Health Promotion Practices of Women With Multiple Sclerosis

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Objective: To explore the health promotion behaviors of women with multiple sclerosis (MS), a chronic, disabling disease affecting the central nervous system.

Design: Participants completed a battery of instruments measuring illness-related disability, health-promoting behaviors, and quality of life. Descriptive statistics were used to examine the frequency of various health promotion practices among women with MS. Participants were grouped according to clinical course and compared on frequency of health-promoting behaviors using multivariate analysis of variance. Path analysis was used to test the hypothesis that health-promoting behavior mediates the relation of illness severity to quality of life.

Participants: Women with physician-diagnosed MS (n = 629) who were community-residing were recruited with the assistance of two chapters of the National MS Society.

Main Outcome Measures: Health Promoting Lifestyle Profile II; Quality of Life Index–MS Version.

Results: Overall, these women scored lower on measures of physical activity (moderate effect size) and spiritual growth (small effect size) than the comparison “normative” sample. Women with benign sensory and relapsing-remitting MS were more likely than women with progressive MS to engage in physical activity and spiritual growth behaviors. Health-promoting behaviors mediated the relation of illness-related disability to quality of life.

Conclusions: Findings highlight the impact of living with a chronic disabling condition on the frequency of health-promoting behaviors. Additional research is needed to identify factors that enhance both the initiation and maintenance of health promotion behaviors.

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CHRONIC DISABLING conditions have profound and pervasive effects on the lives of millions of American women. Although it is rarely addressed, the need for health promotion continues among this group of women, who must adapt to the experience of living with long-term, incurable conditions that impose limitations on their functioning. These women must come to grips, psychologically and organizationally, with the permanent changes presented by the condition, maintain the semblance of normal life within the context of the demands of chronic illness and associated disability, and continuously struggle to balance multiple roles and has valued lives.

The practice of health-promoting behaviors has been acknowledged as an important strategy to maintain and enhance the independence, health, and quality of life of persons with chronic disabling conditions. Health promotion incorporates several self-initiated health behaviors (physical activity, nutrition, stress management) and stresses the need to enhance each person’s commitment to a healthy lifestyle that can prevent premature death and secondary disability and promote quality of life. The definition of health promotion as “activities directed toward increasing the level of well-being and actualizing the health potential of individuals, families, communities and societies” is philosophically congruent with the goals of rehabilitation. Health promotion strategies should be an integral part of the rehabilitation process and continue throughout a person’s life.

Health promotion interventions typically advocated to improve the quality of life for the general population have been assumed to result in the same outcomes for women with chronic and disabling conditions. Although it is true that women with disabilities face many of the same overall health risks as the general population, this “one-size-fits-all” approach fails to address how limitations in time, energy, and mobility force women with disabilities to make choices they perceive as having maximum payoff, given their sense of quality of life. Despite increasing consumer and professional interest, little is known about the health promotion needs and behaviors of persons with chronic disabling conditions, and even less about the health behaviors of women with disabilities. This study explored the health promotion behaviors and outcomes of women with multiple sclerosis (MS). The uncertainty, unpredictability, and potentially progressive and disabling nature of this disease, which predominates in women, makes MS useful as a model for research designed to explore the health promotion behaviors of women with chronic disabling conditions.

BACKGROUND

MS is a chronic disabling condition that is predominantly a disease of women in their middle years of life, many of whom carry heavy work and family responsibilities. Data from the National Health Interview Survey indicate that 75% of persons reporting MS are age 35 to 64 years, 73% are women, 95% are Caucasian, and 71% are no longer in the work force. Current estimates suggest that there are more than 200,000 women in the United States with physician-diagnosed MS.

MS is one of a broad category of demyelinating diseases that affect the central nervous system. In this autoimmune disease, the loss of myelin insulating the axons interferes with the efficiency of electrical conduction within the central nervous system and produces a varied array of symptoms. The cause of MS is unknown, there are no preventative measures, medical treatment is expensive and limited, and the clinical course is difficult to predict. For some, the disease may be relatively benign, resulting in only mild neurologic dysfunction. For others, demyelination and scarring may be extensive, causing major neurologic losses and disability. Although some individuals will be severely disabled, more than two thirds of persons diagnosed with MS remain ambulatory after 20 years.

