802$, $p = 0.074$, indicating full mediation.</p> <p>The full model for symptom impact provided an improved fit, and the chi-square test statistic was still significant, $p = 0.000$. The path coefficient from symptom impact to SQOL remained significant but was reduced, $\beta = -0.007$, $t(4,155) = -3.218$, $p = 0.002$, indicating partial mediation.</p> <p>The modified model provided an improved fit over the prior model, and the chi-square test statistic became nonsignificant, $p = 0.11$. The path coefficient from MS impact to SQOL remained nonsignificant, $\beta = -0.106$, $p < 0.069$, suggesting full mediation.</p> <p>The modified model with symptom impact provided an improved fit over the prior model, and the chi-square test statistic was nonsignificant, $p = 0.126$. The path coefficient from MS impact to SQOL remained significant, but was reduced from the direct effects model, $\beta = -0.249$, $p = 0.002$, suggesting partial mediation.</p>

Authors	Purpose	Design/sample	Instruments/measures	Results
Simmons, Tribe, & McDonald (2010)	<p>1. To measure employment rates in MS patients both cross-sectionally and longitudinally</p> <p>2. To assess the reasons for employment loss and perceived risk of future employment loss</p>	<p>Design Descriptive correlational design</p> <p>Sample AMSLS's Australian volunteers with MS, recruited with the assistance of MS societies in all states and territories. In 2003, 1,135 people responded (53%). In 2007, 1,329 responded (57%). 667 patients responded to both surveys.</p>	<p>Questionnaire Distributed to participants in the AMSLS in 2003 and 2007. Covered the following: 1. Economic circumstances, including questions on present and past employment 2. Self-reported reasons for employment loss and risk of current employment loss 3. Details of living arrangements including type of residence, dependents, income, social security benefits, allowances, and health insurance coverage</p> <p>Disease Steps Scale Physician-reported disability level available for respondents within 12 months of the first survey, 2003.</p>	<p>Longitudinal change in employment</p> <ol style="list-style-type: none"> Overall 5.4% decrease in total employment over 4 years Total <i>return to employment</i> percentage of 4.6% in 2007 8.1% of participants left employment due to MS between 2003 and 2007 55.9% of participants their employment due to MS in 2007 64.2% of the same cohort classified as not in the paid labor force <p>Comparison of employment between people with MS and Australian population in 2007 Respondents with MS differed adversely and significantly from the Australian population in all employment participation categories of expert part-time employment for both men and women</p> <p>Leaving employment due to MS and gender Odds of leaving employment due to MS were 2.5 times higher in men than women ($p < 0.001$). Older respondents were more likely to have left employment due to MS; estimated odds of leaving employment increased by a factor of 1.3 for every decade of life ($p = 0.003$).</p> <p>Leaving employment due to MS and employment category In 2007, 63% of respondents who stated their employment category before MS reported having left work due to MS. There was no clear pattern to suggest an association between leaving employment due to MS and occupation type. Occupation type before MS diagnosis was not a significant predictor of leaving employment due to MS ($p = 0.95$).</p> <p>Age of retirement In 2007, 19.6% of women and 7.6% of men were "retired." Mean age of retirement differed significantly between men (50.0) and women (52.5, $p = 0.010$).</p> <p>Reasons for leaving employment The most common reasons reported in both surveys were related to MS symptoms, particularly fatigue (69.5% of those who left employment in 2007), and physical problems involving legs or feet (43.8%), arms or hands (36.7%), balance or dizziness (31.2%), and heat sensitivity (30.0%). Of those who left work, 27.8% were advised to stop working by a doctor or health professional and 17.6% were asked to resign or fired; 19.2% were not able to find more suitable work within their organization. Less than 20% of respondents listed reasons related to transport.</p> <p>Reasons for perceived risk of employment loss The most frequently reported reasons for risk of current employment loss were MS symptoms including fatigue (77.7% of those reporting risk of employment loss in 2007); problems with legs or feet (40.8%); difficulty with memory, concentration, or thinking (49.5%); problems with arms or hands (31.1%); bladder or bowel problems (24.3%); and pain (24.3%). A total of 42.7% of those who perceived risk to their paid employment felt they "were not good enough for the job", and 27.2% felt "too stressed by the effort". Among the "influence from management" factors affecting employment loss risk, not being allowed flexible work hours or conditions was the most frequently reported (22.3%); workplace architectural barriers were also perceived as a risk factor (20.4%).</p>

