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Edorium J Disabil Rehabil 2019;5:100046D05LP2019.
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RESEARCH ARTICLE PEER REVIEWED | OPEN ACCESS

Patients' experiences of being diagnosed with multiple sclerosis and their support and guidance needs in the first year of illness

Lena Skovgård Petersen, Anne Dichmann Sorknæs

ABSTRACT

Aims: To describe patients' experiences of being diagnosed with multiple sclerosis (MS) and their needs for support and guidance in the first year with the disease. Methods: A qualitative, semi-structured interview study with five patients with MS was conducted. Data were transcribed and analyzed using interpretative phenomenological analysis. Results: Three themes emerged: Frightening to get the diagnosis, needs from family and network, and the importance of continuity in contacts with nurses. The participants struggled with thoughts about serious disabilities and stigmatization, although for some the disease moved more into the background after a period. The patients expressed a need for support and guidance from both families and nurses. They primarily used their families for support, and this was influenced by the family's emotional involvement. Family members typically did not have the necessary experience to give appropriate guidance. The patients were aware of the impact the disease had on their families, and this sometimes stopped them from seeking support from them. The nurse should develop the contact with the individual patient to become familiar with the patient's illness narrative and previous coping strategies so to better provide holistic care. Conclusion: Being diagnosed with MS gives rise to frightening thoughts about the future and the fear of stigmatization. Patients need support and guidance from both their families and the nurses at the MS clinic. Nurses should consider the family's role and how to involve the resources available from family members. It is important that the nurses develop a close relationship with the patient. The possibility of contact nurses may be a useful solution for providing targeted support and guidance to patients diagnosed with multiple sclerosis.

Keywords: Guidance, Lived experience, Multiple sclerosis, Nursing, Qualitative study, Support

How to cite this article

Petersen LS, Sorknæs AD. Patients' experiences of being diagnosed with multiple sclerosis and their support and guidance needs in the first year of illness. Edorium J Disabil Rehabil 2019;5:100046D05LP2019.

Article ID: 100046D05LP2019

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doi: 10.5348/100046D05LP2019RA

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Received: 13 May 2019
Accepted: 21 May 2019
Published: 12 July 2019

INTRODUCTION

Multiple sclerosis (MS) is a neurologic disease that impacts the nervous system and can cause numerous health issues, such as fatigue, cognitive problems, sensory disturbances, and loss of muscle strength. The

number of patients with MS is increasing, and currently about 16,000 people in Denmark have the disease [1]. The numerous health issues mean that optimal care requires comprehensive disease management and expertise in a range of disciplines [2]. The period following the diagnosis of MS is filled with uncertainty and confusion, with an increased need for support to handle a disease whose course of events is unpredictable for both patients and health-care professionals [3]. The 2014 national Survey of Patient Experiences found that the neurological outpatient clinic at Odense University Hospital scored poorly on talking to patients about how they managed their disease in everyday life [4]. This is a paradox compared to the hospital's codex "Patient first," where employees should treat the patient as an equal and be attentive toward the patients and their relatives [5, 6].

The Council for Use of Expensive Hospital Medicine recommends that patients with MS and disease-modifying treatment have a consultation with a neurologist every six months [7]. There are no recommendations for nurse consultations or their content. Malcomson et al. emphasize that many patients with MS seek counseling in relation to emotional issues and readjustment to a life with MS [3]. There is a lack of MS specialists, however, and without a consultation with an MS specialist, patients can miss out on treatment for symptoms as well as information and counseling about their disease [8, 9]. MS clinics are therefore recommended to use more nurses and therapists with specialized knowledge in MS and supervised by MS neurologists [8, 9]. On this basis, it is relevant to study the experiences of patients on being diagnosed with MS and their needs for support and guidance in the first year with the disease.

MATERIALS AND METHODS

Semi-structured individual interviews were conducted with five MS patients. Data were transcribed and analyzed by the first author, who was an experienced MS nurse.

The study used a phenomenological hermeneutic frame of reference as we aimed to understand the participants' experiences of being diagnosed with MS. The chosen research approach was an interpretative phenomenological analysis (IPA), which aims to examine detailed descriptions of the individual experiences of a given phenomenon. Interpretative phenomenological analysis is suitable for studies with sample sizes of three or more [10, 11].

