Symptom Management and Adjustment of Patients With Multiple Sclerosis: A 4-Year Longitudinal Intervention Study

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Abstract:

The researchers studied the effectiveness of a nursing intervention in promoting adjustment and symptom management in individuals with multiple sclerosis (MS). This was a 4-year longitudinal study to determine whether the 4-week intensive outpatient program was effective in increasing adjustment to MS and if the treatment effect would last over time. A sample of 27 individuals with MS participated in the study. Treatment participants had significant improvements in symptom management at the 4-year follow up. This improvement was attributable to significant improvements in sleep and fatigue levels. Although adjustment and self-efficacy scores improved in the treatment group over time, this improvement was not superior to the control group. This was anticipated because the behavioral changes would precede improvement in adjustment to life following the diagnosis of MS.
Keywords: multiple sclerosis; nursing intervention; psychosocial adjustment

Article:

This study tested a comprehensive nursing intervention designed to help individuals with multiple sclerosis (MS) gain better control of their symptoms and improve their adjustment to this progressive disease. The intervention was designed be provided by advanced practice nurses to supplement or augment medical management that these patients receive from their primary care providers.

DIFFICULTIES IN STUDYING ADJUSTMENT TO MS
MS is one of the most common causes of neurological disability in young adults. About 1 million adults are affected with MS worldwide (Williams, Rigby, Airey, Robinson, & Ford, 1995), making MS a significant health care problem. MS attacks white matter in the central nervous system, resulting in physical, sensory, affective, and cognitive difficulties (Devins et al., 1993), and it is characterized by uncertainty and a progressively disabling course (Stuifbergen, Seraphine, & Roberts, 2000). The severity of physical, emotional, and cognitive functioning varies widely between individuals and within individual MS patients over the course of the disease (Beatty, 1993).

PSYCHOSOCIAL ADJUSTMENT
MS often leads to changes in emotion and cognitive ability, to fatigue, and to pain that may challenge the ability of patients to adjust to their disabilities. As a chronic illness, MS requires varying patterns of personal and familial social adjustment. In a study comparing quality of life

(QOL) in 207 individuals who had either MS, inflammatory bowel disease, or rheumatoid arthritis, Rudick, Miller, Clough, Gragg, and Farmer (1992) reported the worst QOL in the participants with MS. All participants had been diagnosed for more than 10 years, yet duration of MS was not related to QOL scores.

The degree of disability is a key variable in studying adjustment to MS. Viney (1986) reported that adjustment to the reality of disability allowed individuals to achieve personal integrity focused on skills, problem solving, and mastery over the degree of disability. Wassem (1992) noted that 51% of the variance in adjustment to MS was predicted by the degree of disability in combination with self-efficacy and outcome expectations.

THEORETICAL FRAMEWORK

The theoretical framework for this study was Bandura's (1982) social cognitive theory, with an emphasis on the construct of self-efficacy. Self-efficacy was Bandura's (1989) term for an individual's confidence in being able to perform a given behavior. As self-efficacy increases, the likelihood of an individual's successful performance of a specific behavior increases, as does the amount of effort and persistence in performing that behavior in the face of obstacles (Bandura, 1982).

For nurses working with clients who have MS, this increased effort and persistence are essential in teaching the behavioral changes necessary for better adjustment to this long-term, progressive disease.

Many chronic, physically disabling conditions have been investigated in relation to self-efficacy expectations and rehabilitation, with higher self-efficacy levels being predictive of success: coronary artery disease, pain tolerance, asthma, bulimia, and hypertension. Increased self-efficacy has been linked with adherence to exercise with chronic obstructive pulmonary disease, increased activity following cardiac rehabilitation, the behavioral treatment of arthritis, and an increased ability to tolerate pain.

Following the diagnosis of a chronic illness, patients often experience decreased well-being, decreases in activities, and symptom amplifications that negatively affect overall adjustment. Introducing the intervention to teach about the disease, symptom management, and self-care behaviors, including stress reduction measures, will increase the use of self-care behaviors, leading to improved well-being, increased activities, and better symptom management. This will bring about better physical, psychological, and social adjustment (see Figure 1). We tested the intervention with outcome variables of adjustment and symptom management.