Each individual’s experience with MS and the associated
demands of the illness are unique, because the pattern of demyelinating lesions can produce virtually infinite combinations of functional abnormalities. Primary symptoms include weakness, numbness, gait disturbances, visual disturbances, dizziness, ataxia, bladder and bowel problems, changes in sexual functioning, pain and muscle weakness, spasm, and spasticity. Cognitive dysfunctions, including impairments of recent memory, sustained attention, verbal fluency, conceptual reasoning, and visuospatial perception, have been reported in 43% of community-residing MS patients. The pattern of cognitive decline is not uniform, rarely severe enough to interfere with rehabilitation, and not significantly related to engaging in health behaviors or perceived quality of life. Fatigue is one of the most common symptoms of MS and may require substantial changes in employment and lifestyle.

The life circumstances and symptoms of women with chronic disabling conditions such as MS may make it difficult for them to implement health-promoting behaviors, even when they possess general knowledge about good health practices. For example, their nutrition may be inadequate because of limited financial resources, they may lack transportation, and they may have difficulty handling large packages. Insufficient exercise and lower levels of fitness may be related to mobility limitations that complicate movement. Earlier studies of persons with disabilities have documented their interest in and desire for health promotion services, as well as the positive outcomes related to participation in health promotion behaviors.

Two health promotion behaviors, exercise and nutrition, are particularly salient to women with MS. Persons with MS have often been advised to “take it easy” and “not overdo,” leading to a decrease in overall physical activity. In addition, one of the most common responses to symptoms such as fatigue, weakness, and loss of balance is stopping leisure-time activities, which often results in physical inactivity. Effects of such prolonged inactivity are well documented—muscle weakness and atrophy, decreased flexibility, fatigue, cardiovascular deficits, depression, and sleep disturbances. Unfortunately, these problems have often been attributed solely to the disease without a consideration of the impact of inactivity.

Promoting physical activity among women with disabilities is challenging, but essential. In the general population, women are less likely than men to engage in regular, light-to-moderate physical activity. Women with disabilities face the added barriers of fatigue, lack of time, inaccessible facilities, impairment, financial constraints, and a lack of knowledge about how to exercise safely. The benefits of physical activity, for women in general, include prevention of osteoporosis, decreasing the risk of cardiovascular disease, diabetes, and some cancers, and reducing anxiety and depression. The importance of physical activity may be accentuated for women with chronic disabling conditions, many of whom have a sedentary lifestyle that increases their risk for developing other chronic diseases.

Studies have shown that women with MS can safely participate in appropriate exercise programs and improve strength, psychosocial status, functional status, and aerobic fitness.

Conclusive evidence of the role of diet in influencing the disease outcomes of MS is lacking. Swank demonstrated that over a period of 34 years, individuals with MS who consumed a low fat diet (<20g/day) experienced less disability than those who failed to follow diet recommendations. Women seemed to benefit from this low fat regime more than men. As with other women, excess caloric intake contributes to the development of obesity (which may further complicate mobility for women with MS), excess fat intake contributes to the development of cardiovascular disease and obesity, and low calcium intake contributes to the development of osteoporosis. Medications commonly used in MS (steroids) make calcium intake and prevention of osteoporosis a significant concern. Adequate fluid intake is essential to prevent urinary stasis and infections in women with MS.

Improved quality of life and health are perceived outcomes of participation in health-promoting behavior. Results of studies conducted with MS populations have suggested that contact with “healthy” people and perceived support from family and friends are related to better psychosocial adaptation. Wineman found that perceived supportiveness of interactions was directly related to purpose in life and that functional disability had a direct effect on the degree of psychosocial adaptation. Reports of health-promoting behaviors are significantly associated with perceptions of quality of life in persons with MS.

