# The effects of MS experienced in the work situation – a qualitative interview study

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## Research team and reflexivity

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## **DUTCH SUMMARY**

Titel: De ervaren invloed van Multiple Sclerose in de werksituatie.

**Inleiding:** Een van de meest invloedrijke gevolgen van Multiple Sclerose (MS) is werkloosheid. Na een gemiddelde ziekteduur van 22.2 jaar is 67.6 % van de mensen met MS werkloos. Onderzoeken tonen aan dat de kwaliteit van leven lager is bij mensen met MS die niet meer werken. Op dit moment ontbreekt onderzoek vanuit het perspectief van de patiënt.

**Doel en onderzoeksvraag:** Het doel van dit onderzoek was om na te gaan hoe MS het werk beïnvloedt. De onderzoeksvraag is 'Hoe ervaren mensen met MS de invloed van MS in de werksituatie?".

**Methode:** Dit is een kwalitatief onderzoek, gebaseerd op de gefundeerde theoriebenadering. De gegevens worden verzameld middels semigestructureerde topic interviews. Data is geanalyseerd middels constante vergelijking.

**Resultaten:** Twaalf MS patiënten zijn geïnterviewd. Na analyse zijn vier thema's ontstaan. De thema's zijn: ervaren consequenties van MS in de werksituatie, belang van werk, barrières en hulpmiddelen. Alle participanten ervaren gevolgen van MS in de werksituatie. Daarbij is het emotionele belang van werk is groot. De grootste barrière in het werk is onbegrip van werkgevers en collega's. Hulp bij het volhouden of anders inrichten van werk is in verschillende vormen aanwezig.

**Conclusie:** Inzicht krijgen in het patiënten perspectief van patiënten met MS in de werksituatie is een kritieke stap om zorg aan te passen aan behoeftes van de patiënt. Informatie uit deze studie helpt zorgverleners om het patiëntenperspectief beter te begrijpen. Het kan gebruikt worden bij het geven van antwoorden op vragen over de werksituatie in combinatie met MS.

Aanbevelingen: Resultaten van dit onderzoek dienen als basis voor het ontwikkelen van ondersteuning. Het geven van informatie dient consistent te zijn met het patiëntenperspectief. Er dient aandacht besteed te worden aan mogelijke doorverwijzingen.
Deze horen aan te sluiten bij barrières die patiënten ervaren.

Trefwoorden: MS, werkloosheid, werk, patiëntenperspectief.

### **ENGLISH ABSTRACT**

Title: The effects of MS experienced in the work situation

**Background:** One of the most impactful consequences of Multiple Sclerosis (MS) is unemployment: 67.6 % of people with MS are unemployed after a mean disease duration of 22.2 years. Quality of life is reduced in people with MS who are no longer employed. Research from the patient's perspectives is lacking.

**Aim and research question:** The purpose of this study was to explore how MS influences work, as experienced by people in their working environments. The research question is, 'How do people with MS experience the effects of MS in their working conditions?'

**Method:** This is a qualitative study based on the grounded theory. Data were collected through semi-structural topic interviews. Data was analyzed through constant comparison.

**Results:** Twelve MS patients were interviewed. Four themes emerged during analysis. The themes identified were: perceived consequences of MS in the work situation, importance of work, barriers and resources. All participants experienced effects of MS in the workplace. The emotional importance of work was large. The major barrier in the work situation was a lack of understanding from employers and colleagues. However, resources for work continuation were available in various forms.

**Conclusion:** Exploring the perspectives of MS patients in the workplace is a critical step to be able to adapt care to the needs of patients. Information from this study can help caregivers better understand patients' perspectives. It will help answer questions from patients about job situations in combination with MS.

**Recommendations:** Results of this study can serve as a basis for developing better support. Information given must be consistent with the patients' perspective. Attention should be given to helping with referrals. Caregivers should be well informed about available resources.

These should fit with the barriers experienced by patients.