Clinical setting

Data were collected at the MS clinic at Odense University Hospital in the Region of Southern Denmark. Patients with MS have consultations with a doctor at the clinic every six months. They are also offered individual consultations with a nurse when they are diagnosed and every six months thereafter. The purpose of the nurse consultations is to provide knowledge and information about the disease to newly diagnosed patients and to show them how to administer their medication [12, 13]. The nurses also discuss with patients about whether they experience physical or cognitive consequences from their disease. The nurses use questionnaires and checklists to identify physical and cognitive issues related to MS, but there is no standard approach to talking about psychosocial aspects for newly diagnosed patients. It is up to the individual patient and nurse to identify psychosocial issues, and the patient can have extra nurse or telephone consultations if desired.

Participants

To gain a broad understanding of patients' experiences of being diagnosed with MS and their needs for support and guidance, a purposive sample of five patients diagnosed with MS was invited to participate. The study participants were recruited when they came to their one-year medical control at the clinic. The inclusion criteria were a mixture of women and men aged 20–40 years who were on medical preventive treatment. We excluded patients with significant cognitive deficits, patients who were unable to speak and understand Danish, and patients who were personally known to the interviewer.

The patients gave written informed consent. The nursing staff helped the researcher to identify patients attending the clinic for their one-year consultations. Characteristics of the participants are shown in Table 1.

Data collection

The interviews were conducted in January and February 2018 using a semi-structured interview guide that was constructed by drawing on available literature [14]. The opening questions asked about experiences relating to the progress of the disease and the participant's conceptions of the disease. The interview then addressed experiences relating to being diagnosed with MS and the need for support and counseling within the first year of illness. The participants were interviewed on a self-chosen day, time, and place. They all chose to be interviewed at home. The interviews lasted approximately one hour and were tape-recorded and transcribed verbatim.

Analysis

The text of each interview was analyzed using IPA [11]. This a phenomenological hermeneutic approach committed to examining how people make sense of their life experiences. Data collection is usually in the form of semi-structured interviews, and the analysis is an iterative and inductive cycle. We used a step-by-step guide to make the process more manageable. After

reading the material several times, the interviewer noted anything of special interest within the transcripts. The aim was to produce a comprehensive and detailed set of notes and comments on the data. The themes that emerged from the transcripts were developed, combined, and abstracted into overall themes.

Ethical considerations

The study was registered with the Danish Data Protection Agency [No. 17/45878] and was reported to the Danish research ethics committees, who found the study exempt from the obligation to notify according to Danish legislation. As patients with MS can experience strong emotional reactions to diagnosis and treatment of MS, and to coping with the disease and its symptoms, we ensured that participants were not personally known to the interviewer so that any earlier reactions would not be an embarrassing factor for the patient.

RESULTS

The five participants had no visible physical signs of MS and had periods when they did not feel unwell. Most of them were in employment or under education. Some were living with partners, and some had children. Their previous knowledge about MS varied.

The three main themes that emerged from the interview material were: Frightening to get the diagnosis, needs from family and network, and the importance of continuity in contacts with nurses. Each theme had underlying themes, as illustrated in Table 2.

Theme: Frightening to get the diagnosis

The participants had different reactions to being diagnosed with a chronic disease.

Anxious for the future

Being diagnosed with MS led to thoughts about a future life with serious disabilities, use of a wheelchair, and early retirement. The participants said it was hard to become a patient and that it induced a radical change in their lives.

For some participants, it was almost incomprehensible to be diagnosed. Three participants imagined their lives being almost at an end or at least with major alterations.

> "I think it was very unreal—I got really scared and thought [...] that soon I would be sitting in a wheelchair and be injured in every imaginable way."

Some participants found it difficult to get a disease without knowing others in the same situation who they could share experiences with. One needed direct support to deal with the insecure perspectives of living with MS in the future. Another participant asked the nurse how other patients managed the disease as they did not want to be confronted directly with other patients. It was frustrating to become a patient and to have to deal with serious thoughts about the future.

