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Running Head: Disclosing a diagnosis of MS

Title: Disclosing a diagnosis in the workplace: Perspective of people with Multiple Sclerosis.

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Abstract

Background: Early withdrawal from the workforce is associated with a diagnosis of multiple sclerosis, with employment retention rates also lower than in the general population. Despite legal requirements, equality in the workplace for people with MS has not been achieved. Disclosure of multiple sclerosis at work is essential for the implementation of accommodations enabling employment retention.

Method: An Interpretive Descriptive study explored participants' decision to disclose or not disclose their diagnosis of multiple sclerosis and the implications this had on work participation and working relationships. Semi-structured interviews were used to collect data from six participants.

Results: Three themes were identified, using a reflective approach to analysis, from the data: accommodations, workplace relationships, and balancing work and home life. Participants had mixed experiences of disclosing their diagnosis. Findings supported the implementation of workplace accommodations including physical, cognitive, and structural supports. Concealment of MS was associated with fear of workplace stigmatization.

Conclusion: Disclosure is multi-dimensional and subjective. It is based on personal, systematic, and social factors. This study was limited by the small number of participants and not including stakeholders in the creation of the topic guide. The results are important for those involved in supporting people with multiple sclerosis to remain in the workplace.

Background

The average general EU employment rate is 70%, with an average employment retention rate of 60% for people with multiple sclerosis (MS) living in the EU, compared to the employment retention rate of 43% for people with MS living in Ireland (MSIF, 2016). The lower employment rates for people with MS in Ireland may be indicative of cultural or systematic barriers associated with this diagnosis (MS Ireland, 2016). This low work retention rate has negative implications on society with role losses costing €135.5 million annually (MS Ireland, 2016). Additionally, 68.5% of people surveyed identified that their career potential was limited as a result of their MS diagnosis (MS Ireland, 2016), with 30% of people with MS reporting financial strain due to reduced income (MS Ireland, 2017). The financial implications of reduced employment opportunities can have a significantly negative impact on individuals with high-cost medical bills (Dyck & Jongbloed, 2000; Vicker, 2012).

The European Directive on Equal Treatment in Employment and Occupation (2000) supports equality in the workforce. The directive prohibits discrimination in the field of employment based on disability and other factors. Individuals must have accessible conditions, vocational guidance, and equal payment (European Agency for Safety and Health at Work, 2019). Concurrently, Article 2 of the United Nations Convention of the Rights of Persons with Disabilities (2007, 2018), identifies that socially and economically employees should receive equal rights in the workplace. For the implementation of these legal documents to support work retention employees are required to disclose their diagnosis to employers.

Variables influencing employment appear to be based on social status, symptom management, and work environment (Schiavolin et al., 2013), with employer's inability to provide reasonable accommodations restrict employment retention. The invisibility of MS symptoms can result in reduced supports (Grytten & Maseide, 2005). Dyck and Jongbloed (2000) suggested that the invisibility of this diagnosis in the initial stages makes it challenging for individuals to alter performance expectations without being subject to prejudice.

Moore et al. (2013) considered clinical factors and demographic data associated with employment and concluded that employment status correlated with educational status, length of disease, fatigue, and disability level. Findings indicated that premature retirement and reduced responsibilities impacted employment satisfaction despite legislative protection. Positive work participation increases quality of life which in turn supports MS symptom management (Pak et al., 2014).

In a review of 31,192 participants, results concluded that MS duration, age, mobility, and fatigue infringed upon work ability (Raggi et al., 2016). There was also evidence of negative relationship between this diagnosis and interpersonal work relationships. Reduced workplace social supports results in discrimination and social isolation, having a negative impact on work performance abilities (Johnson et al., 2004). Excessive supervision, unreasonable work demands, unequal pay, and reduced opportunities for promotions are forms of discrimination reported in the literature (Roessler et al., 2011).