Women with disabilities have unique health needs and are concerned with maintaining and promoting their health in order to carry on their lives. Current management of MS, however, focuses on treating the underlying disease process and managing secondary symptoms. Little attention has been given to promoting the health of persons with MS to enhance their overall well-being and quality of life while they are living with this chronic disabling condition. As the underlying disease and associated disability fluctuates, or even progresses, health-promoting behaviors can serve to nurture the overall physical, mental, and social health of the person so that improvement is achieved within realistic health goals.

As one woman with MS who participated in an earlier study stated, “My MS is worse, but I can handle it better . . . Therefore, I am better.”

The conceptual underpinnings of this research include a multidimensional definition of health and well-being, a holistic focus, and an emphasis on empowering chronically ill and disabled individuals. This is consistent with Pender’s proposition that levels of health exist along a continuum in interaction with the experience of illness. Whatever the qualities of the illness or the limitations of function, the individual continues on a quest for health—a process characterized by frequent experiences of challenge, achievement, and satisfaction. Therefore, good or poor health can exist in the presence or absence of overt illness or disability. Individuals are viewed as fully capable of health and well-being within the context of their chronic condition or disability.

The purpose of this study was to explore the health promotion behaviors of women with the chronic disabling condition of MS. The specific research questions were: (1) What are the health promotion practices of women with MS? (2) What are the differences in health promotion practices of women with MS and a group of community-residing adults? (3) Is there a difference in the frequency of health promotion behaviors among women with different types of MS? (4) Does the frequency of health promotion behaviors mediate the effects of severity of illness on quality of life for women with MS?

METHOD

Data Collection Procedures

This descriptive correlational study was part of a multiphase study of health promotion and quality of life in men and women with chronic disabling conditions. All phases were reviewed and approved by our Institutional Review Board for the protection of human subjects. For this quantitative phase of the study, participants were recruited with the assistance of two MS society chapters in the southwestern US. Information about the study and the criteria for participation (physician-diagnosed MS for 1 year, community-residing) was sent to 2,772 persons on the chapters’ mailing lists. These lists include persons with MS and also persons with other neurologic disorders, family members, and health care and service providers. A total of 936
persons responded to mailings about the study by providing their names and addresses to the investigator and indicating their desire to receive information about the study. A packet containing an informational cover letter, the study instruments, and a stamped preaddressed envelope was mailed to those expressing an interest in participating in the study. Information in the cover letter instructed individuals who needed assistance with reading and recording responses to the questionnaires to call the toll-free number of the research office. Research staff were available to clarify instructions, answer questions, and assist seriously disabled participants with questionnaire completion. Participants were encouraged to monitor their level of fatigue during completion of the questionnaire, and when tired, discontinue, rest, and continue the study at a later time.

Coded packets made possible follow-up of nonresponders. A follow-up postcard was sent to all participants 2 to 3 weeks after the packet was mailed, thanking them if they had responded, and encouraging them to respond if they had not. In all, 834 surveys were returned (89%). Twenty-seven were not usable because of incomplete data or for failure to meet the sample criteria. The remaining 807 usable surveys represent 86% of the 936 individuals who agreed to participate in the study. All respondents received a handwritten thank-you note and a $5 gift certificate to a retail store for their participation.

Sample Characteristics
Analyses in this paper are limited to the 629 women between the ages of 18 and 70 who responded to the questionnaire. All participants had been diagnosed with MS for at least 1 year and were living in the community. Participants were between the ages of 18 and 70 years (M = 46.67, SD 9.94). Most (92%) were white, 4% were black, and 3% were Hispanic. The average years of education was 14.22, and 84% had at least a high school diploma (34% had a college degree or higher). Most respondents were married (70%), and 162 (26%) reported living in a nonmetropolitan or rural part of the state. Thirty-two percent of the respondents reported being unemployed because of their disability, and 28% were working full-time for pay. Fifteen percent were full-time homemakers.

