

Job Retention by People With Disabilities: A Qualitative Study of the Perspectives of People With Multiple Sclerosis

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ABSTRACT

Background: Multiple sclerosis (MS), because of its early age at onset, greatly impacts the working lives of those affected by it in ways linked to different factors, both professional and personal. It has been observed that only a small percentage (20–40%) of workers with MS retain their jobs after the diagnosis. When identifying factors determining job retention or loss in this setting, it is essential to consider the direct perspectives of people with MS (PwMS).

Methods: A qualitative study, based on the conduction of two focus groups, was conducted to explore the personal experiences of PwMS who work. **Results:** The results show that there are numerous factors, both positive and negative, that can influence these people's ability to retain their jobs. The climate established in the workplace and the relationship between workers with MS and their colleagues were fundamentally important aspects, as was knowledge of the disease at the level of public opinion. **Conclusions:** Managing work is a complex undertaking for people with a disabling condition like MS. There needs to be greater awareness of the employment rights of PwMS. Improving these knowledge-based aspects could undoubtedly improve the quality of the working lives of PwM.

1. INTRODUCTION

Multiple sclerosis (MS) is a chronic inflammatory and degenerative disease of the central nervous system [1]. An estimated 127,000 people in Italy have MS and 2.8 million live with the disease worldwide, including a million in Europe [2].

Because of its early age at onset, MS greatly impacts the working lives of those affected by it, in ways linked to different factors, both professional and personal [3, 4]. According to the literature, 90% of people with multiple sclerosis (PwMS) worked before their diagnosis, and around 60% were working at the time of it; however, only a small percentage

(20–40%) continued working after being diagnosed with MS [5]. Recent European studies showed employment rates ranging from 31% to 65%, which depended on many factors: sociodemographic, clinical, therapeutic and related to working conditions [6–9]. Indeed, in a recent Italian study, work difficulties were found to be related to invisible symptoms such as fatigue and mood disorders and not just to the presence of comorbidities and disability levels [10]. These findings suggest that PwMS find it difficult to work or remain in work. However, they also highlight areas ripe for potential interventions and developments.

This study was conducted as part of a broader project, funded by the Italian National Institute for Insurance against Accidents at Work, named “*PRISMA: Prevenzione rischi, Reti collaborative, Inclusione lavorativa nella Sclerosi Multipla dalla conoscenza della realtà lavorativa delle persone con SM in Italia alla messa a punto di modelli e programmi innovativi per l’inclusione lavorativa*” (PRISMA: risk prevention, collaborative networks, work inclusion in multiple sclerosis: from knowledge of the working reality of people with MS in Italy to the development of innovative models and programmes for work inclusion). It was conducted to improve the workplace inclusion of PwMS in compliance with their fundamental rights and with the principles of accessibility and health and safety at work. The findings reported herein refer to a qualitative study undertaken to explore, based on the experiences of PwMS, the main factors associated with job retention/loss in this population. Particular attention was paid to relevant topics such as MS-related symptoms, the work environment, the attitudes of others in the workplace, financial considerations, as well as good practices to promote reasonable accommodations.

2. METHODS

2.1 Study Design and Settings

The study involved creating two focus groups (FGs) which, because of the pandemic, had to meet using web conferencing technology [11]. The FG sessions lasted around two hours, and

each saw the participation of five/six PwMS (the group included residents of both northern and central-southern Italy), as well as a moderator and two observers. The participants were identified through the local sections of the Italian MS Association (AISM) based on the following selection criteria: male or female; being of working age (18–65 years); either being in work or out of work for no more than 3 years. The identified subjects were contacted via email and invited by the researchers to participate in the FG activity after signing the relevant privacy information and informed consent documents.

2.2 Data Analysis

Both FG sessions were recorded with the participants’ consent, and in each one, the moderator, who had an outline of the topics of interest, guided the discussion. On the other hand, the interview’s analysis was guided by a (constructivist) grounded theory [12].

