

Support Group Participation

Effect on Perceptions of Patients with Newly Diagnosed Multiple Sclerosis

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Background: Patients newly diagnosed as having multiple sclerosis (MS) face an overwhelming number of questions about how it will affect their lives. Participation in a support group is one way to obtain information and receive support from others. However, existing support groups are often attended by patients with significant disability, resulting in newly diagnosed patients being hesitant to return.

Methods: This qualitative pilot study explored perceptions of patients with newly diagnosed MS before and after participation in two monthly meetings. A support group was conducted each month using nursing staff, a physician, and a social worker. Prior to the first meeting, participants were asked to complete a questionnaire with open-ended questions to share their thoughts about how MS may affect their lives. After the two meetings, they were asked to complete the same questionnaire again.

Results: Eight themes were identified: uncertain disease course; insecure future; physical, emotional, and cognitive impacts; effect on relationships with family and/or spouse/significant other; ability to develop future relationship with significant other; impact on career plans; impact on ability to achieve future goals; and impact on ability to care for self and family. Five of six participants who attended both meetings and one of four who attended only the first meeting expressed a change in their perception of how MS may affect their lives.

Conclusions: A support group dedicated exclusively to newly diagnosed patients may provide an opportunity for patients to experience a change in perceptions of MS. *Int J MS Care.* 2020;22:115-121.

There are an estimated 947,000 people with multiple sclerosis (MS) in the United States and more than 2.3 million worldwide.¹ Many of these patients are diagnosed in their prime adult years (at age 20-50 years)¹ and often express a feeling of being overwhelmed by their diagnosis.

There is great interest in the concept of social support affecting physical health outcomes, and research has been conducted to provide interventions to determine its benefit, especially involving patients with chronic illness.² A support group is defined as “a group of people

with common experiences and concerns who provide emotional and moral support for one another.”³ (p587) Although there are many types of support groups, from a face-to-face group gathering to an online group, a strong relationship exists between social support and positive health outcomes, especially with chronic disease populations.² Social support can be beneficial to help patients cope emotionally and may increase self-esteem, decrease depression, and improve quality of life.⁴ Support groups can also be a source of information about MS. Research on the benefit of suitable support networks for people with MS is limited,⁵ and even more so regarding newly diagnosed patients.

When considering a support group, one must be conscious of the target audience. It is important that the support group be designed to meet the needs of the participants.⁶ The researchers have been told by some patients with MS that they attended a support group in the past when they were first diagnosed and did not

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return because many of the participants had significant disability and they found it to be a negative experience. At least one study supported this finding when the effectiveness of peer support in improving quality of life and reducing depressive symptoms in persons with MS was evaluated.⁷ Those researchers concluded that support group attendance did not provide improvement in these areas, and in fact, their results suggest that patients with better mental health could be at risk for deterioration with support group participation. This information led the researchers of this pilot study to question whether attending a support group designed for newly diagnosed patients may be a better option for members of this group. The possibility of fear or discomfort that may result from seeing patients with MS with greater disability may certainly be an issue for some individuals. However, an even greater issue is that the needs of this patient population will likely be very different from those of patients who have had MS for many years. A support group designed exclusively for newly diagnosed patients would provide an opportunity to discuss their informational needs as well as their perception of what the diagnosis of MS means to them. Additionally, such a group setting may afford the opportunity for improvement in patient perceptions of MS and how it will affect their quality of life.

Clearly, there is evidence that patients with MS benefit from support and information. However, the literature is lacking in research on what type of support group is needed, as well as defining the support needs of the newly diagnosed patient. No reference in the literature was found addressing support groups specifically designed for newly diagnosed patients and how participation in them may benefit this population. The goal of this descriptive qualitative pilot study was to explore the perceptions of patients with newly diagnosed MS through participation in an informal support group.

Methods

The purposive convenience sample consisted of ten patients with MS from the University of Pennsylvania Comprehensive MS Center who were diagnosed within the previous 6 months. No other criteria were required. The study was reviewed by the institutional review board (IRB) and received exempt status. The consent was reviewed by the IRB but not stamped. However, per the IRB recommendation, the consent was still used because it provided an explanation of the study, including risk and benefit, to the patient. Because of a time constraint, the recruitment period was very short. Fourteen patients were identified in a 2-month period and were referred to the nurses (the authors) by physicians, nurse practitioners,