Women in the sample had been diagnosed for an average of 10.2 years (SD 7.3). Almost half (48%, n = 292) reported relapsing remitting MS with symptoms that fluctuate over time. Benign sensory MS, characterized by sensory symptoms and little or no long-term disability was reported by 14% (n = 89). One third (n = 204) reported chronic progressive MS where symptoms and disability become more serious over time; 5% (n = 28) had severe progressive MS. Twenty-one percent of the women (n = 133) were presently receiving steroids for treatment and 20% (n = 124) were presently receiving treatment with Betaseron. More than half of the sample (60%, n = 381) reported receiving more than two courses of steroid treatment during their life course of MS.

Instruments
Self-report instruments in a booklet format were used to collect data on the study variables. The questionnaire battery completed by respondents included sociodemographic information, measures of severity of illness, health-promoting behaviors and quality of life. Print size was enlarged and items were spaced to enhance readability and ease of completion.

A Background Information Sheet was used to collect demographic and disease-related information. Respondents were provided with a description of the four major clinical courses of MS (benign, relapsing-remitting, chronic progressive, and severe progressive) and asked to select the type that represented their pattern of symptoms.

The Incapacity Status Scale (ISS) provided an objective measure of functional disability due to MS - the physical limitation in ability to perform one's usual roles and activities. For this study, the structured interview form was adapted to a self-administered questionnaire to provide an assessment of the degree of impairment in 16 aspects of personal functioning (eg, ambulation, vision, bladder and bowel functioning) represented on this scale. Each of the 16 items is rated on a 5-point scale, with “0” indicating normal functioning and “4” indicating complete inability to perform the activity. The ISS was thoroughly evaluated by an international panel of MS experts for use as a minimal record for disability for MS; evidence supporting the construct validity of the scale has been presented by Kurtzke. Internal consistency reliability in this study was .86.

Health-promoting behaviors were defined as behavioral, cognitive, and emotional efforts to sustain and improve health and well-being; they are continuing activities that are part of the individual’s lifestyle. Health promoting behavior was operationalized with the Health Promoting Lifestyle Profile II (HPLPII), a revision of the extensively used HPLP. This 52-item, 4-point scale assesses the frequency with which individuals report engaging in activities directed toward increasing their level of health and well-being. Responses are scaled from 1, “Never,” to 4, “ Routinely.” This instrument is composed of six subscales (Physical Activity, Spiritual Growth, Health Responsibility, Interpersonal Relations, Nutrition, and Stress Management) derived from the earlier HPLP. Literature review, and expert confirmation. Selected items from the original 48-item HPLP were revised to reflect more current health information (eg, change from use of the basic four food groups to food pyramid; integration of varied levels of physical activity), and items were more evenly distributed across subscales. Reliability and validity of the HPLPII have been supported in psychometric testing with a sample of 712 adults. The internal consistency reliability of the HPLP has been consistently high. Internal consistency reliability of the HPLPII total score in this study was .92: subscales ranged from .74 to .86. Evidence supports the use of the HPLP as a valid measure of health behavior in persons with chronic disabling conditions.

Quality of life refers to an individual’s overall sense of health and well-being and satisfaction with life. It is defined as a cognitive experience of satisfaction with domains of life important to the individual. In this study, the Quality of Life Index (QLI)-MS version was used as a measure of general satisfaction with and importance of the components contributing to quality of life. The QLI was originally developed to measure quality of life of “healthy persons’ and specific versions have been developed for a number of patient groups, including hemodialysis patients, persons with MS, and persons with cancer. The QLI - MS version is a 72-item measure composed of two parts: Part 1 measures satisfaction with various domains of life, and Part 2 measures the importance of the same domains. Subjects respond to each item on a 6-point scale, ranging from very satisfied to very dissatisfied for Part 1 and “very important” to “very unimportant” for Part 2. Total quality of life scores are calculated by weighting each satisfaction response with its paired importance response. Therefore, scores reflect individual values as well as satisfaction. The highest scores are produced by combinations of high satisfaction/high importance responses. Internal consistency in this study was .95.