Keywords: MS, unemployment, work, patient perspective

#### INTRODUCTION

Worldwide, Multiple Sclerosis (MS) affects more than 2.1 million people (1). In the Netherlands, there are 16,000 people with MS (2). MS is an incurable chronic disease that attacks the central nervous system. Symptoms may be mild, such as numbness or other abnormal sensation, or severe, such as paralysis or visual disturbances (1,2). MS is more common in women than in men. Genetics play an important role in who gets MS. Most people are diagnosed between the ages of 20 and 40, but MS can also appear in young children and teens as well as in older adults (1). The progress, severity, and specific symptoms of MS are unpredictable and vary from person to person (1,2).

One of the most impactful consequences of MS is unemployment (3). In Strober's study, unemployment is defined as not having paid work. MS occurs in individuals during peak years of employment (2). After a mean disease duration of 22.2 years, 67.6 % of people with MS are unemployed. The total unemployment in MS patients is 70%-80%. Especially in the first seven years after diagnosis, unemployment increases substantially (4,5). Multiple studies show that quality of life is reduced in people with MS who are no longer employed (4,6-9).

Several studies on factors associated with unemployment in MS have been conducted (3,4,6-13). The majority focused on health factors related to MS. Multiple health-related risk factors, such as depression, are associated with high unemployment (4,7,8,10,11), fatigue (3,10-12), high neurological impairment (3,4,6,9) and declines in cognition (3,10,10,12). While MS disease features are important contributors, they only account for 14-20% of the variance in predicting employment status. So far, however, it is unclear what other factors might be associated with unemployment in MS (3,14,15).

In other diseases, more qualitative information is available on factors that play a role in chronic illness and unemployment (16-20). Studies show that work is influenced by the physical and mental influence of a disease (17,18,20), adaptation of the content of the job or having difficulties finding a suitable job (16,20), laws and regulations that limit the work options (16) and not much support in the search for work solutions (16-18).

A study of unemployment and MS in Switzerland and Australia showed that work is influenced by physical, social, attitudinal, and policy factors (19). The influence of patient perspective was limited to questionnaires. Therefore, less detail was gathered. Some work-related factors in MS and work are known. Predictive work-related factors are heavy physical or mental work (7), unsuitable working conditions and little support from colleagues (13). However, little research has been found that studied patients' perspectives of MS. By means

of qualitative research, the experiences and perspectives of patients related to MS and work can be obtained. For people with MS, it is of great value to participate in the labour market as long as possible.

## PROBLEM STATEMENT, AIM AND RESEARCH QUESTION

Patients with MS experience several symptoms. These symptoms influence the performing of patients' jobs. Treatment of MS is performed in a multidisciplinary fashion. In implementing care through different caregivers, it is important that the care meets the expectations of the MS patients. All caregivers can field questions about work in combination with MS. To answer these questions correctly, it is important that it is clear what the patients' perspective is in this situation. At this moment, we are not aware enough of this perspective.

## Aim:

To generate insight into MS patients' experiences in the job situation.

## **Research question:**

How do people with MS experience the effects of MS in their job situation?

### METHOD

#### Methodological orientation

To gain insight into the contours of the theoretical model of the MS patients' perspective on the influence of MS in the work situation, the grounded theory method was used. The approach to grounded theory aims to generate a theory around a core category (21), thus explaining how people with MS experience the effects of MS in their job situation.

#### Participant selection

This study examined the perspective of MS patients in the early disease stage. Inclusion criteria were the diagnosis of MS, determined according to the McDonald criteria (22), diagnosed at least a year previously, with a maximum of seven years previously, an employee at the time of MS diagnosis, aged between 18 and 65 years and having a good command of the Dutch language. Exclusion criteria were unemployment by a clear cause other than MS, co-morbidity that could affect work ability, impeding speech problems and mental incapacity, when this is documented in the dossier of the patient. Participants were selected from the outpatient population of a medical university centre in the Netherlands. Criteria-oriented, purposeful sampling was conducted in order to have the maximum variety of cases according to the following characteristics: gender, type of work, employment and disease state.

The researcher distributed nineteen invitation letters to inform suitable patients of the study. A week after sending the letter, the researcher had telephone contact with each patient. The researcher asked whether there were any questions and whether the patient wished to participate in the study. If the patient wanted to take part in the study, an appointment for conducting the interview was made. Participants were approached according to the research protocol and informed consent was obtained.

#### Settings

The interviews took place at the hospital where the patients were in care and where the first author worked. The interviews were carried out by the first author. In three cases, a partner/relative of the patient was present at the interview.