and pharmacists who see the patients in the MS clinic. The providers in the MS clinic were asked to mention the support group to newly diagnosed patients, assess interest, and ask the patients to provide their contact information to the nurses. The patients were then contacted by the nurses through secure e-mail. The message contained information about the group as well as its purpose. The message also included a copy of the consent, the demographic sheet, and a questionnaire consisting of three open-ended questions about how they perceive MS will affect their lives (Table 1). The purpose of the questionnaire was to determine how the patients felt the diagnosis would impact them, how it may affect relationships, and whether it may affect their future goals. The message also contained the phone number of the nurse sending the message, and the patients were invited to call and discuss the study. Those who chose to participate were asked to complete the documents in advance and bring them to the initial meeting. At that time, the same nurse who sent the documents reviewed the consent form with the patient, provided an opportunity for questions and answers, and finally, provided a copy of the signed consent form to the patient. The patients were asked to put a unique identifier on the questionnaire that they would also be asked to put on the final questionnaire. The forms were collected before the start of the meeting by an administrative assistant to keep the four nurses blinded. Only one participant forgot to complete the forms and did so immediately before the meeting.

Two main support group meetings were conducted in the MS center. In the first meeting, the MS-certified nurse practitioner provided a PowerPoint presentation consisting of an overview of MS, with an opportunity for informal questions and discussion with the two nurses and two nurse practitioners who conducted the meeting. In addition, two patients with long-standing MS from the MS clinic, one male and one female, were also invited to attend the first meeting. These two patients were specifically chosen because they had MS for longer than 10 years, have been on disease-modifying therapy (DMT), and expressed that they have continued on with their life goals such as career and family. They also participated in the general discussion and answered questions from the group. The second meeting consisted of a presentation by the MS-certified social worker on MS in the workplace covering topics such as disclosure, the Family Medical Leave Act, and employee rights. The opportunity was provided for an interactive discussion among the group members. At the end of the second meeting, participants expressed their desire for an additional informal session to provide an opportunity to meet and review

Table 1. Questionnaire

Question 1	Do you feel that your diagnosis of MS will impact you? And if so, how?
Question 2	Do you think your MS diagnosis may affect your relationship with your family and/or significant others? And if so, how?
Question 3	Does the diagnosis of MS change your future goals? And if so, how?

Abbreviation: MS, multiple sclerosis.

what they had learned. One of the MS physicians attended that extra session and provided an additional presentation on MS, and also participated in the final group discussion.

At the end of the second meeting, the participants were asked to answer the same three open-ended questions, include their unique identifier, and bring that completed questionnaire to the extra session, and they did so. The patients who had attended only the first meeting were contacted via e-mail, and they returned their final questionnaire via secure e-mail to an administrative senior secretary, who then returned the printed questionnaires to the nurses. Therefore, the data from the final questionnaire were not related to the extra session, and these methods enabled the four nurses to remain blinded.

The data from both questionnaires from all participants were analyzed using thematic analysis to identify key patterns or themes. The four evaluators, the same four nurses (the authors) who conducted the study, manually reviewed the data using coding, sifting, sorting, and identifying themes. The nurses met as a group to share their identified themes and discuss any discrepancies to establish the final list.

Results

Study Participants and Overview

Of 14 patients invited to participate in the study, ten accepted. The mean \pm SD age of the participants was 35.4 ± 7.6 years. Nine participants were female and one was male. Five participants were white, three were African American, one was Hispanic, and one was mixed race. All participants had been diagnosed with relapsing-remitting MS. One participant had an associate degree, four had a bachelor's degree, four had a master's degree, and one had a doctorate.

All ten patients attended the first meeting, six patients attended the second meeting, and those same six patients attended the extra session. As noted in the Methods section, at the end of the second meeting, the participants shared that the meetings were helpful and proposed having an additional session. Two others from the first meeting provided regretful reasons why they were unable to attend this extra session.

Five of the six participants who attended both main meetings expressed a change in their response to the questions before and after the meetings. Only one of the four participants who attended only the first meeting expressed a change. Of the three open-ended questions, there were seven patient responses that reflected a change in their perception of how MS will affect their lives after attending the support group meetings.

Eight themes were identified from the questionnaires from all ten participants: uncertain disease course; insecure future; physical, emotional, and cognitive impacts; effect on relationships with family and/or spouse/sig-

nificant other; ability to develop future relationship with significant other; impact on career plans; impact on ability to achieve future goals; and impact on ability to care for self and family (Table 2).

Impact of Diagnosis on Self

Uncertain Disease Course

The overall perception of the participants was that MS will impact them. "I do feel that my diagnosis will impact me and I am concerned about the long-term consequences of this disease." The patients also expressed the uncertainty of what to expect with this diagnosis. "I feel like it will impact me . . . I am still learning what my 'new normal' is and how that impacts the commitments I choose to keep."