Authors	Purpose	Design/sample	Instruments/measures	Results
Plow, Mathiow, & Resnik (2008)	<p>1. To determine the impact of physical activity (PA) interventions and experience with PA on psychosocial constructs</p> <p>2. To identify constructs that correlate with PA</p> <p>pre- and postintervention</p> <p>3. To determine whether changes in constructs are associated with changes in PA</p>	<p>Design Quasi-experimental study design</p> <p>Sample 50 individuals with MS recruited through a letter from the Minnesota Chapter of the National MS Society and by postings in neurology offices</p>	<p>Intervention 7-week group education intervention: program based on a modified wellness intervention by Stuijbergen et al.; holistic approach including topics that promote PA</p> <p><i>Individualized physical rehabilitation intervention</i></p> <p>Measures <i>Physical activity (PA)</i>: Modified Health-Promoting Lifestyle Profile II (HPLP-II) <i>Psychosocial constructs</i>: Four psychosocial constructs measured at four time points. Self-Efficacy for Exercise Scale Expectation Self-identity Social support for exercise</p>	<p>Pretest 1 ($n = 39$, data missing = 3) and follow-up ($n = 37$, data missing = 5). No significant differences between groups for any demographic or dependent variables.</p> <p>MANOVA and effect size analysis MANOVA of five measures indicated significance for within-subjects effects ($p < 0.01$), but no significance for between-subjects effects ($p = 0.93$). Two-way interaction was not significant ($p = 0.83$). Self-identity and PA improved significantly across both groups ($p < 0.01$), whereas self-efficacy ($p = 0.01$) and expectation ($p = 0.02$) decreased significantly. Interventions in effect sizes were not more than 0.42.</p> <p>Regression analysis The pretest correlation matrix indicated that self-identity ($p < 0.01$), social support ($p = 0.01$), and expectation ($p = 0.03$) were significantly correlated with PA ($p = 0.07$). The pretest cross-sectional regression analysis explained 44% of the variance in PA ($p < 0.01$): Self-identity ($\beta^2 = 0.44$, $p < 0.01$) and social support ($\beta^2 = 0.34$, $p = 0.02$) had significant beta coefficients Expectation and self-efficacy had nonsignificant beta coefficients The follow-up correlation matrix showed that self-efficacy ($p < 0.01$), self-identity ($p < 0.01$), social support ($p = 0.01$), and expectation ($p = 0.02$) were significantly correlated with PA. The cross-sectional regression analysis explained 38% of the variance in PA ($p < 0.01$): Self-efficacy ($\beta^2 = 0.38$, $p = 0.04$) and social support ($\beta^2 = 0.31$, $p = 0.04$) had significant beta coefficients Self-identity and expectation had nonsignificant beta coefficients When previous PA was used in the analysis, 45% of the variance was explained in follow-up PA. The p-values of beta coefficients for past behavior and self-efficacy were 0.06 and 0.09. In the correlation matrix of construct change scores, only change in expectation showed significant correlation with PA ($p = 0.03$). The regression model indicated that changes in construct measures had a small nonsignificant relationship with changes in PA ($p = 0.86$). Group membership has also a poor correlation with PA ($p = 0.89$).</p>
Hartley (2009)	<p>To describe the development components and evaluation of the service model, which was developed to address perceived shortfall in provision for MS patients</p>	<p>Design Quasi-experimental study design</p> <p>Sample 33 participants met the inclusion criteria; 25 completed the information and exercise sessions in the hospital; 17 participants opted to continue the exercise in the leisure center setting</p>	<p>Program protocol The program was named the ACTIVE program, an acronym for advice, coping mechanisms, training, information, value your health, and exercise</p> <p>Outcome measures Physical functioning: 10-m walk test Leeds MS Quality of Life Fatigue Severity Scale (FSS) Disability status: Kurtzke Expanded Disability Status Scale, Guy's Neurological Disability Scale (GNDS) Hospital Anxiety and Depression Scale (HADS) Patient satisfaction: Patient satisfaction questionnaire</p>	<p>Analysis of mean scores for all participants at baseline and following intervention indicated improvement trends in a number of measured parameters 10-m walk test: significant improvement ($t = 3.23$ and $p = 0.0006$) Quality of life: significant improvement ($p = 0.0375$) FSS and HADS: improvements not statistically significant GNDS: no significant changes in disability level</p> <p>Participants reported a range of perceived physical and psychological benefits as a result of attendance 85% (Table 5 indicated 100%) thought the course information was helpful in increasing understanding of MS 85% rated sessions as held at a suitable time 100% rated the venue as suitable 100% rated supervision by the physiotherapist as excellent 79% rated the program as having effects on change in any aspect of life 76% preferred group to individual sessions 92% rated the service as excellent 100% rated the service provided by the health and fitness adviser as good or excellent</p>