Table 1: Characteristics of the five participants

Number	Gender	Age	Highest education	Work status	In a relationship	Children	Knowledge of the disease
1	Female	22	Vocational degree	Employed full-time	yes	no	yes
2	Male	20	Secondary education	Student	no	no	no
3	Female	21	Primary education	Unemployed	yes	no	no
4	Male	40	Vocational degree	Employed full-time	yes	yes	yes
5	Female	35	Bachelor's degree	Employed full-time	yes	yes	yes

Table 2: The three main themes with their underlying themes

Themes	Underlying themes
Frightening to get the diagnosis	- Anxious for the future - Becoming a patient—new identity
Needs from family and network	- Family are important but complicated supporters - Guidance from the family is based on feelings - Considerations about involving the place of employment
The importance of continuity in contacts with nurses	- Difficulties of talking to different nurses - One-sided guidance from nurses is not enough

Becoming a patient—new identity

Being diagnosed with a disease whose course of events is unpredictable to both patients and health-care professionals was difficult for the patients. Although none of them had visible physical signs of the disease and had periods when they did not feel unwell, they had to relate to a future life with a chronic disease. That induced different thoughts about the future and how to handle a life with a chronic disease. Some experienced it as a dilemma to imagine a life with MS.

One of the participants reflected on her situation after numerous visits to the hospital:

"Shit—will this be my life for the rest of my life!"

Even when they did not feel unwell, they were reminded of the disease when they took their medication or had consultations at the MS clinic. For some patients it was difficult to sit in the waiting room being confronted with other patients who had more visible signs of MS. The awareness of becoming a patient, knowing that the future was now more insecure, and the wish to live a normal everyday life led to a range of thoughts.

Some participants were afraid of other people's reactions and what they would think of them when they heard about the diagnosis. This caused thoughts about who they should tell about the disease, and several participants used a lot of energy keeping the disease secret to others.

One patient expressed it like this:

"I don't like saying that I am sick, not that I don't acknowledge that I am sick, but it would have a strong presence then."

After much consideration, a young man had decided that his friends and his teacher at the school should know about his MS. The teacher's reaction was to offer him to use the elevator at the school even though he could walk without problems, and was thus exactly as he feared.

Some participants felt that after some time the diagnosis had given their dreams for the future a new and more positive perspective. One woman noticed that she had changed her priorities in life, had a better feeling of what she needed, and was truer to herself. She had become better at sensing the important things in her life and had learned something about herself. She thanked the disease for that.

Being diagnosed with MS thus affected the participants' thoughts about their future in both negative and positive ways.

Theme: Needs from family and network

All participants expressed that the family was especially important in the first time after being diagnosed with MS, although in different ways.

Family are important but complicated supporters

Family members served as their primary supporters when it came to emotional support, and they were the first ones to talk to when the disease was active. Some participants expressed that they did not need the support from nurses at the MS clinic because they had their family members to talk to.

At some point the participants felt limitations talking to family members about their disease, however, because they were afraid to cause them more concern, emotional upset, or burden. The participants then felt more alone with their concerns, and they realized that family members sometimes found it difficult to provide the needed support. One woman explained that her mother was affected a thousand times harder when some aspect of the disease had worsened, and she therefore chose not to tell her mother when she felt sad about her situation. A young man said that his mother had such strong reactions that he felt that he should manage the situation without involving her.

"I actually lied when I was going to the hospital [...] I had in mind that she couldn't handle it."

Because family members were so emotionally involved, the participants sometimes chose to talk to good friends instead. Guidance from a good friend seemed to be more pragmatic when it was based on a personalized, close familiarity and knowledge of the participant's values. Thus it seemed that both family and friends provided important support for the participants although they were used differently in relation to emotional aspects.

Guidance from the family is based on feelings

Two participants had called on the MS clinic several times to receive instructions on how to manage unpleasant side effects to the medical treatment. They had been advised to continue the treatment until the next consultation, but they had wanted to stop. When they did not get the advice they needed to cope with intolerable side effects, it appeared that they chose to talk to family members instead.

"I went to her [the mother] and said that I didn't want to take the pills anymore, and then she said: "okay, that's fine."

By talking to family members, they were seeking accept for a decision they had already made. They used their family members when they felt they were not understood or taken seriously by staff at the MS clinic, even though the participants might have known that it was a risky decision.