Disclosure is often deemed as a 'high risk' strategy where individuals are subjected to the moral dilemma of being truthful in relation to their health, which subsequently may have implications on their employment conditions (Reed et al., 2017). Grytten and Maseide (2005) considered the ethical challenges associated with this decision, indicating that one's identity is central in guiding this process. Additionally, loss of self-identity is a variable guiding individuals to conceal their diagnosis (Dyck & Jongbloed, 2000) and trying to maintain previous levels of work and concealing diagnosis is one way in which this is achieved.

Emotional and psychological strain of concealing this diagnosis can be challenging (Dyck & Jongbloed, 2000; Vicker, 2012) with people feeling highly vulnerable as they experience constant fear of being exposed by others in their daily working lives. This heightened fear of potential role loss can have implications on personal identity and workplace participation. Personal safety may be in danger when individuals conceal their diagnosis due to the strain and burden, they may experience whilst maintaining their workload (Kirk-Brown & Van Dijk, 2014). The unpredictability of this diagnosis can further impact the pressure associated with concealment (Johnson et al., 2004). Individuals who disclose their diagnosis in the work environment have been shown to experience improved symptom management, greater accommodation supports and in turn increased social engagement (Kirk-Brown et al., 2014).

It is evident that disclosing MS has a variety of implications on work participation and engagement. Literature suggests that disclosure of MS is highly subjective and based on personal, societal, and workplace variables. Individuals personal experiences cannot be categorized due to the variety of perspectives from literature examined (Frdak et al., 2014; Johnson et al., 2004; Kirk-Brown & Van Dijk, 2014; Mattarozzi et al., 2015). Individuals conceal their diagnosis due to concerns related to discrimination impacting employment identity and work relationships (Mattarozzi et al., 2015; Roessler et al., 2015). It is evident that long-term financial instability associated with this diagnosis can have a negative impact on symptom management and quality of life (Van der Meide et al., 2018). There is a need to explore the considerations that impact disclosure status and individuals'

rationale for disclosure. Deciding to disclose a diagnosis can be stressful and "high risk" for people with MS. Understanding the experience of disclosing a diagnosis is key to ensuring that people receive guidance and support in this process if required.

The primary aim of this study is to understand the experience of disclosing or not disclosing a diagnosis in the workplace for people with MS.

The objectives of this study are:

- To identify the rationale for disclosing or not disclosing MS diagnosis.
- To explore the impact of disclosing or not disclosing MS on work relationships and workplace engagement.

Method

A qualitative research design was used to gather data including interpretations, thoughts, views, and perspectives for a set group of individuals (Pearson, 2010). An Interpretative Descriptive research design was employed (Thorne et al., 1997), which focuses on research that explores the significance of the subject matter and participants' perception as a means of guiding clinical practice (Hunt, 2009). In this case the subject matter of disclosure in the workplace was explored based on participants' experiences and views (Glanz et al., 2012). In addition, the social factors impacting personal perceptions and understanding of events is explored and intertwined in the data analyzed (Thorne et al., 2004). Using a reflective approach to analysis, our aim was to generate enough data to tell a rich story that answers the research questions set (Braun & Clarke, 2019b).

To ensure that factors which influence disclosure status of individuals with MS in the workplace were addressed, a semi-structured interview guide was devised. Individual interviews were deemed appropriate as this topic is complex with broad variations in experiences. This was a potentially sensitive topic which may be upsetting as role loss may be addressed. Semi-structured interviews were flexible and adaptable enabling a variety of experiences to be captured (Irvine et al., 2013). The interview format focused on the study's aim and objectives ensuring all information required was gathered (Silverman, 2014). The semi-structured interview schedule was guided by literature related to the topic of MS in the workplace. Jellie et al. (2014) qualitative interviews on maintaining work positions for individuals with MS outlined questions that guided the interview process. Additionally, the interview guide used in Dyck and Jongbloed (2000) study on employment concerns and Grytten and Maseide (2005) study related to stigmatization associated with this diagnosis guided the interview schedule. Interview guide available in Appendix A.

Pilot face-to-face interviews were completed with four people who were of different ages (range 26-56) and employment status. They provided feedback related to accessibility of language, format of questions, and time requirement for comprehensive answers. The format of interviews included face-to-face, telephone or Skype-based interviews to reduce the potential financial burden and fatigue that may be associated with only using face-to-face interviews (Patejdl et al., 2016; Wiberg et al., 2015). Skype and telephone interviews allow for recruitment from a wide geographical location and have reduced expenses associated with participating.