Authors	Purpose	Design/sample	Instruments/measures	Results
Stuijbergen, Becker, Blozis, Timmerman, & Kullberg (2003)	To determine the effects of the wellness intervention on self-efficacy, resources, barriers, health-promoting behaviors, and QOL	<p>Design Experimental study RCT</p> <p>Sample 113 women with MS (56 assigned to treatment, 57 assigned to control)</p>	<p>Intervention program Two-phase intervention program included lifestyle change classes for 8 weeks and supportive telephone follow-up for 3 months</p> <p>Treatment group Data were collected after the program (2 months) and after 3 months of supportive telephone follow-up (5 months postintervention); total of 3 data collection points over 8 months</p> <p>Control group Control group participants had contact only with the project manager. Participants were offered the lifestyle change program and telephone follow-up after completion of the data collection period (8 months)</p> <p>Instruments Incapacity Status Scale Barriers to Health-Promoting Activities for Disabled Persons Scale Personal Resource Questionnaire (PRO-85, Part 2) Self-Rated Abilities for Health Practiced Scale (SRAHP) Health Promoting Lifestyle Profile II (HPLP-II) 36-Item Short-Form Health Survey (SF-36)</p>	<p>By month 8, women in the intervention group were more likely to be employed than women in the control group ($\chi^2 + 3.91, p < 0.05$).</p> <p>A statistically significant intervention effect, reflected in the column labeled "Group" in Table 3, was found for the total SRAHP score, suggesting that across the three follow-up occasions, individuals in the intervention condition reported greater average levels of self-efficacy after adjusting for baseline differences in self-efficacy scores and severity of impairment.</p> <p>The effect of the baseline measure of severity of impairment was not statistically significant, whereas the baseline measure of self-efficacy was statistically significant, suggesting that preintervention levels of self-efficacy related positively to self-efficacy scores through follow-up.</p> <p>No intervention effect was found for either the Barriers Scale or the Personal Resource Questionnaire (measure of social support)</p> <p>The effects of the baseline measures of the respective variables were statistically significant, suggesting that preintervention levels of these measures related positively to respective scores across all three follow-up points.</p> <p>Statistically significant intervention effects were found for all subscales of the HPLP-II. Baseline scores on each subscale were positively and significantly related to the respective scale scores across all follow-up occasions.</p> <p>In all cases, the effect of the baseline measures of severity of impairment was not statistically significant, suggesting that there was no relation between level of impairment at baseline and health-promoting behaviors across the study period.</p> <p>Statistically significant effects were found for two subscales, bodily pain and mental health, after adjusting for baseline differences in the respective subscale and severity of impairment, suggesting that average scores for both scales were higher for the intervention group.</p> <p>The effects of baseline measures of the individual scales were statistically significant on individual outcome variables measured across follow-up, suggesting that preintervention levels of each scale related positively to the respective scale scores across follow-up.</p> <p>Statistically significant negative effects were found for physical function, role (emotional), role (physical), social functioning, and vitality in the Incapacity Status Scale, suggesting an association between lower individual scale scores across the follow-up period and higher levels of impairment severity at baseline.</p>

Authors	Purpose	Design/sample	Instruments/measures	Results