In summary, MS is a chronic, progressively disabling neurological disease with no known cure that can cause physical, sensory, affective, and cognitive symptoms. These difficulties challenge the ability of patients to adjust to their disabilities and require varying patterns of personal and familial psychosocial adjustment. Bandura's (1982) social cognitive theory with the construct of self-efficacy has provided a useful framework for adjustment studies with other chronic illnesses and
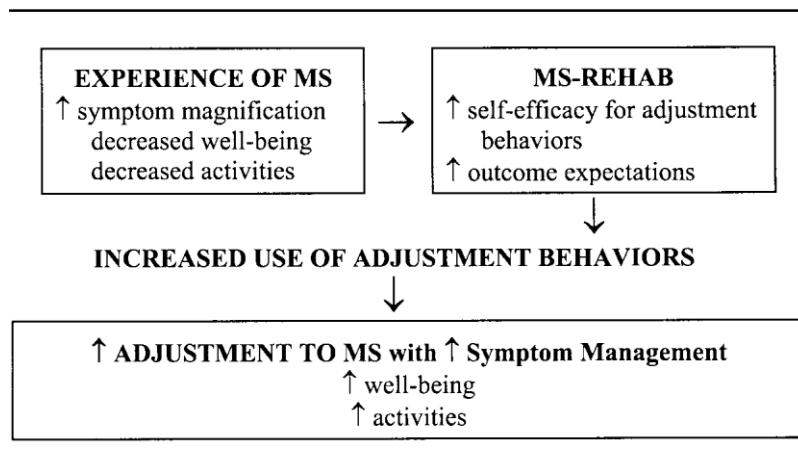
Figure 1. Proposed model.

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┌─────────────────────────┐        ┌──────────────────────────┐
│   EXPERIENCE OF MS      │        │       MS-REHAB           │
│ ↑ symptom magnification │   →    │ ↑ self-efficacy for      │
│   decreased well-being  │        │   adjustment behaviors   │
│   decreased activities  │        │ ↑ outcome expectations   │
└─────────────────────────┘        └──────────────────────────┘
                                              ↓
         INCREASED USE OF ADJUSTMENT BEHAVIORS
                        ↓
┌───────────────────────────────────────────────────────────┐
│ ↑ ADJUSTMENT TO MS with ↑ Symptom Management               │
│                   ↑ well-being                             │
│                   ↑ activities                             │
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Figure 1. **Proposed model.**
NOTE: MS = multiple sclerosis.

was used in this study to test an intervention for promoting symptom management and adjustment to MS.

PURPOSE OF THE STUDY
The purpose of this study was to test the hypotheses that participants in the intervention group, compared to those in the control group, would have improved (a) symptom management (pain, fatigue, sleep), (b) self-efficacy for adjustment behaviors, and (c) adjustment at posttest measures. Because this was an exploratory study, these hypotheses were tested at the $p < .10$ level of significance.

DESIGN
The study used a randomized, two-group (treatment and control) experimental, longitudinal study design. Because of the chronic nature of MS, we measured both short-term and long-term effects of the treatment. The expected short-term improvements would mean little if the participants did not make the behavioral changes necessary to create long-term benefits in improved symptom management and adjustment.

SAMPLE
The target population for this study consisted of individuals with MS. It is preferable that the intervention be delivered within the early years following diagnosis to cut down on the initial rough years of trial and error attempts to manage patients' symptoms. Twenty-seven participants were recruited for the study. Study participants were fairly representative of the population on the parameters of age (range 18 to 54 years, M = 44 years), number of years with MS (range 0.5 to 7, M = 3.49), disability levels (range 0 to 9, M = 3.36, where 0 represents no disability and 9 being confined to bed), and gender (72% female, which is slightly higher than the incidence of MS for the female gender [66%]). Treatment and control participants did not differ significantly on pretest measures of age, degree of disability, number of years with MS, or adjustment.

Sample attrition was a problem because 5 participants died or were lost to follow-up during the course of the study, and 6 were lost after being assigned to the control group. We conducted an

attrition analysis comparing those who dropped out of the study with those who continued. The dropouts did not significantly differ from those who continued with the study on key variables of adjustment, self-efficacy, and symptom distress. However, the dropouts (M =17.2) had more symptom distress (range 0 to 30) at a clinical level than those who continued (M = 12.5). The attrition rates for the treatment (22%) and control (23%) groups did not differ after deleting those who completed only baseline measures.