RESULTS
Descriptive statistics, multivariate analysis of variance (ANOVAs), and path analytic techniques were used to answer the research questions. Means, standard deviations, and the range

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of scores for each subscale of the HPLPII appear in table 1. Respondents’ actual scores were distributed across the possible range of scores. Examination of individual items of the HPLP indicated that less than half of these women reported an adequate intake of calcium-rich foods (44%), 2 to 4 servings of fruit per day (40%), or 3 to 5 servings of vegetables (47%). Few reported that they often or routinely performed exercise-related behaviors. For example, only 37% reported stretching exercises 3 times a week; 35% get exercise during their usual daily activities, 22% engage in light to moderate exercise, and only 19% take part in leisure time physical activity. In contrast, more than half of the women reported that they were able to talk with friends about problems (53%), take some time for relaxation each day (61%), believe that their life has a purpose (77%), question health professionals to understand instructions (74%), pace themselves to prevent tiredness (60%), feel connected with a greater power (78%), and get sufficient rest and sleep (64%).

The average item subscale scores (mean subscale score divided by the number of items) was computed to allow comparison of scores across subscales with unequal number of items. An examination of the health-promoting lifestyle subscale patterns using average item subscale scores (table 2) revealed that overall these women scored highest on the subscales of interpersonal relationships and spiritual growth and lowest on physical activity. Scores from the women in this sample were pared to the normative group (n = 712). This sample included 217 men and 495 women with mean age of 42.4 years (SD = 15.4). Most (72%) were employed, married (63.5%), and white (74%).

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Table 1: Total and Subscale Scores on the HPLPII (n = 629)

As shown in figure 1, the coefficient for the indirect path of incapacity status on quality of life through health promoting behavior differed significantly from zero (β = -.08, p < .01). This coefficient was also negatively signed. The other estimated paths were also significant. Incapacity status directly affected health promoting behavior (β = -.16, p < .01) as well as
quality of life ($\beta = -.45, p < .01$). These findings suggest that as an individual’s illness progresses and disability becomes more of a concern, quality of life diminishes and the frequency of health-promoting behavior decreases. At the same time, there is a robust relation between health promoting behavior and quality of life ($\beta = .45, p < .01$), suggesting that health-promoting activity, regardless of incapacity status, can enhance the quality of life that women with MS experience.

**DISCUSSION**

This study provided important descriptive data about a large sample of community-residing women diagnosed with the chronic disabling condition of multiple sclerosis. It has limitations, however, that must be acknowledged and considered when interpreting the findings. Data in this study were self-report, obtained from a convenience sample recruited through the National MS Society, and included very few minority respondents. The possibility of bias in self-report data about health practices exists. Respondents, however, did have a wide range of scores with an approximate normal distribution. Although this study used a convenience sample, the impressive response rate (89%) of those identifying themselves as potential participants suggests that health promotion is an important area of interest for persons with chronic and disabling conditions. It is possible that women with MS who do not identify themselves to this group, or live in different geographic areas, may have different attitudes and behaviors.

Multiple roles in family, work, and community, sociocultural values that derive from ethnicity and class, and personal beliefs and attitudes related to health have all been cited as important influences on women’s health promotion. Findings from this study suggest that the experience of living with a chronic disabling condition, and the particular course of that condition, also affects the behaviors women use to maintain and promote their health. Although it is not surprising that women with fatigue, weakness, and balance and coordination difficulties would have low scores on the physical activity subscale, this finding should be of concern to health care professionals. In the general population, physical activity is inversely associated with morbidity and mortality from several chronic diseases that become more frequent with increasing age. The impact of inactivity, especially when compounded by the physical changes of aging, may be even more significant for a group of individuals with MS who are already experiencing some physical limitations.