Typical case purposeful sampling technique was employed when recruiting participants. This sampling method identifies a demographic whose experiences are transferable in a context (Cleary et al., 2014). This sampling method may have been impacted by researcher bias, as participant inclusion is reliant on the judgement of the researcher (Suri, 2011).

Inclusion criteria for participants in the study were as follows:

- A formal diagnosis of Multiple Sclerosis.

- Over 18 years.

- A minimum of six months in the same employment position in the previous five years.

- Not retired for longer than 5 years.

Exclusion criteria was set as:

- Individuals who are self-employed.

- Individuals unable to understand and communicate fluently in English

- Individuals unable to provide written informed consent.

Rigor was achieved in the following ways:

1. Confirmability was achieved through audio recordings to ensure that information disclosed during the interview was directly transcribed (Darawsheh, 2014). Additionally, confirmability was achieved through reflecting on personal biases throughout the research including whilst analyzing literature, completing interviews, and examining data (Jootun et al., 2009).

2. Credibility was achieved through sourcing external feedback of findings and actively acknowledging personal prejudices (Ryan-Nicholls & Will, 2009). Piloting supported the development of skills required when probing participants whilst remaining neutral to the research topic (Houghton et al., 2012). Bracketing was also employed when transcribing interviews, ensuring preconceived views did not impact this process (Power & Williams, 2001).

3. Transferability was achieved through providing accounts of how participants were recruited and criteria for recruitment, methodology guiding data collection and analysis procedure (Houghton et al., 2012). A rich presentation of the data analyzed was achievable through referencing quotations (Graneheim & Lundman, 2004) and important aspects related to transferability such as the context of the experience are presented for the data to be meaningful to the reader (Korstjen & Moser, 2018).

4. Reflexivity increased dependability by supporting the researcher to reflect personal viewpoints using a reflective diary which increased the studies quality (Jootun et al., 2009). All data obtained through semi-structured interviews were transcribed unless personal and sensitive matters not related to the research were discussed. As personal perspectives on disclosing MS in the workplace varied based on individuals' experiences, information contradictive in nature was investigated and interpreted (Bradbury-Jones et al., 2017). Coding quality, in the reflexive thematic analysis approach taken here, comes from the depth of engagement with the data (Braun & Clarke 2019a), rather than data saturation or consensus between researchers.

NVIVO software supported the organization of the data set (NVIVO, 2014). A reflexive approach to thematic analysis was taken, and as such codes are never finally fixed (Braun & Clarke, 2019b). The six steps of Thematic Analysis which supported this process are outlined below (Braun & Clarke, 2006):

1. Familiarization with data collection.

Once data was collected and transcribed, the researcher immersed themselves in the data by reading and re-reading transcriptions seven times.

2. Generation of initial codes.

The researcher then compiled a list of initial codes from the raw data, coding all transcripts separately. This coding supports the organization of data into purposeful segments. NVIVO software and paper copies were used when organizing these codes (NVIVO, 2014).

3. Searching for themes.

This phase examines the data collected at a broader level. The researcher considered how the codes established in phase two could be merged to create appropriate themes through a word document which listed all codes. A thematic map was a supportive visual representation when examining the relationship between codes to establish themes.

4. Review of themes.

The candidate themes were evaluated to ensure all themes identified were of relevance. Evidence supporting each theme was considered, with some themes having a stronger foundation of evidence. Ensuring themes were identifiable and clear was essential in this phase.

5. Definition and naming of themes.

Definitions for each of the themes were established. The name provided was brief, comprehensible, and logical. Explanations were clear, concise, and rationalized. An example of Thematic Mapping is available in Table One.

INSERT TABLE ONE AROUND HERE

6. Production of a study.

The final stage involved writing up the report by analyzing the research. Quotations from participants were immersed in the data analysis supporting creditability (Houghton et al., 2012).

