Exploring Benefits, to Both Patients and Healthcare Providers, of a Dedicated Support Group for Young Adult Patients with Multiple Sclerosis

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Background

Multiple sclerosis (MS) is a chronic, life-long, unpredictable and potentially highly debilitating neurological condition. It strikes most often in young adulthood, but can start in childhood and adolescence. Young patients diagnosed in the pediatric setting, where they have close follow-up, may have difficulty with transfer of care (TOC) to the adult setting. Alternatively, those diagnosed at age 18 or older in the adult care setting may not have adequate support. Lack of information and support may have a negative effect on these patients. Participation in a dedicated young adult support group is one way for providers to obtain information about their needs and for the patients themselves to receive support from others.

Statement of Problem/Purpose

The purpose of this qualitative pilot study was to learn more about how young adult MS patients are managing their MS, perceive the level of care they are receiving, and if attending a dedicated young adult support group would provide benefit.

Methods

Research Methods and Design:
This qualitative study explored the needs of young adult MS patients through participation in a dedicated support group along with pre and post questionnaires.

Population:
The purposive, convenience sample consisted of a single group of 8 patients from the MS Center between the age of 18 and 25..

Materials/Instruments
The patients were asked to attend 6 monthly virtual support group meetings. Prior to the first meeting they were asked to electronically complete a consent form, a demographic questionnaire, and answer 6 open-ended questions. After the 6 meetings they were sent the final questionnaire with 5 open-ended questions.

Data Collection, Processing, and Analysis
The data were analyzed using thematic analysis to identify key patterns or themes. The five evaluators manually reviewed the data using coding, sifting, sorting, and identifying themes.

Demographics
A total of 18 patients were invited to participate in the study and 8 accepted. The mean ± SD age of the patients was 22 ± 2.1 years. The mean ± SD age at diagnosis was 19 ± 2.6. All participants were female. The sample included 6 Caucasian and 2 African American patients. The education level included: 2 High School, 2 Some College, and 4 Bachelor Degrees. Of the 8 patients in the sample, 6 were diagnosed with MS, 1 was considered CIS and 1 RIS. Five of the patients began their MS care in a children's hospital and three began in an adult care setting. Five patients were on Ocrevus, 1 was on Plegridy, 1 was on Mavenclad, and 1 was not on disease modifying therapy (DMT). All 8 patients identified having a support source including parents, siblings, family, friends, and boyfriends.

Questions Pre-support Group Meetings

1. If you transitioned from CHOP to Penn, OR if you started your MS care at Penn, what were both the positive and the negative parts of that experience?
2. What would you like to see different for others in the future who will begin or transition their MS care to Penn as a young adult?
3. How would you describe how you have been managing your MS medical care?
4. How would you describe how you are coping living with MS?
5. What topics would you like to see offered in this MS support group dedicated to young adults with MS?
6. Should there be one or more programs where, if you have support persons, they would be invited to attend?

Questions Post-support Group Meetings

1. How would you now describe how you have been managing your MS medical care? Has participation in this group changed your description in any way, and if so, please explain how.
2. How would you now describe how you have been coping living with MS? Has participation in this group changed your description in any way, and if so, please explain how.
3. Were the topics presented in the meetings helpful to you? If so, how?
4. Was it helpful for you to talk with other MS patients in your same age bracket? If so, what were the benefits?
5. Did your group participation affect your relationship with others? If so, how?

Patient Quotes

Patient Quotes About the Meetings:

- "It was 100% helpful. It made me feel way more 'normalized'."
- "I feel less alone."
- "I don't feel lonely coping with living with MS after participation in this group. Before, I didn't know anyone my age with MS."
- "It was so, so helpful, mainly because I don't know anyone else with MS. I felt very sad and alone because when I had flare-ups. . . no one else understood what I was going through . ."
- "I feel like my MS care has been better since this group. I feel more connected and 'normalized' being with others who are experiencing their 20s the same way."
- "I feel less of a burden, hearing others opinion on how to deal with others who don't understand how I am feeling."
- "I have been coping better since this group. Hearing how everyone's experiences are so similar to mine, such as relationships, coping, etc., makes me feel way more normalized and connected."
- "I'm way more open with communicating information about my MS. The group provided a place of comfort that made it easier to talk about my MS diagnosis outside of the group."
- "My transition experience was not what I expected it to be. I was given all the numbers of names and people, but it wasn't explained to me what I should be going to each of them for. Having a nurse navigator to call or text was very helpful. The nurse and the doctor asked me and my mother to write down our feelings and recommendations regarding the TOC. If they could alleviate some of the stress during this process, it would help to better manage both my physical and mental health."

Themes Pre-support Group / Patients

Need for Help with:

- Coping with diagnosis of MS
- Support
- Cognitive issues
- Transfer of Care (TOC) issues

Themes Post-support Group / Patients

Information Gained by Patient Responses

- Positive experience of talking to others in same age group with same issues
- Support person and patients - benefited from hearing other young adult patients and information on MS presented by NP
- Positive feeling of support with the group – group chat is comforting
- Benefited from more information on medication, relationships, and pregnancy / family planning

Additionally, patients established their own online group meeting for anyone interested in just talking or needing additional support.

Themes Post-support Group / Providers

Information Gained by Providers

- Patients expressed desire to continue this young adult support group
- Need was identified to address cognitive issues
- Patients would like to continue to have information from NPs, pharmacists, nurses, and other MS providers
- Still areas for Improvement in TOC process – keep the patients informed who to call and how to navigate the new system
- Positive comments were offered on having a nurse navigator
- The pandemic has contributed to fragmented care. Given the new hybrid work model, there is need to determine how to best utilize telemedicine for additional counseling and support.

Limitation

Given the small sample size, the findings cannot be generalized to a larger population.

Conclusion

The results of this study suggest that a dedicated young adult MS support group can be beneficial in providing support, as well as knowledge about living with MS. Additionally, patient feedback has provided information that will enable providers to offer improved MS care to meet the needs of this population.