At the end of each FG session, two researchers (AV and EP) independently codified the raw transcripts. Basically, after a joint discussion of the interpretations, they developed a coding framework [13] and used the constant comparative technique (open coding) to identify emerging themes [14].

3. RESULTS

In total, 17 PwMS were contacted (12 women and 5 men). Of these, only 10 (all women) agreed to participate in the study. The participants (a healthcare worker, two office workers, a researcher, a freelancer, a hotel employee, two teachers, a social worker and a call centre operator) ranged in age from 30 to 65 years, and all but one were actually in work at the time of the survey. Most participants had a disease duration of less than 10 years; in just one case, the diagnosis dated back more than 30 years. The PwMS taking part in the study reported different degrees of disability: two PwMS used walking aids (sticks), another had difficulty climbing stairs/steps, one used a wheelchair, and all struggled with fatigue.

Table 1. Topics that emerged during the FG sessions within the different areas of discussion

Areas of discussion	Topics
Diagnosis disclosure	The role of colleagues and superiors/employers
Work benefits, especially during the pandemic	Contract types Working remotely Reasonable accommodations
Institutional figures of reference	The occupational physician
Aspects influencing job retention	The role of colleagues Support for managing family life/work Getting to and from work

3.1 Diagnosis Disclosure

Only one main topic emerged in this area of discussion, namely the role of colleagues and of the individual's superior or employer.

Various interventions by the participants underlined just how crucial it is to get on well with colleagues. Good working relations can help build a climate of trust in which PwMS find they can disclose their condition and talk about their difficulties.

...My colleagues were very sympathetic and supportive... they don't discriminate against me or judge me in any way.

The findings differed regarding the role of superiors/employers, given that these figures seemed to play no part in the participants' decisions to disclose their diagnosis. Only one participant mentioned her superior, but more to underline that person's particularly empathetic nature rather than any aspects linked to their role. In this case, the superior even took the trouble to identify the "best" hospital where the participant might seek a diagnosis.

...I really couldn't understand what was wrong with me, and it was my boss who made the necessary enquiries and got me admitted to an excellent hospital where I finally got the correct diagnosis.

In short, being met with empathy and understanding from colleagues and direct superiors is fundamentally important when a person with MS has to disclose their diagnosis. Having an understanding and sensitive colleagues or a boss with the

same attributes, capable of putting the person with MS at their ease and reassuring them that their condition will not be used as an excuse to slow down/block their professional growth or career, emerged as an important aspect during the discussions.

...when I got my diagnosis, I didn't mention it at work as I was afraid that I might end up being excluded from work projects or applications for funding... when we got a new supervisor, who is an understanding and helpful person, I did speak out about my illness; it didn't change a thing at work, no allowances are made for me, which is fine by me!

Other participants in the public and private sectors had no problems informing their colleagues of their diagnosis. In some cases, colleagues were the first to be told; in others, it was the superior/employer.

Finally, it was found to be fundamental to have good relationships with colleagues in order to accept or enjoy certain benefits without feeling uncomfortable or fearful of being judged by others.

...colleagues made me feel bad about the remote working, they weren't happy about it...

All the FG participants stated that they never used their illness as a way of "getting out of things" at work but only mentioned it to get help when necessary (e.g., in the case of the healthcare worker, who needed to avoid excessively physically demanding tasks or patients).

...my colleagues help me out; they deal with the most challenging neurological and orthopaedic patients because I can no longer treat them. It's too much of a struggle for me...

3.2 Work Benefits

Three main topics emerged in this discussion area: the types of work contracts assigned to PwMS, their access to remote working, and reasonable accommodations. All the participants except the freelancer had standard work contracts and could, therefore, be absent due to illness for a period of six months without significant consequences.

...I am allowed up to six months of sick leave per year by contract and I use it when I need to.

The discussion on work benefits also revealed that the possibility of working remotely, granted to

some participants during the pandemic, sometimes created difficulties, either because the women felt that their colleagues were not happy about it, or because they would prefer to have been assigned other duties so that they could continue to come into work.

...they got me to stay at home because I am immuno-suppressed, but I would have preferred to change roles and work on refresher courses or something else...