After attending the support group meetings, the second response to the same question for one participant reflected a change in perception of the impact of an MS diagnosis. "I feel it will, but probably not as quickly as I thought it was going to before."

Insecure Future

An insecure future, given the diagnosis of MS, was expressed. "It impacts my health and feelings of security for the future—hard to foresee what the future will bring, complicates financial planning, stress about paying medical bills." However, this same patient expressed a change in perception of how MS may affect the future on the final questionnaire. "I am becoming much more centered on what I need to do to be healthy. I feel more comfortable regarding the future. I think your classes have helped me with that."

Physical, Emotional, and Cognitive Impacts

Physical, emotional, and cognitive impacts were concerns when asked about the impact of MS. One participant initially expressed a feeling of lack of control over health outcomes. "Based on statistics I've seen, I can safely assume I will experience negative health effects and can do no more than hope for mild to moderate ones." Multiple DMTs are a crucial resource now available

Table 2. Themes

Question 1	Uncertain disease course
Impact of multiple sclerosis	Insecure future Physical, emotional, and cognitive impacts
Question 2	Effect on relationships with family and/or spouse/significant other
Relationships	Ability to develop future relationship with significant other
Question 3	Impact on career plans
Future goals	Impact on ability to achieve future goals Impact on ability to care for self and family

that can improve patient outcomes,⁸ including physical, emotional, and cognitive impacts. The MS therapies were discussed by the nurse practitioner at the first meeting. MS therapies were also discussed in response to group questions throughout both meetings. This same participant, whose perception was that of having no control over MS, displayed a change in that initial perception after attending the two main meetings. “Potential cognitive symptoms continue to be of great concern to me. After the two meetings, however, I do feel that I have a better appreciation of the range of medications available and feel slightly more optimistic about disease management.”

Effect of Diagnosis on Relationships

Effect on Relationships with Family and/or Spouse/ Significant Other

The effect of MS on relationships with family and/or spouse/significant other was expressed as a concern. One participant expressed concern that the disease may confuse the basis of the relationship. “Now that I have this diagnosis, I wonder if we will stay together because that’s what we want, or if we will stay together because I want the stability of a partnership in face of an uncertain future for my health.” Another participant, mentioned problems that her spouse was having accepting her diagnosis. It was interesting that other members of the group offered support as well as suggestions on how she could relay not only her own concerns but also share information with him that she has learned about MS treatment and management that can lead to more positive outcomes.

The concept of MS as an “invisible illness” that could affect the perception of others was also addressed. “My diagnosis could impact my relationships due to the fact that MS is an invisible illness so it may be easier to forget sometimes I am not well.” Although not directly about relationships, such an example was offered in the first meeting by one of the invited participants who has had MS for many years. He related an experience he had regarding the use of a handicap placard for his car, which enables him to park closer to his workplace. He said that if he did not have this benefit, severe fatigue would prevent him from completing his workday. On one occasion, after he had parked in a handicapped parking space, a woman came up to him and told him he was despicable for using that parking space when he clearly did not need it.

Ability to Develop Future Relationship with Significant Other

The ability to develop a future relationship with a significant other was expressed as a concern. Patients are often diagnosed at a young age and may not have established a partner relationship. Some members of this group expressed concern about how to disclose this information to a partner. “I am single and I fear this will affect my ability to find a suitor. If I meet someone, when do I mention it and how?” However, after attending the two meetings, this participant’s response to the same question changed, despite the fact that minimal guidance was offered in this area. “I am feeling better about being a single person with MS.”

Diagnosis and Future Goals

Impact on Career Plans

Impact on career plans was expressed as a concern by members of the group. One participant’s response demonstrates how this diagnosis changes total life plans from career opportunities to living location. “. . . It does. I work in a less developed part of the world. However, there are a number of institutions . . . that offer lucrative research fellowships and permanent positions. Where previously I thought I would pursue these in addition to American and European positions, I now will not, because I have little faith in the MS care in a less developed country. Even looking at jobs in the US, my preference for being near a metropolitan center has grown. Having grown up in a rural area, I know that the quality of available health care varies widely in this country. If I’m going to be needing neurologists for the rest of my life, I want them to be good ones.” These patients will need continued quality medical care for the rest of their lives to manage their MS. Therefore, the location of where they live and work becomes a big decision to young, newly diagnosed patients and may affect the ability to pursue a career plan that was established before the diagnosis.