Wassem & Dudley (2003)	To explore the effectiveness of a nursing intervention (MS-RE-HAB) in promoting adjustment and symptom management in individuals with MS	Design Experimental, longitudinal study design Theoretical framework Based on Bandura's (1982) social cognitive theory Sample 27 individuals with MS in the early years following diagnosis; participants were randomly assigned to either the treatment or the control group	Intervention MS-REHAB used four forms of behavior acquisition proposed by Bandura in his social cognitive theory. The program consisted of four 2-hour sessions, with the treatment group participants meeting once a week for four consecutive weeks. Instruments Variables were measured at the time of enrollment, 3 months post-intervention, and every 6 months for 4 years after enrollment in the study (10 time points) Self-Efficacy for Adjustment Behaviors (SEAB) Scale Psychosocial Adjustment to Illness Scale-Self-Report (PAIS-SR) Self-Report Visual Analogue Scale Modified Disability Status Scale	Hypothesis 1: symptom management would be improved in the treatment group. Fatigue symptom management improved for the treatment group (TG) at all posttest measures Fatigue levels of the TG were lower than the control group (CG) at most points, as indicated by a group-by-time interaction ($F = 1.74, p = 0.09$) Sleep disturbance scores for TG were lower than CG at the 4-year follow-up, as indicated by a group-by-time interaction ($F = 1.85, p = 0.07$) Pain levels increased at all posttest points The impact of improved sleep and decreased fatigue contributed to the significant findings for improved symptom severity scored at the 4-year follow-up, as indicated by a group-by-time interaction ($F = 2.15, p = 0.003$) Hypothesis 2: self-efficacy would increase following intervention, with higher SEAB scores for TG than CG on the posttest measures (not supported) SEAB score patterns over time did not differ between TG and CG, as indicated by the nonsignificant group-by-time interaction ($F = 0.89, p = 0.55$) Hypothesis 3: adjustment for TG would be higher than CG on posttest measures (not supported) PAIS-SR score patterns over time did not differ between TG and CG, as indicated by the nonsignificant group-by-time interaction The pattern of total adjustment scores at one data collection point in TG was improved, but the group-by-time interaction at the 4-year follow-up was not significant ($F = 0.69, p = 0.72$)
Barlow, Turner, Edwards, & Gilchrist (2009)	1. To determine the effectiveness of the Chronic Disease Self-Management Course (CDSMC) for people with MS 2. To examine the characteristics of people with MS who chose not to attend the CDSMC	Design Experimental study design Comparative study design Sample Two-group, randomized, controlled trial with (<i>random assigned</i>) - Intervention group (IG, $n=78$) - Waiting-list control group (WLCG, $n=64$) Additional data were collected from a comparison group (CG, $n=74$) who chose not to attend the CDSMC	Intervention The Chronic Disease Self-Management Course (CDSMC) focused on promoting the individual's ability to select the appropriate self-management tools to meet their current individual needs. It consisted of six weekly sessions, each lasting approximately 2 h, delivered in a community setting. Measures Demographic information (age, gender, race, employment status, etc.), collected at baseline only 11-Item Liverpool Self-Efficacy Scale Multiple Sclerosis Impact Scale (MSIS-29) Pain and fatigue (10 cm, horizontal, visual analogue scales [VAS]) Hospital Anxiety and Depression Scale (HADS) Behavioral and cognitive self-management techniques (scales designed for use in evaluations of ASMP and the CDSMC)	RCT: comparison of IG and WLCG at baseline MSIS-29 psychological impact, which was greater for the IG ($p = 0.010$). RCT: 4-month follow-up comparison of IG and WLCG CDSMC had an impact on self-management self-efficacy (ES .30, $p = 0.009$) and MSIS-29 physical status (ES .12, $p = 0.005$). There were trends toward improvement in depression (ES 2.1, $p = 0.05$) and MS self-efficacy (ES .16 $p = 0.04$). RCT: 12-month follow-up comparison of IG and WLCG Compared to responders, nonresponders in the RCT at 12-month follow-up scored statistically lower on self-management self-efficacy (mean 46.8 and 40.8, $p = 0.003$) and higher on depression (mean 5.7 and 7.4, $p = 0.009$). A repeated measures ANCOVA over time did not reveal any statistically significant changes between groups. RCT: diet and physical activity Approximately two-thirds of participants in the IG and WLCG reported following a "healthy diet" for at least 5 days out of the "past week" in response to questions relating to low fat, fruit, and vegetable intake; fewer followed a diet with cereals and calcium-rich foods. No significant changes were found over time. Participants drank an average of seven cups of fluid per day. Walking and stretching were the most common exercise activities, performed for >1 h during the previous week by two-thirds of all participants. There were no statistically significant changes over time. Comparison of RCT participants and informed nonattendees (CG) There were statistically significant differences at baseline between the RCT participants and the CG participants: CG had a higher mean age ($p = 0.001$), longer disease duration ($p = 0.009$), and less anxiety ($p = 0.009$). Over the 12-month period of the study, there were no statistically significant changes in outcome variables for the CG.