Ethical approval was received from National University of Ireland Galway, College of Medicine, Nursing and Health Sciences Research Ethics Committee.

Results

Six participants were recruited to the study. Four face-to-face interviews took place, one Skype, and one telephone interview. Participants' length of time diagnosed ranged from 2.5 to 27 years. Demographic data of participants are displayed in Table Two. Employment details have been removed to protect the identity of participants. Pseudonyms are presented for each of the participants.

INSERT TABLE TWO AROUND HERE

The data will be discussed under the headings of the themes that were identified through the analysis of the data.

1. Accommodations
2. Workplace Relationships
3. Balancing work and home life

Theme One: Accommodations

Accommodations in the workplace were identified as key by all participants. The need for work adjustments was emphasized in order to have equal opportunity with peers allowing for fulfilment of employment expectations.

> 'Obviously I don't look for and I don't get any special treatment just accommodations that's all. Like it's, I don't need any walking aids, I don't need accommodations that way. There's only small little things but all added together can be a big deal if they're not aware'. [Nancy]

Participants noted that they altered their environment through aids or additional supports. Equipment such as an arm raiser or "special chair" were common in desk-based jobs and provided by employers. Practical steps were taken by the participants themselves when necessary too, depending on their own symptoms.

> 'In my desk drawer I have a change of clothes. I haven't needed it yet but [pause], but this morning it was very close to it. So, and yah that's just it like a professional thing that I'm doing but I keep and change of clothes now, and yeah other than that just that'. [Ronan]

Dissimilarly one participant rejected physical supports offered as they felt this was unwarranted and did not wish to be perceived as different.

> 'Now they have said to me you have to walk upstairs at work, do you need any help? They even offered to put in a lift. No, I said I will crawl up that before anyone does anything to make me different. Because I won't, it's me doing it my way'. [Fintan]

Although participants used various aids and equipment at home to help when with daily tasks, some were not comfortable bringing these into the workplace and when they needed to do this there was a fear that colleagues would see them and think differently of them as a result.

> 'You know it's fine at home I have all these things but like opening my jars and opening whatever you know, they are personal things you know that you don't want people to know, you carry them to work and you're afraid in case they fall out of your bag and you know, different stuff like that'. [Jane]

Some of the participants spoke of reducing working hours. This was a decision that was made because of the work pressures and the impact of symptoms on work. This resulted in reduced employment demands and increased supports from others.

> 'So, they ah allowed me to work less hours, allowed me to do more stuff in the office, not having to go out to clients, they really adapted my workload to suit my medical requirements. So, they were fantastic'. [James]

This was not the case for all participants, with one participant having increased responsibilities in the last number of years because they were promoted.

It was also important for participants that colleagues understood when accommodations were required and were happy that they were necessary for that person.

> 'My colleagues are great they're never like 'oh she got special treatment' or anything like that cause they know that if I do get special treatment its required, not because I'm being the bosses favorite like that. It's just the way it is'. [Lisa]

Theme Two: Workplace relationships.

For some of the participants they felt an obligation to disclose their diagnosis. It was a decision that they felt they had to make, and an essential part of keeping their job. The unpredictability of the symptoms that participants were experiencing, and the implications for others, was one of the reasons that participants gave for disclosing their diagnosis at work.

> 'Well just because they wouldn't be able to 100% depend on me being there on any given day because I can go from sort of 0 to 100 and back again in a matter of days'. [Lisa]

Physical abilities, including chronic fatigue, restricted workplace involvement and could at times impact others in the work environment. All participants indicated they experienced reduced mobility as a result of their MS. Mobility restricted participants by having negative implications on their responsibilities in the workplace. Participants spoke of reduced walking endurance limiting their ability to complete tasks they were expected to fulfil in their roles.

> ' I'm not good at walking distances five minutes walking and I start to get very shaky I feel like I'm stomping around the office and the floors are annoying because I just feel very loud'. [Ronan]

A number of participants discussed how others were informed of their diagnosis from colleagues without them giving permission to do so. This inhibited them from deciding when it was appropriate to share information relating to their diagnosis. Some of the participants discussed how it was distressing for others to be informed of their personal information, whereas other participants were not impacted by this.