#### Data collection

Semi-structured interviews were about the participants' experiences with MS in the job situation, with open ended questions. Questions that were asked are shown in Table 2. The interviews were also voice recorded. On average, the interviews lasted three quarters of an hour. Interviews were conducted until interview data revealed no new information, and saturation had been reached. Based on similar studies, it is expected that ten interviews are needed to achieve saturation.

#### Data analysis

The recorded interviews were transcribed verbatim by the first author. Data was analyzed through the constant comparison method (21), which is appropriate to the research method. Data from each interview were analyzed for themes and then organized into major categories that addressed the underlying issues. Data analysis began following the first interview, and data from each interview were used to inform subsequent interviews. In the analysis process, the structure of the code tree was adjusted for optimal usability. The transcripts were analyzed by means of NVIVO software (23). When using quotes in the results section, quotes are translated from Dutch to English by the first author. The core concepts are the job-environment experiences of people with MS.

#### Validity and reliability

The interview questions were pilot-tested in a test interview. As the test interview resulted in the desired quality of answers, the results of this interview were also included in the analysis. There were no adjustments to the questions in the following interviews. All interviews and the analysis process were checked and discussed by the supervisor. As a member check, a summary of the interview was sent to the participants for comment and correction. All participants agreed with the content of the summary. Outcomes of this study are compared with similar previous studies.

#### **Ethical considerations**

The research protocol was submitted to the Committee for research involving human subjects (CMO) Arnhem -Nijmegen. The committee decided this study is not subject to WMO-compliance, meaning their formal approval was not needed according to Dutch healthcare research laws. In this study, participants have not been subjected to behavior, and there is no deviation from standard care.

## RESULTS

A total of 12 people with MS were interviewed. Seven patients who were approached to participate did not participate in the study. The main reason for not participating in the study was that it was too burdensome for the patient. The average age of the participants is 39 years. The participants had the diagnosis of MS for 3.4 years on average. All participants were employees at the time of diagnosis. Ten of the twelve participants worked for 32 hours or more before diagnosis. The occupations of the participants varied considerably from instance to instance. Table 1 shows the demographic data of the sample group.

The influence of MS in the paid job situation was analyzed. Four themes emerged from the data. All themes were mentioned within each interview. The themes identified were (1) perceived consequences of MS in the job situation, (2) importance of work, (3) barriers and (4) resources.

## 1. Perceived consequences of MS in the job situation

For all participants who took part in this study, there were changes in the job situation as a consequence of MS. These were changes that occur within a job, as well as changes of job or employer.

Regularly, it happens that participants, whether temporary or not, reduce the number of working hours within the current function. This may be a way to keep up with the demands of working, or to combine work with disease-specific events, such as a rehabilitation course.

Through fatigue and other symptoms I started working for fewer hours. This will probably become more hours, but the question is when it happens. I now started a rehabilitation course. During this course, I continue to work less. After the process, my working hours may be expanded.

Some participants indicate that working fewer hours as a result of the MS triggered feelings of guilt:

If I'm going to work less, I feel like I am not allowed to do fun things.

When the symptoms of MS give difficulties in the execution of a job, patients often seek short-term solutions to be able to work longer. Examples of practical adjustments are fewer. Examples therefore are a customized seat or customized work surface. What often happens is that patients give up certain tasks to other colleagues and more quickly ask colleagues for help. This ensures that work can be maintained longer. Often, adjustments within the current function are not possible or feasible. When patients realize this in advance, they decide to look for a new job. Making the decision to change employers or jobs is not without consequences. As a result, some participants reduced salary, or the work they perform is below the level of training.

Now I have a different function than before. The work I'm doing is two function-grades lower than the work I was doing.

## Another participant reported:

The diagnosis of MS has created the feeling that my life must change....I went looking for another employer, which can give more certainty. That brings rest....This change still feels like a demotion.

When MS comes with so many restrictions that the work cannot be done anymore, dismissal or occupational disability follows. Reintegration is used to switch from the current function to an appropriate new function.

At this moment I'm working on my reintegration process....I started in another position within the same company....Now I'm working on expanding my working hours within this function.

Several participants have been in a reintegration process.