Considerations about involving the place of employment

Seeking support from the workplace was managed differently by the participants. One male participant had experienced great support from his place of employment and could take time off to visit the hospital without explaining his absenteeism. He had already spoken to his employer about staying at the workplace even though the disease would worsen over time. That made him feel safe and secure. Other participants felt anxious that they would be discriminated and chose therefore not to tell their employer about the disease:

> "I actually had a big ethical dilemma about—should you tell this, should you not tell this [...] because it might be, that they must not judge me that I have a disease, but I don't think it is a secret that workplaces do that. That they choose the well [person] rather than the person who isn't."

One participant needed support and guidance from the nurses on how to take the medication in secret when she was at work because she feared she would have fewer options to pursue her career if her colleagues knew about MS.

The interviews showed that the participants had many ethical considerations about whether to tell their place of employment about the disease.

Theme: The importance of continuity in contacts with nurses

For most participants, being diagnosed with MS means a long-term association with the MS clinic.

Difficulties of talking to different nurses

Some participants found it difficult to talk to different nurses about emotional difficulties, and they preferred to have a contact nurse they could go to if they had a question.

> "So, I think, if you just had a certain nurse you could go to [...] it's different than just calling the MS clinic. Because then you have to start over all the time."

Participants had sometimes needed support from the nurses rather than guidance. A woman who had side effects from the medical treatment needed the nurses' support to handle it, and not just their guidance of how to use the medication.

The relationships with the nurses at the MS clinic were affected by the participants' emotions and degree of vulnerability at the time. This was reflected in their narratives about the support they received.

One-sided guidance from nurses is not enough

The participants had different needs when they called the nurses at the MS clinic. Two participants felt a great confidence knowing that they could call the MS clinic if they had questions and considered the role of the MS clinic as responsible for guidance more than a supportive service. If the participants needed a specific plan of action in a particular situation with physical symptoms, the relation to the nurse was less important. Other participants articulated that the character of the problem they experienced was decisive for whether they wanted a phone conversation or a clinic consultation. If the problem was psychosocial, there was a greater need for support and for having a contact nurse. One young woman felt ambivalent and alone with decisions about her education and had many thoughts about that.

> "But it's more when I am going to make big decisions like taking an education [...] Why? Why do I have to? I'm not sure that I ever get a change to use it!"

This indicated that there was sometimes a need for personal support to discuss preferences and make decisions.

DISCUSSION

Being diagnosed with MS caused thoughts about a future life with serious disabilities, use of a wheelchair, and early retirement. This is in line with previous findings where fear of serious disabilities was dominant at the onset of disease [15]. The unpredictable and unknown future with MS affects patients, and it can be difficult for them to accept and manage this uncertain course [3, 15]. Discussions between the patients and nurses at the MS clinic can be helpful here. Kleinman notes that it is important to be honest about the uncertainty of the course of the disease [16]. Thus the patient should know that functional deterioration cannot be avoided, and the professionals must support the patient physically, mentally, and existentially over time [16].

The need for empathy and sensitivity in the period after the MS diagnosis is described in several articles [3, 17]. The intense emotional reactions in the first year with the disease can affect how patients judge their capacity to manage problems, as described by Bandura [18]. People's ideas of life with certain diseases are created in the culture where they grow up, including concrete experiences of disease and expectations for the course of the disease [16, 19]. Multiple sclerosis nurses must listen to patients with a genuine interest, try to understand the patients' experience with the disease, and give relevant support and guidance.

Our participants experienced that when they were feeling well, their worries moved more into the background. Similarly, Malcomson et al. found that patients had to rethink plans and personal goals in the awareness that life had changed [3]. It is a reminder that nurses need to continue to talk to patients about the emotional sides of having MS.

Our participants had to revise their conceptions about the disease and needed understanding and support to handle this. It is important that patients' experiences are taken seriously in contacts with the MS clinic and that patients can get support, information, and guidance for different types of challenges. All our participants expressed anxiety for the future and a need for support to deal with this.

Similar to our study findings, Miller found that patients with MS often get the greatest support from family members or a few good friends [15]. When a person becomes ill, the family members can also be affected, stressed, or hit by crisis [19]. It can be hard to see a family member suffer [15]. Family members gave our participants emotional support with the perspective of avoiding discomfort for the patient. Each member of the family experiences and interprets the situation differently, and this perception reflects their truth [20]. The family does not always have the qualifications to give appropriate guidance about treatment, however, which could lead to negative consequences for the course of the disease.