There are many workplace issues to consider for the newly diagnosed patient. The social worker discussed some of these issues at the second support group meeting, including disclosure, the Family Medical Leave Act, and employee rights. The participants stated that the information was helpful. Two participants expressed this position in their response to the question: “The support group gave me a chance to consider my issues in greater depth, gave me a broader perspective on these issues, and encouraged me to think critically about how I might respond to potential issues in the workplace.” A support-

ive work environment will enable the person with MS to continue to be a productive member of the workforce. “I really appreciate the opportunity to be included in the support group. I think it is extremely helpful to speak to other people with MS and share experiences. The session confirmed how fortunate I am to have an employer that is willing to accommodate my condition.”

Impact on Ability to Achieve Future Goals

The diagnosis of MS for young patients can greatly affect their thoughts on what they had hoped to achieve in their lifetime. “I worry about my ability to achieve my goals. There is fear in the unknown and I do not know what the future will hold for me.”

One initial patient response reflected concern regarding MS and future goals. “I am living in the present. I am not setting lofty goals for myself. I don’t know what shape I’ll be in at 5, 10, or 15 years.” During the two meetings, the idea was presented and reinforced that the outlook for patients with MS is far better because of many new therapies and better ways to manage symptoms. The response of this patient to the same question after attending the two meetings reflected a change in perception. “I don’t know what the future holds, but I feel better about it. I feel more comfortable pursuing goals that will take time to achieve. Your class helped with that.”

Impact on Ability to Care for Self and Family

The impact of MS on ability to care for self and family was a concern for the future. Most participants said that they felt their immediate family would be supportive. However, one individual expressed fear that MS will have an impact on the ability for self-care. “I feel like I am going to pose an unnecessary burden to my family.”

Discussion

Based on the results of this pilot study, these patients were very interactive and willing to share their perspectives on how they thought MS will affect their lives. They found the support group meetings beneficial, as evidenced by their verbal responses to the nurses, the request for an additional session, and changes in their responses to some of the same questions after attending the meetings.

From the classic work of Kleinman,⁹ the purpose of this research was to study the perspective of the newly diagnosed patient with MS, not from the biomedical sense of disease but rather from the illness or patients’ experience of it. In a study that explored the perspective of patients with MS on drug treatments, Lynd et

al⁸ found that very few studies involved a qualitative approach that involved the patient perspective. The best example in this study is the patient who expressed the assumption that there will be negative effects from MS and he or she “can do no more than hope for mild to moderate ones.” The implication is that the patient has no control over the illness. However, the patient’s perception of MS was different on the final questionnaire with more optimism expressed. One may consider that this patient had already received information from the neurologist during the diagnosis discussion and treatment selection and also met with the pharmacist to set up that treatment and discuss its effectiveness. Yet, that patient felt no control as reflected in the first response to the initial question for this study. However, after only two relatively short meetings, this patient felt more optimistic based on the information provided.

Despite the availability of a multidisciplinary MS team, the first line of information for the patient begins with the neurologist-patient relationship. Together they can discuss the diagnosis and select the appropriate DMT. However, in the current health care setting, the time allotted with the neurologist is limited. Therefore, the patients’ educational needs about MS and its treatment must come from other sources. The nurse practitioners and nurses can fill part of this void in the clinic setting, as can other members of the comprehensive MS team. The support group can provide not only an avenue for the patients with MS to obtain information about DMTs, but also the opportunity to share how they feel about the concept of a long-term treatment.

Social media plays an increasingly important role as a source of patient information and support. There are websites that offer the opportunity for patients with MS to communicate with other people with common experiences and concerns, the same function of a support group. This resource is especially beneficial for patients with MS with significant disability who may find it difficult to join face-to-face groups. Websites managed by organizations such as the National MS Society offer a connection to other individuals with MS and their caregivers in a safe and secure environment.¹⁰ Members of the MS team have the opportunity to expand or clarify information that patients obtain from social media, and the support group setting can provide an opportunity for this discussion.

The diagnosis of MS may affect relationships. The patients in this group expressed concerns about relationships with family and existing spouses or significant oth-

ers and disclosure to an individual in a new relationship, and identified this topic as an area of need. This information can be used by the nurses in planning future programs. Group discussion in a support group may be beneficial in this area. The opportunity for group support can be a beneficial experience for patients, especially if family members and friends are overburdened with the diagnosis.²

Patients with MS may have symptoms that can be misunderstood by members of the community. The patient with long-standing MS cited earlier offered the example of fatigue being the reason for his handicap placard and an observer verbally telling him that he did not deserve to use the handicapped parking space. As many as 90% of people diagnosed as having MS experience fatigue.¹¹ Patients often experience this symptom that affects their ability to carry out routine activities of daily living. Yet, this fatigue may not be visible to others. This patient took the opportunity provided by the support group to share his experience as an example of how some members of society may not understand a disability they cannot see. The group reacted with surprise to this example and expressed the unfairness of the situation. However, the discussion could serve as preparation for such an event that they themselves may encounter.