It is not always possible to reintegrate. Some of the participants fall under the disability law or are laid-off. Some participants mention this is not wrong in all circumstances.

It gives rest not having to work.

and

I'm totally disallowed. In order to maintain social contacts, I still work a few hours a week...without the stress that I should do this or that I have to perform.

## 2. Importance of work

Participants were asked about the importance of work. The responses show both emotional and financial impacts. For the majority of the participants, emotional impacts are paramount. *You want to keep busy, otherwise you're just worrying yourself.* 

and

Even if I did not get paid for the work, I would still want to work. I would not know what to do at home all day long.

Other reasons mentioned for wanting to continue to work are social contacts, being useful, satisfaction, prevention of loneliness, performance drop and pleasure from the work.

Finances play an important role in a different way. If the financial situation is not well organized or is uncertain, it creates stress. Participants indicated that they have a certain image of the future life.

You do have future plans. Your own house and that kind of stuff, that plays a role.

Money is needed to make future plans happen. Besides that, most participants indicate that it feels good to have a personal income.

## 3. Barriers

In the first place, MS symptoms themselves ensure that there are difficulties in the workplace. These include that work can no longer, or less easily, be carried out. In addition to symptoms, patients mentioned several other sources causing difficulties at work.

In about half of the participants, MS was diagnosed quickly. Other participants describe a long process before the final diagnosis. This also has consequences at the workplace. Due to certain symptoms, participants do not succeed in performing the work, but at that moment it is still unclear what the cause is. Lack of understanding can have a major role in this.

Outside it was 32 degrees. I was very sick. I could not walk. You're in a wheelchair and cannot do much. Then you get a lack of understanding at work. They say: the weather is nice, so you're sitting at home. While it really was not possible to work. In addition, even when the diagnosis is known, in some cases there is no understanding from the employer or colleagues. If they do not show understanding for the situation, this will immediately influence the work. At some point in time, all participants have to deal with a lack of understanding. Participants expressed lack of understanding as follows:

Almost nobody knows what MS is. Often people think it is a muscular disease. To get understanding, first you should explain exactly what it is.

or

It was not accepted when I failed to come to work. Colleagues thought I could easily come to work.

Besides a lack of understanding from others, uncertainty about the future plays a role. You do not know when MS symptoms present and which symptoms they are.

and

An employer can tell you that he wants you to continue to work for him, but how do you know that for sure?

When there are problems in the work situation, patients have to deal with the law and regulations concerning work. A large proportion of the participants said they were not well aware of these regulations. They want to delve into it no earlier than necessary.

The rules are quite complicated. By myself, I had no overview.

and

I do not want to be sick and not be able to work any longer. Therefore, I don't want to know what rules there are, before the situation is so far.

Uncertainties that revolve around work provide additional stress. This stress, in turn, has an influence on MS symptoms.

## 4. Resources

There are different types of resources when problems arise in the workplace. These resources are roughly divided into the following categories: resources at work, professional support and resources found by the participants themselves.

Resources offered through the employer include adjustments at the workplace and occupational health services from the company. Many participants used the occupational health service. The manager referred them to it.

From the beginning, the occupational health service was concerned. They were well aware of the situation.

For professional support, different sources are used. Mentioned sources are a specialized MS-nurse, social work, rehabilitation, representative social security and the Institute for Employee Insurance. Participants indicated the use of these sources to obtain information and get help in integrating MS in their lives and in their jobs.

Staff from the rehabilitation course help me think about how to distribute my work hours over the week.

and

At the social security office they could explain all the regulations regarding work.

The MS-nurses are often referred to as referring patients to other disciplines.

Patients also look around for help in their own network. One participant used a lawyer; another participant participated in a mindfulness course, and a labor union was asked for support. Participants noted that open communication has a major positive impact. It helps other people to better understand the situation. This can also be obtained through support from colleagues.

If you have been open about the situation, then that is also clear to the employer and to colleagues. Then they know better what they can expect.

Patients indicated that taking initiative is important.

I did take the initiative. As a result I am at the point where I am now.

Patients notice that taking the initiative results in faster steps and there is more space for self-determination.

## DISCUSSION

This study described the effects of MS in the job situation seen from patients' perspectives. The experiences of the 12 MS patients in this study show that MS influences work in different ways.