The participants in this study were aware of the impact the disease had on their family members, and they did not always tell the family about their worries because they were afraid to cause them further burden. Similar findings were reported by Miller [15]. This may mean that patients do not get the family support that they need, however. Cooperation with the family is therefore necessary to get the best possible course while also relieving the family of worries and responsibility. This is in line with the nursing strategy at our hospital, which includes ensuring that the patient's relatives are listened to and involved in the new situation [6]. The nurse can offer guidance to patients and their families in relation to the patients' experiences. Family-focused nursing involves the understanding of the processes within families and how family members interact[20]. Nurses should consider whether it may be more relevant to have both the patient and the family participate in consultations, especially if these occur outside traditional working hours.

Some of our participants asked the nurses how other patients coped with MS. Bandura noted that patients can use experiences from other patients they can relate to [18]. Malcomson et al. found that it was meaningful to patients with MS to share experiences with others who were more disabled than themselves [3]. Most of our participants felt the opposite as they found it difficult to meet patients with more disabilities and felt uncomfortable in the waiting room where they were confronted with patients in wheelchairs. We inform patients about the MS patient organization, so patients can choose whether they want to meet other patients and perhaps those in a similar situation. The nurses at the MS clinic need to be aware of and respect patients' wishes regarding interactions with other patients.

Our interview findings showed that guidance on health-related physical needs were generally positively received. This was typically by patients who expressed a faith in the future and had a well-functioning support network.

Patients' coping abilities for handling challenges are an important determinant of their need of support from the nurses at the MS clinic [18]. The nurses should always be aware that new situations can arise and the need for guidance and support can change. In every contact with the patient, the nurse should thus take note of the patient's current need for support.

Staying in the labor market and having opportunities for a career meant a great deal to our participants. Some participants were concerned about involving their place of employment in their MS. This was also found by Malcomson et al., where maintenance of the job function meant a great deal and several patients experienced work changes after being diagnosed with MS [3]. The MS nurse should give the patient an opportunity to reflect on their perceptions about the workplace and its intentions.

Some participants needed more focus on emotional difficulties and would have liked a contact nurse to talk to about the psychosocial aspects of living with MS. These patients wanted support for personal issues, and according to Kleinman, this support is best when it comes from someone who is familiar with the patient's personal narrative and concrete lifeworld [15, 16]. The importance of illness narratives is underlined by Methley et al., who concluded that bad experiences with support and guidance in the post-diagnosis phase are caused by lack of continuity in care and involvement of too many different health professionals [17]. It is not only a question of listening to the illness narratives; the nurse must also get to know the patient over time to be able to provide focused and effective support. The nurse can perhaps help by convincing a patient to handle a specific situation using previous managing strategies, although this requires a deeper knowledge about the individual patient [18].

Patients want the professionals to direct, support, and guide them in a holistic manner, with special attention to psychosocial aspects [3]. Methley et al. found that continuity of care was a key factor for newly diagnosed patients who helped them to avoid feeling left behind or isolated with their disease experiences [17]. Patients could thus benefit from having a contact nurse in the first vulnerable period while they struggle to adapt to the disease and its consequences.

Methodological considerations

Our investigation of individual patient experiences is based on unique situations between interviewer and participant and is therefore hard to reproduce. The reliability of the findings thus need to be evaluated using the approach that generated the results [14]. The validity of the study is evaluated on the basis of its purpose and the applied investigative method [21]. We chose to use semi-structured interviews for collecting empirical data as this approach is suitable for illustrating the human lifeworld and experiences [21].

The interviewer was employed at the MS clinic from which the empirical data were collected. Doing interviews in this field requires a constant reflexivity, and the pre-understanding of patients' experiences could have influenced the results of the study. Furthermore, the interviewer's own cultural values and contextual knowledge may have influenced the interpretation of the empirical data [22].

The interviewer's pre-understanding of the needs for support and guidance for patients with MS is an unavoidable factor in interviewing patients and could have altered the curiosity for clarifying participants' perspectives [22]. Interviewing patients from one's own department can be seen as a weakness as a blind egocentrism can mask relevant themes in the material [23]. To minimize the influence from the interviewer and to avoid personal interaction, we ensured that the participants were not known to the interviewer.

Participants who fulfilled the inclusion criteria were included. Some patients declined to participate as they felt they lacked the energy for it. It is possible that those patients could have contributed with other perspectives.