Comparison of these women’s scores to other groups was made difficult by the recent revision of the HPLP. Comparison data on the HPLP was available for only one group that included both men and women. Although the women with MS scored significantly differently than the comparison group in four areas, the effect size was small in three of the four comparisons. The difference in the physical activity subscale scores was moderate, suggesting that this is the area of most difference between these women with a chronic disabling condition and other “nondisabled” individuals. It should also be noted that although the women with MS scored significantly lower on physical activity and spiritual growth, they scored significantly higher on two other subscales, stress management and interpersonal relationships. Perhaps it would prove useful for rehabilitation professionals to capitalize on these two areas of strength when developing programs to enhance health promotion for women with MS. For example, women already engaging in stress management activities might be attracted to the stress-reducing benefits of exercise, especially stretching exercises and programs that incorporate both mind and body activities such as yoga and tai-chi. Interpersonal relationships could be used to support the initiation and maintenance of other health behaviors.

In this study, women with “less progressive” forms of MS (benign sensory and relapsing remitting) had significantly higher scores on the physical activity and spiritual growth subscales. More severe symptoms, especially fatigue, weakness, and incoordination, limit mobility and make it more difficult for these women to incorporate physical activity. The women with chronic progressive and severe progressive MS are more likely to need greater assistance and adaptation to increase their level of physical activity. Although items on the spiritual growth subscale did not directly speak to physical attributes, scores were affected by group membership. The perspective of “growth” (“I am growing and changing personally in positive directions.”) and “future orientation” (“I look forward to the future.”) of the spiritual growth items may also be more difficult for women with progressive forms of the disease.

The cross-sectional design and nonexperimental nature of this study make it impossible to directly test for causality. However, causal hypotheses derived from a model supported by theoretical and empirical literature can still be evaluated with nonexperimental data using causal modeling analyses (eg, LISREL). Path coefficients obtained using these methods support the direct effect of the antecedent variable (incapacity status, health-promoting behavior) on the outcome variable (quality of life). As hypothesized in the model, both disability and health-promoting behaviors have moderately strong ($r = .45$) direct effects on perceptions of quality of life, although the sign of their effects are opposite. In addition, there are significant negative
indirect effects of incapacity status on quality of life that are mediated by health-promoting behaviors. This significant indirect effect and health promotion's considerable association with quality of life suggests that the detrimental effect of incapacity status on quality of life may be mitigated, in part, by participation in health-promoting behaviors. A longitudinal follow-up of this sample over time will enable a clearer assessment of the impact of both progression of disability and health promoting behaviors on quality of life over the course of living with a chronic disabling condition.

Rehabilitation professionals wishing to promote the health of persons with chronic and disabling conditions will find few empirically validated interventions. Descriptive data from this study and others, however, indicate that this a priority area of intervention. Pilot programs building on existing descriptive data can and should be designed with a strong evaluation component that can provide much needed information regarding the short-term and long-term effectiveness of interventions to enhance health promotion behaviors among persons with disabilities.

Findings from this descriptive study suggest that there are many potentially fruitful areas for future research regarding health promotion for women with disabilities. Research has revealed that people with disabilities in general, and persons with MS in particular, believe that they lack the knowledge and skills needed to exercise safely. The finding in this study that women with MS had the lowest scores on physical activity supports the need for additional research regarding ways to maximize physical activity among this population. In particular, greater attention should be directed to programs of adaptive activity and related research to evaluate its effects. Research is also needed to address the multiple issues related to health practices, aging, and disability.

CONCLUSION

Although rehabilitation professionals can often do little to influence the progression of MS and the resulting disability and its effects on quality of life, there are many ways to enhance physical activity, nutrition, stress management, and spiritual growth so that quality of life may be enhanced for persons living with a chronic disabling condition. Too often, health care professionals see only the disease and disability and focus their practices, aging, and disability.

Effective strategies are needed to enhance both the initiation and maintenance of health promotion behaviors among persons with chronic and disabling conditions. Future research should explore differences related to both gender and ethnicity among persons with a wide variety of disabling conditions. Findings from such research can foster the development of interventions that incorporate the diversity of beliefs, attitudes, and roles that characterize women living with chronic disabling conditions.

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References