Very little was found in the literature from patients' perspectives (19). What this study added is that patients were asked about the importance of work. This study showed that having a job is of great emotional importance, and for most patients of greater value than the financial importance of a job. Having a job gives a sense of belonging and value. Besides that, this is the first time that a review was done of what the various barriers in the workplace are and what resources are used. Lack of understanding from employers or colleagues is perceived as the biggest barrier. It has a negative impact on job satisfaction. Resources for work are present in various ways. In many cases, help is first sought from within the company. Later, patients receive help from outside the company, such as the Institute for Employee Insurance or a social security representative. When patients look for help by themselves, they engage a lawyer or take courses. Patients take the initiative to seek help or ask caregivers for advice when seeking help.

Previous studies already showed that health factors related to MS are associated with unemployment (3,4,6-13). Participants in this study confirm that. Patients who are more affected by MS experience more problems in the job situation. In many cases, fatigue causes a reduction in work hours.

The importance of work is also confirmed in other research, which is linked to quality of life (4,6,9). MS patients who are employed have a better quality of life. The results from the qualitative studies in other chronic diseases are similar (16-20). In these studies patient also indicated that work is influenced by physical and mental symptoms of the disease. Symptoms of MS require that work be adjusted or that switching to another job be considered. Laws and regulations are not always known. For this, patients often seek assistance.

The limitations of this study need to be acknowledged. For the interviewer, it was the first time she conducted interviews. To ensure quality, all interviews were discussed with the supervisor. As a result, the interviews conducted in a reliable way. The analysis process was carried out by one person, the first author. However, there was always a supervisor who checked the process. Imperfections were timely seen and resolved. In three cases, the participant and the interviewer knew each other from a previous care situation. Possibly,

participants would be more likely to give socially desirable answers. Further, by knowing the background situation of the patients, the interviewer was able to ask for more detail in these situations. In conclusion, it can be stated that there is a possibility of bias.

In this study, participants were in the first years after the diagnosis of MS. When patients are further in the disease process, other problems could arise. The results from this study are probably not generalizable to the whole group of MS patients.

## CONCLUSION

Exploring the patients' perspectives of MS in the workplace is a critical step to being able to adapt to the needs of patients. Information from this study can help caregivers better understand patients' perspectives. It will help to answer questions from patients about the job situation in combination with MS. Each participant of this study experienced impacts of MS within the job situation. It is clear that work is of great importance for MS patients. Now we know what the major barriers are and what resources can help; this information can be used in the care of patients.

## RECOMMENDATIONS

Results of this study can serve as a basis for developing better support. Giving information must be consistent with the patients' perspective. Attention should be given to help with referrals. Caregivers should be well informed about the availability of resources. These should fit with the barriers experienced by patients.

Further research should be done to investigate patients' perspectives when patients are further in the disease process. Possibly, it would generate new insights in this area. This can be done by using qualitative research.

## TABLES

Respondent	Gender	Age	Years	Type of work	Work status	Original	Work hours at
			of MS			work hours	this moment
1	F	38	1	Team leader	Reintegration	32	16
2	М	29	6	Mechanic	Reintegration	40	40
3	F	26	3	Florist	Employee	36	36
4	М	58	4	Warehouse assistant	Unemployed	40	0
5	М	33	4	IT	Employee	40	40
6	F	36	2	Team leader	Employee	35	35
7	F	34	3	Nurse	Employee	32	32
8	F	54	3	Doctor assistant	Employee	13	13
9	F	28	4	Cashier	Reintegration	32	5
10	F	40	4	Accountant	Employee	24	8
11	М	55	5	Military	Unemployed	40	0
12	F	38	2	Private company	Unemployed	40	0

## Table 1. Description of the participants.

#### Table 2. Basic interview questions

How does MS express itself in your situation? What are your main symptoms and what is

the course of MS?

What was your job at the time of diagnosis? How many hours did you work?

What is your job at this moment? How many hours do you work?

What is the content of your workday?

What burden do you experience in work?

What is the importance of your work?

What is the impact of MS in your work situation?

Is your work changed by influence of the MS?

What problems are encountered?

Which sources of information, guidance or support are used, which are missed?

What solutions are used?

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