The interviews were conducted in the participants' own homes on their own request. The private settings constituted a relaxed atmosphere, where also the interviewer was away from the daily setting at the MS clinic. This contributed to open and personal narratives with many perspectives on experiences with disease, support, and guidance.

Five interviews were conducted, and this seems reasonable according to the IPA method [10]. Idiographic analysis of the collected material made it clear where there was coincidence or discrepancy in the individual interviews. The results are illustrated by quotations, which allow others to assess the connection between the data and the interviewer's interpretation [24].

CONCLUSION

Being diagnosed with MS gives rise to frightening thoughts about the future and the fear of stigmatization. By listening to the patient's perceptions and experiences with the disease, the nurse can better understand the consequences the disease has on the patient's personal life and social world. Our analysis showed that the participants had varying needs in relation to support from the nurses, especially in dealing with emotional issues induced by the disease.

Our participants expressed a need for support and guidance from both families and nurses. They primarily used their families for support, but this was influenced by the level of emotional involvement, and family members could not always give appropriate guidance. The participants were also aware of the impact the disease had on their family members and thus often preferred to have help from the nurses to handle emotional aspects of having MS. It was especially important to have contact to a nurse on the basis of current needs. We conclude that a close relationship between nurse and patient can contribute to more reliable and relevant guidance. The possibility of contact nurses may be a useful solution for providing targeted support and guidance to patients diagnosed with multiple sclerosis.

REFERENCES

1. Koch-Henriksen N, Thygesen LC, Stenager E, Laursen B, Magyari M. Incidence of MS has increased markedly over six decades in Denmark particularly with late onset and in women. Neurology 2018;90(22):e1954–63.
2. Jansen DE, Krol B, Groothoff JW, Post D. Integrated care for MS patients. Disabil Rehabil 2007;29(7):597–603.
3. Malcomson KS, Lowe-Strong AS, Dunwoody L. What can we learn from the personal insights of individuals living and coping with multiple sclerosis? Disabil Rehabil 2008;30(9):662–74.
4. LUP – The National Danish Survey of Patient Experiences. 2014. [Available at: http://www.oecd.org/els/health-systems/Item10b2-National-Danish-Survey-Patient-Experiences-Mainz.pdf]
5. OUH codex. 2017. [Available at: https://www.epostersonline.com/isqua2017/node/2261]
6. OUH patient first. 2019. [Available at: http://en.ouh.dk/research/research-strategy-2016-2020/involving-patients-and-relatives/]
7. RADS – The Danish Counsil for the use of expensive hospital medicine. 2019. [Available at: https://medicinraadet.dk/om-os/in-english]
8. Neurology Live. 2019. [Available at: https://www.neurologylive.com/clinical-focus/lack-approved-therapies-ms-symptoms-present-difficulties-treatment]
9. Rønning OM, Tornes KD. Need for symptomatic management in advanced multiple sclerosis. Acta Neurol Scand 2017;135(5):529–32.
10. Smith JA, Flowers P, Larkin M. Interpretative Phenomenological Analysis: Theory, Method and Research. Los Angeles, London: SAGE Publications Ltd; 2009.
11. Smith JA. Qualitative Psychology: A Practical Guide to Research Methods. 3ed. London: SAGE Publications Ltd; 2015.

12. Roman C, Menning K. Treatment and disease management of multiple sclerosis patients: A review for nurse practitioners. J Am Assoc Nurse Pract 2017;29(10):629–38.
13. Saunders C, Caon C, Smrtka J, Shoemaker J. Factors that influence adherence and strategies to maintain adherence to injected therapies for patients with multiple sclerosis. J Neurosci Nurs 2010;42(5 Suppl):S10–8.
14. Kvale S. Doing Interviews. Los Angeles, London: SAGE Publications Ltd; 2007.
15. Miller CM. The lived experience of relapsing multiple sclerosis: A phenomenological study. J Neurosci Nurs 1997;29(5):294–304.
16. Kleinman A. The Illness Narratives: Suffering, Healing, and the Human Condition. New York: Basic Books; 1998.
17. Methley AM, Chew-Graham C, Campbell S, Cheraghi-Sohi S. Experiences of UK health-care services for people with Multiple Sclerosis: A systematic narrative review. Health Expect 2015;18(6):1844–55.
18. Bandura A. Self-Efficacy: The Exercise of Control. New York: W. H. Freeman; 1997.
19. Benzein EG, Hagberg M, Saveman BI. 'Being appropriately unusual': A challenge for nurses in health-promoting conversations with families. Nurs Inq 2008;15(2):106–15.
20. Wright LM, Leahey M. Nurses and Families: A Guide to Family Assessment and Intervention. 6ed. Philadelphia: F.A. Davis; 2013.
21. Green J, Thorogood N. Qualitative Methods for Health Research. 4ed. London, Los Angeles: SAGE; 2018.
22. DeWalt KM, DeWalt BR. Participant Observation: A Guide for Fieldworkers. Blue Ridge Summit: AltaMira Press; 2010.
23. Malterud K. Qualitative Metasynthesis: A Research Method for Medicine and Health Sciences. 1ed. London: Routledge; 2019.
24. Brinkmann S. Qualitative Interviewing. New York: Oxford University Press; 2013.