Generally speaking, for all the participants, the expression “reasonable accommodations” had negative connotations, which made us realise that none of them really understood its true meaning.

In fact, they themselves admitted that they weren’t familiar with the term, or associated it with the idea of having to “make do” or “compromise”, and therefore with the idea of having to give up or forfeit something.

...it’s a compromise, a negative thing, because you have to give up one thing in order to get another... [it’s something] designed more to benefit the company than the person... [it’s] about having to give up a part of yourself... or having to adapt to what the company wants from you.

When explicitly asked, “What comes to mind if I talk of reasonable accommodations?” the participants gave answers relating to settings that have nothing to do with work. Again, this suggests that none of the participants knew what “reasonable accommodations” meant.

...Having to wait a year for a new car to arrive to have one with superior specifications...

Only one person knew the true meaning of reasonable accommodations and the laws governing this field.

3.3 Relations with Institutional Figures of Reference

The only topic to emerge in this discussion area concerned occupational doctors and their role towards workers affected by MS. While recognising the importance of the occupational doctor, the participants generally felt that these professionals were “not experts” in the field of MS, as they had not managed to suggest suitable tasks/duties based on the severity of the condition.

...I got no suggestions on how my role at work might be adapted...

Furthermore, the participants tended to be rather “suspicious” of the occupational physician in the company’s employ and could potentially place obstacles in the way of their professional advancement.

...after all, the doctor is paid by the company and, therefore, has the company’s interests at heart, not ours

This professional figure was found to be absent in public sector workplaces; only in one particular case, at the specific request of the participant, was a meeting with an occupational physician organised. On the other hand, as reported by the participants, an occupational physician was more likely to be present in private workplaces.

...you don’t find them in schools, I don’t know of any... but in the private sector, you do, and they can be a mixed blessing!

Finally, an unmet need came to light, namely the need for the presence, within the company, of a specially trained person capable of modifying the tasks/duties of PwMS in the event of any worsening of their condition.

...our coordinator is very understanding and supportive, and she talks over my situation with the bosses, but she is not trained... my area manager understands because he is in a similar position, but he is not trained ...

3.4 Aspects Influencing Job Retention

In this area, the discussion centred on three main aspects, seen as factors influencing job retention, namely the role of colleagues, the presence of support for managing work-life demands, and the “burden” of getting to and from work.

Once again, a plus point was being on good terms with colleagues, since they are in a position to encourage PwMS, and can understand the situations and problems they have to deal with. In some cases, colleagues could be a source of “gratification” for PwMS, when they recognise and acknowledge the strength and courage they show in addressing and overcoming their difficulties.

...I thought that my colleagues might discriminate against me, but instead they admired me for how bravely I face my daily difficulties. ...I felt quite moved

when the principal, during a meeting, said that diversity is a source of enrichment.

Juggling work and family life can be challenging, especially for women with MS. One of the participants, who still lives with her elderly parents, described the situation as “heavy”.

...my mother has been looking after me for more than 20 years, but it's heavy, it stresses me out...

In many cases, the women needed external support to manage the home (once a week, or as needed), or their husbands contributed. One of the participants, who lives alone and uses a wheelchair, said she needed round-the-clock support.

...I live alone and am in a wheelchair, and so I need help. I have found a carer who lives in with me...

In one case, AISM was asked to provide support in managing the period immediately after the birth of the participant's first two daughters.

...with my first two pregnancies, AISM helped me manage the post-partum period...

Getting to and from work was found to be a burden either because public transport is not geared for those with walking difficulties or, in the case of those using their own cars, because it is onerous and time-consuming, taking away time that could otherwise be spent on self-care.

...for me it's a real problem getting to work. I struggle with one leg and can't use public transport, so I take the car, but parking is really expensive...; physiotherapy is really important, but you have to have time for it. If you work, and it takes you ages just to get to work, then there isn't much time left over for physiotherapy...

The participant, who uses a wheelchair, said that she has to pay someone to take her from home to school (due to inefficient local council social services) and someone else to help her get around once she is at work.