Patients in this group expressed concern about how MS will impact future goals. A support group can afford an opportunity for discussion and provide knowledge from the social worker, therapist, and others. Members of the group expressed that the one brief meeting with the social worker discussing issues with MS in the workplace provided valuable information as they try to determine what MS will mean to their career goals.

Information and knowledge about MS are crucial for patients to select treatment options and manage their disease. The 21st Century Steering Group¹² described the concept of patient engagement in their own health care as the “blockbuster drug of the century” and emphasized the impact of the patient’s own skill to optimize available health benefits. The findings of the steering group suggested that benefits of patient engagement in MS included education and confidence building, credible sources of accurate information, and treatment adherence. If patients perceive the diagnosis of MS as something they can manage and are knowledgeable and receptive to available treatments, they have a better chance of decreasing disease progression as well as improving quality of life. Treatment with DMTs can significantly contribute to better outcomes by reduc-

ing the frequency and severity of relapses and slowing disability progression, which ultimately results in lower health care costs.¹³

An understanding of the perceptions of newly diagnosed patients about how MS will affect their lives will add to the existing body of knowledge to assist health care professionals in providing education and support about MS and effective management strategies. A support group may offer patients the benefit of gaining knowledge about MS and available resources for its management, as well as hearing the perceptions of others living with MS who may feel that they are able to achieve their life goals while living with MS. If the concept of a support group specifically for the patient newly diagnosed as having MS is effective, it could become an option in other MS centers. It may also become an effective strategy provided by national organizations to offer a support group or program designed specifically for newly diagnosed patients.

This pilot study paved the way for a larger study that will examine the effect of support group participation on perceptions of newly diagnosed patients with MS and will consist of more meetings. Based on feedback from participants of this pilot study, there will be a presentation by a local psychologist certified in MS therapy to address the topic of relationships with a spouse/significant other. The MS pharmacists will also present a program on available medications to treat MS and its symptoms. Participation of health care professionals from these disciplines will provide a comprehensive multidisciplinary approach. Additionally, more time will be allotted simply for interaction among members of the group.

There will also be an additional questionnaire geared toward long-standing patients in the MS clinic. The questionnaire will consist of open-ended questions asking if they attended a support group when they were newly diagnosed and, if so, how would they describe that experience. The goal will be to determine the perception of that experience by these patients.

An additional implication for future research would be to conduct a longitudinal study involving these existing patients who had early intervention through participation in a support group dedicated to newly diagnosed patients. The goal would be to determine whether they had more positive outcomes in management of their MS compared with patients who have not had such an experience. This information would add to the literature

on the impact of educational group meetings, which is rarely studied.⁵

Several limitations existed in this small pilot study. The use of a written questionnaire rather than an oral interview was chosen to give the participants the ability to answer the questions in private and at their own pace. The researchers also thought that in an oral interview the patients may be more hesitant to share their true perceptions of the MS diagnosis. However, an oral interview may have had advantages such as providing the patient direct access to the researcher for questions, as well as providing the researcher the opportunity to ask the patient to expand on a response. All members of the sample were highly educated, with all having degrees beyond high school. Therefore, the findings cannot be generalized to a population with a lower educational level. These participants were not specifically selected to be part of the group. The only criterion was to have been newly diagnosed. However, the time constraints on recruitment limited the number of potential participants. Four patients were invited who did not choose to participate; the educational level of those patients is unknown. The higher educational level of participants may have contributed to their desire to take part in the study to gain knowledge and support. The hope is that with a larger group in the future study, where participation is offered to all newly diagnosed patients in an extended period, the sample will be more diverse in level of education. Additionally, the time constraints of this pilot study limited the ability to afford benefit to the participants. However, despite the limited time frame, some patients related a change in their perception of MS concerns. One could postulate that additional meetings may result in a greater opportunity for patient education and additional benefit.

In summary, this pilot study suggests that a support group specifically designed for newly diagnosed patients

may be beneficial to change perceptions about the diagnosis of MS. The concerns expressed by this group relate to their future and their fears about how MS will affect their lives. They may not yet be concerned about chronic symptoms because the diagnosis is still new. They are at the stage where they need information and the ability to talk about their concerns for the future. The members of this pilot study expressed that this support group setting helped to meet those needs. □

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PRACTICE POINTS

- A group of patients newly diagnosed as having MS may have concerns about the uncertainty of the disease, how it will affect their ability to develop relationships, and its effect on their future career goals.
- A support group specifically geared to newly diagnosed patients may serve to improve perceptions of how the disease may affect their future.