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Acknowledgments
We thank the study participants for their support of this research. Furthermore we want to thank Claire Gudex, MD, PhD, Adjunkt for editing the manuscript

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Lena Skovgård Petersen – Analysis of data, Interpretation of data, Drafting the work, Final approval of the version to be published, Agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved

Anne Dichmann Sorknæs – Analysis of data, Interpretation of data, Drafting the work, Final approval of the version to be published, Agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved

Guarantor of Submission
The corresponding author is the guarantor of submission.

Source of Support
None.

Consent Statement
Written informed consent was obtained from the patient for publication of this article.

Conflict of Interest
Authors declare no conflict of interest.

Data Availability
All relevant data are within the paper and its Supporting Information files.

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Article citation: Petersen LS, Sorknæs AD. Patients' experiences of being diagnosed with multiple sclerosis and their support and guidance needs in the first year of illness. Edorium J Disabil Rehabil 2019;5:100046D05LP2019.

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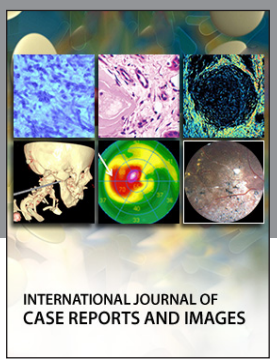

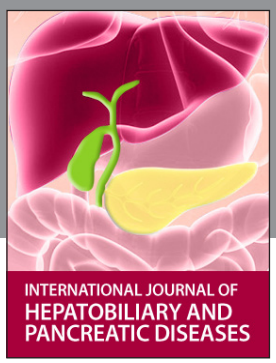

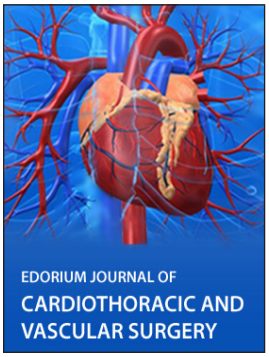

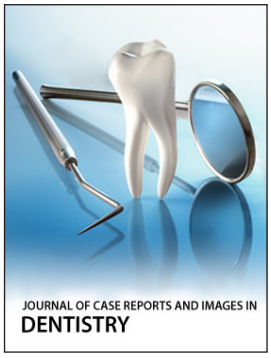

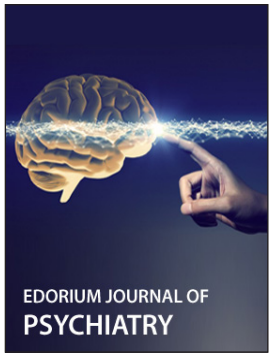

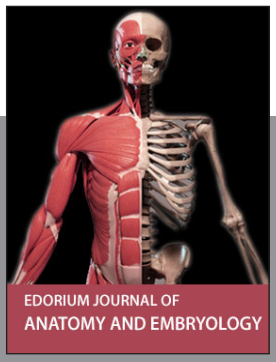

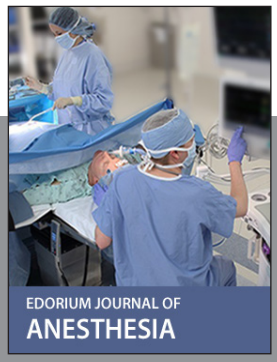

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