...I live 5 minutes away from my place of work, which is a quarter of an hour in a wheelchair, but I have to pay someone to take me to school because I get no help from council social services, they never got back to me.

4. DISCUSSION

The PwMS taking part in the two FGs, talking about “disclosing the diagnosis”, revealed that it helped to have empathetic and sensitive colleagues, putting

them at ease. Such colleagues can create a relaxed working environment and climate of trust in which PwMS can raise the subject of their condition and discuss their difficulties. An easy environment can also help them avoid feeling uncomfortable or criticised whenever a benefit (such as remote working) is offered. Very often, however, participants, especially in the private sector, felt “inhibited” about informing their superior or employer of their diagnosis; conversely, public sector workers often informed their superior/employer of their illness before their colleagues. These results align with the literature, in which a fear of being discriminated against is reported as the main reason for not communicating the diagnosis [15]. Finally, all the FG participants agreed that the reason they disclosed their diagnosis was never to obtain concessions or benefits but only so that they might get any help they needed. This shows that PwMS just want “normality”, i.e., to have a job and be treated like their colleagues, without any special favours.

The discussion of “work benefits” showed that PwMS, both in the public and private sectors, have standard work contracts that do not cater to disease-related needs. However, these contracts allow up to six months of sick leave, meaning PwMS can be off work without creating any particular problems. Remote working was found to be a helpful measure, but also difficult to manage. During the pandemic, some of the PwMS taking part in this study, depending on the nature of their work, were allowed to work from home; for some of them, however, this was not a positive experience since they felt that their colleagues were not happy about the decision, especially when it affected their workloads. In one case, remote working was a negative experience because it made the participant in question feel excluded from the workplace, so much so that she offered to undergo specific training to be able to switch to another role. This led us to question whether the participants knew the meaning of the expression “reasonable accommodations”. Their various answers, negative or unrelated to the working environment, suggested that the term is not very well known. Therefore, there seems to be a need for an awareness-raising campaign about MS, aimed both at employers and at PwMS who work.

Society today generally demands that people participate more actively in their own self-determination, but in the case of PwMS, this is complicated by the fact that they are often unaware of the range of opportunities, such as reasonable accommodations, that are open to them.

Previous studies report that PwMS have a particular need for reasonable accommodations, which are essential to allow them to continue doing their jobs even as the disease progresses [16, 9].

During the discussion on “*Institutional figures of reference*”, it became clear that the role of occupational physician is poorly recognised. Indeed, these doctors are not always present, and even when they are present, they often fail to appropriately review the work roles of PwMS. This could possibly be due to a lack of specific training. In private workplaces, where occupational physician are more likely to be present, workers with MS have some misgivings about them since they are employed by the company and could, therefore, potentially interfere with their careers. In accordance with the literature, our results suggest that occupational doctors need to be provided with targeted and ongoing training to ensure that they are better able to respond to the needs and wishes of PwMS [9].

Finally, in the discussions on “*aspects influencing job retention*”, good relations with colleagues, help from family members, carers/home helps, and patient associations (e.g., AISM), and a short distance to work all emerged as elements making it easier to continue working. On the other hand, a lack of efficient local social services and a medium-long commute (deemed burdensome due to walking difficulties, a lack of adequate public services, or the expense involved) were found to be obstacles. Here, our results again reflect the evidence of elements that emerged during our FG discussions [16].

One major limit of our study is the absence of men among the PwMS taking part in the SG sessions, given that it would certainly have been interesting to have the perspectives of working men with MS. It is also to be noted that most of the patients who withdrew their consent to take part did so at the last minute, mostly due to feelings of anxiety or mood disorders. This latter aspect shows how

emotional factors often interfere with the social and relational dimensions of these individuals’ lives.

