

# Support group participation: Effect on perceptions of newly diagnosed MS patients

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## Background

Patients newly diagnosed with multiple sclerosis (MS) face an overwhelming number of questions about MS, including treatment options, its effects on their life, family, employment, and finances. Participation in a support group is one way to obtain information about MS and receive support of others with the same diagnosis. However, existing support groups are often attended by patients with significant disability, resulting in newly diagnosed patients being hesitant to return. Lack of information and support can affect perceptions of MS. Research suggests that positive disease perception can benefit patients with chronic illness. Little information in the literature addresses the effect of support groups on patients with MS, including those who are newly diagnosed.

## Statement of the Problem/Purpose

The purpose of this descriptive qualitative pilot study was to learn more about perceptions of patients newly diagnosed with MS before and after their participation in two monthly support group sessions.

## Research Question

Can participation in a support group affect perceptions of patients newly diagnosed with MS.

## Methods

### Research Methods and Design:

This descriptive qualitative pilot study explored the perceptions of newly diagnosed MS patients through participation in an informal support group.

### Population:

The purposive, convenience sample consisted of ten MS patients from our Comprehensive MS Center who were diagnosed within the past six months.

### Materials/Instruments

The patients were asked to attend two support group meetings. Prior to the first meeting they were asked to complete a questionnaire consisting of three open-ended questions about how they perceive MS to impact their life and a brief demographic questionnaire. There were two presentations provided at the meetings. The first was an overview of MS and the second was a presentation by the social worker on MS and its implications in the workplace.

### Data Collection, Processing, and Analysis

The data was analyzed using thematic analysis to identify key patterns or themes. The four evaluators manually reviewed the data using coding, sifting, sorting, and identifying themes.

### Demographics

A total of 16 patients were invited to participate in the study and ten accepted. Four of the ten attended only one meeting, of which two attended the first and two attended the second meeting. The average age of the patients was 35 ( $M=35.4$ ,  $SD=7.63 \pm 2.41$ ). Nine of the participants were female and one was male. Five participants were Caucasian, three were African American, one was Hispanic, and one was Mixed Race. One of the participants had an associate degree, four had a bachelor's degree, four had a master's degree, and one had a doctorate.

## Results

### Question 1: Do you feel that your diagnosis of MS will impact you? And, if so, how?

| Pre-intervention   | Post-Intervention  | Emerging themes   |
|--|--|---|
| <p><i>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.</i></p> <p><i>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.</i></p> | <p><i>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.</i></p> <p><i>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 – thank you.</i></p> | <ul style="list-style-type: none"> <li>• Uncertain disease course</li> <li>• Insecure future</li> <li>• Physical, emotional, and cognitive impacts</li> </ul> |

### Question 2: Do you think your MS diagnosis may affect your relationship with your family and/or significant others? And if so, how?

| Pre-intervention  | Post-Intervention  | Emerging themes  |
|---|--|--|
| <p><i>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?</i></p> <p><i>With my significant other, I do worry. I am left wondering if we will stay together because that's what we want, or because I want the stability of a partnership in the face of an uncertain future for my health.</i></p> | <p><i>I am feeling better about being a single person with MS.</i></p> <p><i>Knowing that the majority of MS patients continue to work fulltime helps, in that perhaps once I feel more secure in my employment I will stop worrying that I need to maintain my relationship as a safety net, and will know that I am staying in it because I want to and not out of fear.</i></p> | <ul style="list-style-type: none"> <li>• May affect relationship with family and/or spouse/significant other</li> <li>• Ability to develop future relationship with significant other</li> </ul> |

### Question 3: Does the diagnosis of MS change your future goals? And if so, how?

| Pre-intervention  | Post-Intervention   | Emerging themes  |
|---|---|--|
| <p><i>I am living in the present. I am not setting lofty goals for myself. I don't know what shape I'll be in in 5, 10, 15 years.</i></p> <p><i>I don't know what to expect, what my physical abilities will be a year, 5 years, 10 years, 20 years from now.</i></p> | <p><i>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 – thank you.</i></p> <p><i>I feel confident that I can meet all the goals I had prior to finding out I had MS.</i></p> | <ul style="list-style-type: none"> <li>• Will/may impact career plans</li> <li>• May impact ability to achieve future goals</li> <li>• May impact ability to care for self and family</li> </ul> |

## Conclusions

- Five of the six participants who attended two sessions expressed improved perceptions of how MS may affect their life.
- Three of the four participants who attended only one session did not report change in their perceptions.
- All participants attending the second and final session, when asked, agreed they would like an additional session and six of the ten attended that session.

### Limitations of this study include:

- 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 education level.
- The time constraints of this pilot study limited the ability to afford benefit to the participants. One could postulate that additional sessions may result in even more positive results.

## Implications for Future Research

This pilot study paved the way for a larger study which will examine the effect of support group participation on perceptions of newly diagnosed MS patients. The larger study will consist of a greater number of sessions. In addition to presentations by providers with an overview of MS and a presentation by the social worker on MS and the workplace, there will be programs related to psychosocial needs, pharmacy, and physical therapy.