Conclusion

This literature review inductively affirmed the significance and potential of investigating self-management for people with HAM. It has provided a foundation of knowledge and understanding for an investigation of self-management for people with HAM.

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References

- World Health Organization Innovative care for chronic conditions: building blocks for action: global report. 2002; <http://www.who.int/diabetesactiononline/about/iccreport/en/index.html>.
- Holman H, Lorig K. Patient self-management: a key to effectiveness and efficiency in care of chronic disease. *Public Health Rep* 2004; 119: 239–243. [Medline] [CrossRef]
- Osame M. Review of WHO Kagoshima meeting and diagnostic guidelines for HAM/TSP. in *Human Retrovirology: HTLV*. Blattner, W. A, Eds. Raven Press, New York, 1990; 191–197.
- Yamaguchi S. Structure of the “Illness” in patients with HTLV-I- associated myelopathy: a phenomenological study (Unpublished master’s thesis). Kagoshima University, Kagoshima, Japan, 2005 (in Japanese, Abstract in English).
- Lorig K. Self-management of chronic illness: a model for the future. *Generations* 1993; 17: 11–14.
- Gibson PG, Powell H, Wilson A, *et al*. Self-management education and regular practitioner review for adults with asthma. *Cochrane Database Syst Rev* 2002; 3.
- Deakin T, McShane CE, Cade JE, *et al*. Group based training for self-management strategies in people with type 2 diabetes mellitus. *Cochrane Database Syst Rev* 2005; CD003417. [Medline]
- Riegel B, Moser DK, Anker SD, *et al*. American Heart Association Council on Cardiovascular Nursing American Heart Association Council on Cardiovascular Nursing American Heart Association Council on Clinical Cardiology American Heart Association Council on Nutrition, Physical Activity, and Metabolism American Heart Association Interdisciplinary Council on Quality of Care and Outcomes Research State of the science: promoting self-care in persons with heart failure: a scientific statement from the American Heart Association. *Circulation* 2009; 120: 1141–1163. [Medline] [CrossRef]
- Stanford Patient Education Research Center Stanford Self-Management Programs. 2010; Retrieved from <http://patient-education.stanford.edu/programs/>.
- Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med* 2003; 26: 1–7. [Medline] [CrossRef]
- Barlow J, Wright C, Sheasby J, *et al*. Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns* 2002; 48: 177–187. [Medline] [CrossRef]
- Rae-Grant AD, Turner AP, Sloan A, *et al*. Self-management in neurological disorders: systematic review of the literature and potential interventions in multiple sclerosis care. *J Rehabil Res Dev* 2011; 48: 1087–1100. [Medline] [CrossRef]
- National Multiple Sclerosis Society Symptoms. 2010; Retrieved from <http://www.nationalmssociety.org/about-multiple-sclerosis/what-we-know-about-ms/symptoms/index.aspx>.
- Bishop M, Frain MP, Tschopp MK. Self-management, perceived control, and subjective quality of life in multiple sclerosis- an exploratory study. *Rehabil Couns Bull* 2008; 52: 45–56. [CrossRef]
- Stuifbergen AK. Health-promoting behaviors and quality of life among individuals with multiple sclerosis. *Sch Inq Nurs Pract* 1995; 9: 31–50, discussion 51–55. [Medline]
- Stuifbergen AK, Becker HA. Predictors of health-promoting lifestyles in persons with disabilities. *Res Nurs Health* 1994; 17: 3–13. [Medline] [CrossRef]
- Stuifbergen AK, Becker H, Blozis S, *et al*. A randomized clinical trial of a wellness intervention for women with multiple sclerosis. *Arch Phys Med Rehabil* 2003; 84: 467–476. [Medline] [CrossRef]
- Courts NF, Buchanan EM, Werstlein PO. Focus groups: the lived experience of participants with multiple sclerosis. *J Neurosci Nurs* 2004; 36: 42–47. [Medline] [CrossRef]
- Isaksson AK, Ahlström G. Managing chronic sorrow: experiences of patients with multiple sclerosis. *J Neurosci Nurs* 2008; 40: 180–191. [Medline] [CrossRef]
- Malcomson KS, Lowe-Strong AS, Dunwoody L. What can we learn from the personal insights of individuals living and coping with multiple sclerosis? *Disabil Rehabil* 2008; 30: 662–674. [Medline] [CrossRef]
- O’Hara L, De Souza LH, Ide L. A Delphi study of self-care in a community population of people with multiple sclerosis. *Clin Rehabil* 2000; 14: 62–71. [Medline] [CrossRef]
- Bishop M, Frain M. Development and initial analysis of multiple sclerosis self-management scale. *Int J MS Care* 2007; 9: 35–42. [CrossRef]
- Lorig K, Holman H, Sobel D, *et al*. *Living a healthy life with chronic conditions: Self-management of heart disease, arthritis, diabetes, asthma, bronchitis, emphysema and others*. Bull Publishing Company, Boulder, 2006.