5. CONCLUSION

These results show that managing work is a complex undertaking for people with a disabling condition like MS. They also show that there are numerous factors, both positive and negative, that can influence these people’s ability to retain their jobs. The main influencing factor is the role that can be played by colleagues with whom they have a good relationship; colleagues who are able and willing to provide support at difficult times facilitate the ability to remain at work. Another aspect found to be crucially important in this setting is the need for greater knowledge of MS both at the level of public opinion (colleagues and superiors/employers) and among occupational doctors. Similarly, there needs to be greater awareness of the employment rights of PwMS. Improving these knowledge-based aspects could undoubtedly improve the quality of the working lives of PwMS.

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REFERENCES

1. Compston A, Coles A. Multiple sclerosis. *Lancet*. 2008;372(9648):1502-17. Doi: 10.1016/S0140-6736(08)61620-7
2. Walton C, King R, Rechtman L, et al. Rising prevalence of multiple sclerosis worldwide: Insights from the Atlas of MS, third edition. *Mult Scler*. 2020;26(14):1816-1821. Doi: 10.1177/1352458520970841. Epub 2020 Nov 11. PMID: 33174475
3. Koch-Henriksen N, Sørensen PS. The changing demographic pattern of multiple sclerosis epidemiology. *Lancet Neurol*. 2010;9:520-532.
4. Thompson AJ, Baranzini SE, Geurts J, Hemmer B, Ciccarelli O. Multiple sclerosis. *Lancet*. 2018;391(10130):1622-1636.
5. Johnson KL, Yorkston KM, Klasner ER, Kuehn CM, Johnson E, Amtmann D. The cost and benefits of employment: a qualitative study of experience of persons with multiple sclerosis. *Arch Phys Med Rehabil*. 2004;85:201-209.
6. Kobelt G, Thompson A, Berg J, Gannedahl M, Eriksson J, MSCOI Study Group; European Multiple Sclerosis Platform. New insights into the burden and costs of multiple sclerosis in Europe. *Mult Scler*. 2017;23(8):1123-1136.
7. Vitturi BK, Rahmani A, Dini G, et al. Spatial and temporal distribution of the prevalence of unemployment and early retirement in people with multiple sclerosis: a systematic review with meta-analysis. *BMJ Open* 2022-a; 12:e058948. Doi: 10.1136/bmjopen-2021-058948
8. Gerhard L, Dorstyn DS, Murphy G, Roberts RM. Neurological, physical and sociodemographic correlates of employment in multiple sclerosis: A meta-analysis. *J Health Psychol*. 2020;25(1):92-104. Doi: 10.1177/135910531875526
9. Persechino B, Fontana L, Buresti G, Fortuna G, Valenti A, Iavicoli S. Improving the job-retention strategies in multiple sclerosis workers: the role of occupational physicians. *Ind Health*. 2019 ; 57(1): 52-69.
10. Ponzio M, Podda J, Pignattelli E, et al. Work Difficulties in People with Multiple Sclerosis. *J Occup Rehabil*. 2023 Nov 3. Doi: 10.1007/s10926-023-10149-9. Online ahead of print
11. Tuttas CA. Lessons learned using Web conference technology for online focus group interviews. *Qual Health Res*. 2015;25(1):122-33. Doi: 10.1177/1049732314549602. Epub 2014 Sep 5.
12. Charmaz K (2006) Constructing Grounded Theory: A practical guide through qualitative analysis. London: Sage.
13. Guest G, MacQueen KM, Namey EE. Applied thematic analysis. SAGE publications, 2011.
14. Glaser B, Strauss A (1967) The Discovery of Grounded Theory: Strategies for Qualitative Research. New York: Aldine de Gruyter.
15. Vitturi BK, Rahmani A, Dini G, et al. P. Stigma, Discrimination and Disclosure of the Diagnosis of Multiple Sclerosis in the Workplace: A Systematic Review. *Int J Environ Res Public Health*. 2022 ;19(15):9452. Doi: 10.3390/ijerph19159452
16. Vitturi BK, Rahmani A, Dini G, et al. Work Barriers and Job Adjustments of People with Multiple Sclerosis: A Systematic Review. *J Occup Rehabil*. 2022-b Nov 18. Doi: 10.1007/s10926-022-10084-1. Online ahead of print. PMID: 36399281