METHODS
PROCEDURES
Following human participants approval, potential participants were recruited from attendees at an MS workshop and physician clients and through an advertisement in the newsletter of the state chapter of the National Multiple Sclerosis Society (NMSS). Letters were sent to all potential participants, and informed consent was obtained from those individuals who agreed to participate in the study. Participants were randomly assigned to either the treatment or the control group following receipt of informed consent. Participants selected for the treatment group were contacted by phone to assign them to either the Tuesday or Thursday treatment session. Both treatment and control participants were sent an introductory letter explaining their group assignment with their first questionnaires.

The nursing intervention (MS-REHAB) used the four forms of behavior acquisition proposed by Bandura (1989) in his social cognitive theory: verbal persuasion, role modeling, performance accomplishment, and vicarious experience). Details of the MS-REHAB program that was tested in this study are presented in Table 1. The intervention was designed as a group program so that participants could use others in the group as positive role models. The discussions (verbal persuasion) were designed to expose participants to methods for modifying their responses to MS. Participants were given homework assignments to use these learned behaviors in everyday life (performance accomplishment), with a discussion of their successes in the group sessions the following week. The successes of the other group members (vicarious experience) encouraged other individuals to attempt the adjustment behaviors.

The MS-REHAB program consisted of four 2-hour sessions with treatment group participants meeting once a week over 4 consecutive weeks. Program content was developed from the literature and 25 years of experience working with individuals with MS. During the first session, participants discussed the disease process of MS, factors that influence MS, pain control, and the need to manage stress in one's life. Participants were also taught how to do progressive muscle relaxation. After using their newly learned progressive muscle relaxation daily and keeping 3-day diet diaries, participants discussed the dietary concerns of MS, the pacing of activities, energy conservation techniques, and how best to communicate with their health care providers in the second session. They also learned how to do guided visual imagery, which they were instructed to use daily for the intervening week. At the third session, psychosocial issues, including role changes, the importance of a support network, MS care and management decision making, and employment were discussed. At the fourth session, participants covered memory storage and retrieval as well as how to deal with cognitive problems and the need to return

Table 1
Treatment Session Content and Homework

Week 1
  Discuss
    1. The disease process of MS
    2. Factors influencing MS and past experiences
    3. Reinforce need to stretch and exercise daily
    4. Medications used to help manage MS symptoms
    5. Recommended medication sheet to take to primary care provider
    6. Nonpharmacological pain management strategies
    7. How to communicate with health care providers
    8. Need to manage stress: teach muscle relaxation
  Behavior training (teach and practice)
    1. Head-to-toe stretching exercises
    2. Progressive muscle relaxation (PMR)
  Homework
    1. Keep a journal of all activities for week
    2. Keep a 3-day diet recall
    3. Use PMR daily
Week 2
  Discuss
    1. Reports on effects of using PMR
    2. Review of 3-day diet recall, teach four food groups and amounts,
       address helpful diet supplement, and warn about abuse of
       over-the-counter substances
    3. Relationship between fatigue, pacing, balance of rest and activity,
       and energy conservation
    4. Need for appropriate and regular exercise
  Behavior training
    1. Head-to-toe stretching exercises
    2. Guided visual imagery (GVI)
  Homework
    1. Practice GVI daily
    2. Use energy conservation principles
    3. Eat a well-balanced diet
    4. List factors (+/−) shaping reaction to MS
Week 3
  Discuss
    1. Psychosocial influences on MS (role changes, support network,
       decision making, and prioritizing activities)
    2. Handling reactions of others/self to MS symptoms
    3. Employment issues and and sources of help (social security,
       vocational rehabilitation, and support groups and agencies)
    4. Sleep promotion, medications, and good sleep hygiene
  Behavior training
    1. Head-to-toe stretching exercises
    2. Low-impact exercises

(continued)

Table 1 (continued)

Homework
    1. Note times when cognitive dysfunction (CD) is most problematic
    2. Track methods used to control CD
Week 4
  Discuss
    1. Effects of MS on CD
    2. Memory and information storage
    3. Effects of CD on life
    4. Ways to help decrease the impact of CD on life
    5. Helpful medications
  Behavior training
    Use methods taught to control symptoms and live a more healthy life
  Homework
    1. Keep track of use of adjustment behaviors on patient flow sheet
    2. Return questionnaires in a timely manner
    3. Notify the researcher of any address change
    4. Contact the researcher by phone for needed assistance
    5. Return study questionnaires promptly

questionnaires in a timely manner. Table 1 outlines the treatment sessions' content and homework.