- National Multiple Sclerosis Society The MS Disease-Modifying Drugs General Information. 2009; <http://www.nationalmssociety.org/DMD>.
- Heesen C, Kasper J, Segal J, *et al*. Decisional role preferences, risk knowledge and information interests in patients with multiple sclerosis. *Mult Scler* 2004; 10: 643–650. [Medline] [CrossRef]

26. Ryan P, Sawin KJ. The Individual and Family Self-Management Theory: background and perspectives on context, process, and outcomes. *Nurs Outlook* 2009; 57: 217–225.e6. [[Medline](#)] [[CrossRef](#)]
27. Thorne SE, Harris SR, Mahoney K, *et al.* The context of health care communication in chronic illness. *Patient Educ Couns* 2004; 54: 299–306. [[Medline](#)] [[CrossRef](#)]
28. Paterson B, Thorne S, Russell C. Disease-specific influences on meaning and significance in self-care decision-making in chronic illness. *Can J Nurs Res* 2002; 34: 61–74. [[Medline](#)]
29. Fraser C, Polito S. A comparative study of self-efficacy in men and women with multiple sclerosis. *J Neurosci Nurs* 2007; 39: 102–106. [[Medline](#)] [[CrossRef](#)]
30. Grytten N, Måseide P. ‘When I am together with them I feel more ill.’ The stigma of multiple sclerosis experienced in social relationships. *Chronic Illn* 2006; 2: 195–208. [[Medline](#)]
31. Peters TJ, Somerset M, Campbell R, *et al.* Variables associated with attendance at, and the perceived helpfulness of, meetings for people with multiple sclerosis. *Health Soc Care Community* 2003; 11: 19–26. [[Medline](#)] [[CrossRef](#)]
32. Barlow J, Turner A, Edwards R, *et al.* A randomised controlled trial of lay-led self-management for people with multiple sclerosis. *Patient Educ Couns* 2009; 77: 81–89. [[Medline](#)] [[CrossRef](#)]
33. Wasseem R, Dudley W. Symptom management and adjustment of patients with multiple sclerosis: a 4-year longitudinal intervention study. *Clin Nurs Res* 2003; 12: 102–117. [[Medline](#)] [[CrossRef](#)]
34. Plow MA, Mathiowetz V, Resnik L. Multiple sclerosis: impact of physical activity on psychosocial constructs. *Am J Health Behav* 2008; 32: 614–626. [[Medline](#)] [[CrossRef](#)]
35. Hartley S. Developing a self-management and exercise model for people with multiple sclerosis. *Int J Ther Rehabil* 2009; 16: 34–42. [[CrossRef](#)]
36. Shevil E, Finlayson M. Process evaluation of a self-management cognitive program for persons with multiple sclerosis. *Patient Educ Couns* 2009; 76: 77–83. [[Medline](#)] [[CrossRef](#)]
37. Bishop M, Shepard L, Stenohoff DM. Psychosocial adaptation and quality of life in multiple sclerosis: Assessment of the Disability Centrality Model. *J Rehabil* 2007; 73: 3–12.
38. Shaw C, Logan K, Webber I, *et al.* Effect of clean intermittent self-catheterization on quality of life: a qualitative study. *J Adv Nurs* 2008; 61: 641–650. [[Medline](#)] [[CrossRef](#)]
39. Simmons RD, Tribe KL, McDonald EA. Living with multiple sclerosis: longitudinal changes in employment and the importance of symptom management. *J Neurol* 2010; 257: 926–936. [[Medline](#)] [[CrossRef](#)]