The treatment sessions were offered in the evenings from 7 p.m. until 9 p.m. over 4 consecutive weeks at the College of Nursing. Participants discussed issues related to controlling MS, were taught adjustment behaviors, and were given homework assignments, as described in the MS-REHAB program. They practiced the behaviors learned in the previous class and then reported on their successes at the following meeting.

Both treatment and control participants completed the study instruments at the time of enrollment, 3 months after the intervention was completed, and every 6 months over a 4-year period after enrollment in the study. All instrument packets were assigned participant numbers to assure confidentiality. The master sheet matching participants with numbers was kept in a locked office accessible only to the research team. The assignment of participant numbers was also necessary because of the repeated-measures design of the study so that scores were accurately assigned to the appropriate participants over time.

INSTRUMENTS
The Self-Efficacy for Adjustment Behaviors (SEAB) Scale consists of 26 adjustment behaviors with a 4-point, Likert-type response pattern. Each item ranges from 0 (no confidence in being able to perform the behavior) to 4 (total confidence in being able to perform the behavior), giving a range of potential scores of 0 to 104. The SEAB was developed to be used as a mailed, self-report checklist. A sample of 256 individuals with MS completed the SEAB in the instrument development study (Wassem, 1992) with the original 29 items on a scale ranging from 1 to 5 (M = 112, range 65 to 145, SD = 17.23). Cronbach's alpha coefficient of internal consistency reliability was .91. Correlations of SEAB scores with single self-report visual ana-logue adjustment items were significant at a moderate level: social (r=.40), psychological (r=.39), and physical adjustment (r = .43) (Wassem, 1987). The test-retest level at 4 weeks for control participants in a larger study was r = .827 (Wassem, 1992). Cronbach's alpha statistic for internal consistency reliability for the SEAB with the present study was .87.

Adjustment was measured using both the Psychosocial Adjustment to Illness Scale–Self-Report (PAIS-SR) (Derogatis, 1986) and total adjustment scores calculated from visual analogue scales. The PAIS-SR has been shown to be a valid, reliable, and objective measure of adjustment to illness. The PAIS- SR has been used in the measurement of psychosocial adjustment in respondents with chronic illnesses or injuries, such as Hodgkin's disease, cancer, renal dialysis, burns, hypertension, and cardiac disease. Although the 45-item instrument consists of seven subscales, those pertaining to sexual relationships and extended family relationships were not used in this study because they have low reliability levels and have been frequent sources of missing data in prior research. Subscales included in the study were Health Care Orientation, Vocational Environment, Domestic Environment, Social Environment, and Psychological Distress. This dropped the number of items used to 34, with a range of possible scores of 1 to 136. Because of the small sample size of the current pilot study, the PAIS-SR was used as a total score. Cronbach's alpha statistic for internal consistency reliability for the PAIS-SR with the current sample was .91.

In addition to the PAIS-SR, self-report visual analogue adjustment items of psychological, social, and physical adjustment were used to measure adjustment. These three items were summed to give an overall total adjustment scale with a range of 0 to 30. The total adjustment scale was used as another measure of the primary outcome variable of adjustment to supplement information from the PAIS-SR.

The Modified Disability Status Scale has been used as an objective and reproducible method of assessing the degree of disability in individuals with MS. Modification of Kurtzke's (1955) tool, the Disability Status Scale, was made because only the second part of the instrument, which ranks disability levels from 0 (no disability) to 9 (complete bed rest), was used. The participants were asked to circle the item that best represented their current level of functioning. Because this is a self-report physical ability level, reliability measures, including test-retest reliability, are not appropriate because patients' conditions may change between measurements.

We collected data on the participants' self-reported symptom severity scores (pain, fatigue, sleep) and adjustment scores (psychological, social, and physical) using visual analogue scales ranging from 0 to 10. The symptom severity scales of pain, fatigue, and sleep were summed to give an overall symptom severity scale with a range of possible scores of 0 to 30. Although there are lengthy and elaborate instruments for measuring these symptoms, we used the visual analogue scales because they give reliable information without placing an undue burden of time on the participants to complete the questionnaires at each data measurement point.

Items on the personal inventory were selected for relevance to the study, significance from the review of literature, and selection rating by a panel of experts. The personal inventory was designed by the investigators to gather demographic data, including age, gender, age at diagnosis, number of years with MS, and length of disability.

DATA ANALYSIS

The data were entered into a computer on receiving the completed instrument packets. The researchers used the SPSS (Version 10.1) (SPSS Inc., 2000) and SAS (SAS Institute, 1999) software packages for data analysis and hypothesis testing.

Because this was an exploratory test, all hypotheses were tested at the $p < .10$ level of significance. Analysis of the change in means over time for all outcome variables was conducted with the SAS mixed-model procedure PROC MIXED. This analysis-of-covariance approach employs an iterative maximum likelihood estimation approach, which allows for the analysis of repeated measures of all cases, even when some data are missing (Kleinbaum, Kupper, Muller, & Nizam, 1998; Littell, Milliken, Stroup, & Wolfinger, 1996).

FINDINGS

Because of the strong impact of age at diagnosis and illness severity on key outcome measures, these variables were added into the analysis as covariates for each hypothesis. The analytical approach used was a repeated-measures MANCOVA, with age at diagnosis and illness severity as covariates in the analysis. Data were analyzed at 10 time points from baseline to the 4-year follow-up.

Hypothesis 1 proposed that symptom management would be improved in the treatment group. Fatigue symptom management improved for the treatment group at all posttest measures compared to the pretest scores. The fatigue levels of the treatment participants were lower than those of the control participants at most data collection points, as indicated by a group-by-time interaction ($F=1.74$, $p =.09$). Sleep disturbance scores for the treatment group were significantly better than for the control group at the 4-year follow-up, as indicated by a group-by-time interaction ($F = 1.85$, $p = .07$). Pain levels increased at all posttest data collection points. Symptom severity scores were computed by adding together the three symptom severity scores (possible range 0 to 30). The impact of improved sleep and decreased fatigue contributed to the significant findings for improved symptom severity scores at the 4- year follow-up, as indicated by a group-by-time interaction ($F = 2.15$, $p = 0.03$; see Figure 2).

Hypothesis 2 proposed that self-efficacy, as measured by SEAB scores, would increase following the intervention, with higher SEAB scores for the treatment participants on posttest measures than for control participants. Although the inspec-
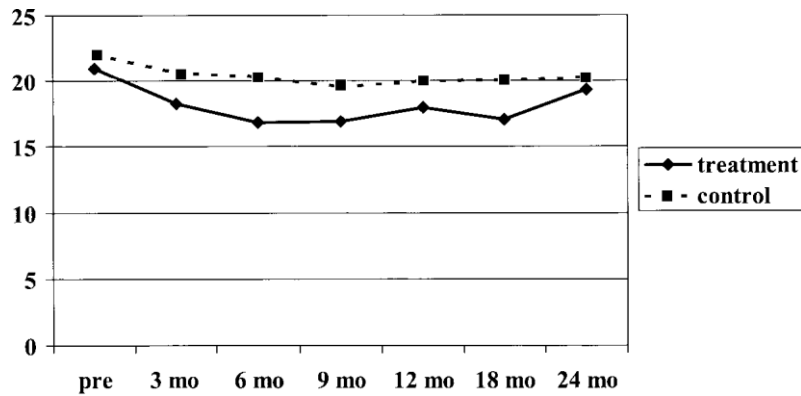
Figure 2. Symptom severity.

tion of mean SEAB scores at each data collection point revealed increases for the treatment participants on most posttreatment measures, the pattern of scores over time was not different from that of the control group, as indicated by the nonsignificant group-by-time interaction (F = 0.89, p = .55). Hypothesis 2 was not supported.

Hypothesis 3 proposed that adjustment, as measured by PAIS-SR scores, for the treatment participants would be higher than for the control participants on posttreatment measures. Although the inspection of mean PAIS-SR scores at each data collection point revealed increases for the treatment participants on most post treatment measures, the pattern of scores over time was not different from that of the control group, as indicated by the nonsignificant group-by-time interaction. The three-item adjustment scale (psychological, social, and physical) functioned better than the PAIS-SR with this sample. The treatment group improved at all but one data collection point using this three-item adjustment measure, but the group-bytime interaction at the 4-year follow-up was not significant (F = 0.69, p = .72). Hypothesis 3 was not supported.

DISCUSSION
Because there is no cure for or effective treatment of MS, behavioral adaptation to the disease (such as symptom management and adjustment) is key to maintaining QOL with MS. This study demonstrated decreases in fatigue and improved sleep among the treatment participants. The management of pain was not improved by the intervention. This finding is consistent with Nurmikko's (2000) report that despite the prevalence of MS pain, few patients find relief from this symptom. Stenager, Knudsen, and Jensen (1995) found that there were significant increases in the number of acute and chronic pain syndromes, including tension and pain in the extremities, spasms, lower back pain, Lhermitte's sign, and neuralgia over the 5-year course of their study with MS patients. It may be that more aggressive medical management is needed to supplement the intervention for better control of patients' pain.

In contrast to the treatment effect on symptom management, the more global scales of self-efficacy and adjustment were not significantly improved by the treatment. Adjustment to a chronic, incurable illness such as MS is very complex. Self- efficacy scores were moderately high for all participants. Although there was a treatment effect on self-efficacy scores at 6

months, scores varied between moderate scores of 60 to 70 for the remainder of the data collection points. Both treatment and control participants had moderate levels of confidence in performing the adjustment behaviors. Within the social cognitive theory, Bandura (1982) proposed that individuals must believe not only that they can do a behavior (self-efficacy) but also that the behavior will make a difference in the outcome of their illness, and they must use the behavior consistently over time. It may be that even though they believe that they can do a given behavior, patients are unable or unwilling to make the behavior changes that would improve their symptom management. The small sample size precluded testing ideas about the interplay among these variables.

The increases in PAIS-SR scores for the treatment group were encouraging. The control group, however, also reported increased PAIS-SR scores. This may be an effect of being tested or seeing the list of adjustment behaviors every 6 months, cueing them to try these behaviors in an attempt to manage their MS. The self-report single adjustment items were better predictors of change than the PAIS-SR scores with this group of participants. It may be that the PAIS-SR does not measure adjustment to MS as well as it measures adjustment to other chronic illnesses.

LIMITATIONS
The sample size was small, and there was attrition over the 4 years reported in this article, but a strength was that participants were followed for 4 years. The sample included members of a state chapter of the NMSS, who may be representative of those individuals with MS who are not members of the NMSS. Although assignment to treatment and control groups was random and occurred after consent was obtained, participants obviously knew of their assignment to the treatment or control group, and this may have influenced their responses.

A methodological problem and potentially useful finding was that many of the control participants wrote on their questionnaires that they liked receiving their questionnaires because completing the SEAB reminded them to do the "right things" to manage their MS. This effect in combination with a possibly strong Hawthorne effect negatively skewed the results and may have given many of the control participants a weaker form of the intervention.

Future research will include an intensive maintenance program to cue participants to make the behavior changes necessary to manage their MS, and control participants will not complete the self-efficacy measure to prevent pretest sensitization and dilution of the treatment. Additionally, nurse practitioners will be added to prescribe an optimal uniform medicine protocol to augment the nursing intervention with the hope of a more standardized design and increased symptom control.

APPLICATION OF RESEARCH TO PRACTICE
It is clear that many aspects of successful living with MS fall well outside the traditional medical model. Nursing interventions that focus on improving symptom management through the use of adjustment behaviors, however, may have an impact on the well-being of patients with MS. We have included the content of our intervention in Table 1 so that practitioners can teach these behaviors to their MS patients. With decreased length of stay in the hospital and higher patient-to-nurse ratios, patient teaching is one area that often suffers. This research project presented an outpatient evening program for promoting adjustment to MS that was conducted by a nurse.

Participants enjoyed the classes and learned how to manage their illness. This type of program could be offered in any geographical area by a knowledgeable nurse in a very cost-effective manner.

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