> 'All my work colleagues are great I'll tell anyone that will listen. I don't care who knows. Like I said I'm from a small place, so everyone knows anyways'. [Nancy]

For one participant concealing their diagnosis was necessary and they did not feel that it impacted on their work or productivity. This participant was the only individual to voice this perspective.

> 'I didn't think it was relevant to my ability to do the job, primarily because I was good. So, my concern would have been that people would have reacted to me in a manner that was colored by the fact that I had an illness'. [Ronan]

This concern was seen by the way some colleagues reacted to the disclosure of the diagnosis by some participants which at times led to strained relationships.

> 'Sometimes you tell people and they look at you like you're a leper or something'. [Jane]

Two participants discussed colleagues' expectations of how individuals with MS should physically present and the challenges which they faced in explaining their own abilities. The invisibility of the symptoms at times made it challenging for others to understand the impact that the diagnosis can have.

> 'Trying to explain relapse and remitting is difficult enough because they're looking at you going well you look fine, and ah sure after a while when you spend some time with me you begin to realize she's grand but [laugh]'. [Nancy]

One participant discussed how their friendships with colleagues was negatively impacted from disclosure due to their MS being incorporated into conversations when it was unnecessary.

> 'Yah, I think that the main topic of conversation now is 'how you feeling, are you okay' and like it's been four years now, I'll tell you when I'm having a bad day. Sometimes it would be nice to chat about something else you know but sure they mean well, I can't fault them really'. [Lisa]

All participants discussed employers' influence on their disclosure and their understanding of their needs. Two participants explored the positive reception they received from employers upon disclosing. This positive experience made future work easier and created open communication with the employer. For these participants they would disclose their diagnosis upfront in any future jobs. Participants emphasized the importance of open communication in the initial stages of their diagnosis and how open communication continues as their employment role progresses.

> 'I knocked on his office door and I was nervous; it is a big deal, but he didn't make a big deal of it. He was just like 'oh okay that's fine no problem'. We continued on and like that as issues arise, they're talked about and that's fine'. [Nancy]

The importance of open communication came across in terms of the weight that is lifted after the disclosure has been made. For some disclosure enabled open communication. The pressure of concealment resulted in unnecessary stress.

> 'I haven't seen any negative. I do know people who won't disclose because of negative, if anybody walks in here and tells you they are not disclosing, that's an awful burden to carry into work every day. People have to know it; they have to know that you are'. [Fintan]

One participant indicated she was subject to negative responses from her employer after disclosing her diagnosis. She felt that after the disclosure there was an assumption made by her employer that

she was unable to fulfil her role at work and that future actions were seen under the veil of the diagnosis.

> 'Yah, I've had narky sort of comments from my boss like am, one day last week I felt really bad and I said 'do you mind if I don't come in until lunch time cause I'm feeling pretty rubbish?' and I got a comment like 'oh well you know if we can't rely on you to be in, it causes a bit of a problem sometimes'. [Lisa]

Participants discussed how concealment of this diagnosis impacted the way they interacted with colleagues and management. One participant spoke of her worries of potential exposure and the scrutiny which her work was subjected to.

> 'You always feel like there's someone behind you watching you. Are you doing stuff right? It's constant checking that's what, you know, and you don't do it right then it's pointed out to yah and you know you're not going to be arguing all the time'. [Jane]

Theme Three: Balancing work and home-life

Participants discussed their obligations to understand and respect their symptoms and how their diagnosis constantly affects all areas of participation and influences their outlook on life. This diagnosis supported participants to understand the context of work demands in their lives. Maintaining positive perspectives and being motivated to succeed in employment roles was discussed.

> 'But if you're saying all the time 'I can't do this' and 'I can't do that' well you believe it yourself. I actually can do it. So, I try keep as positive as I can'. [Jane]

Family members offered a supportive environment where participants could express challenges experienced in the workplace. One participant discussed how she required parental support when diagnosed.

> 'Until the minute I stepped off that plane until I got my steroid treatment, I had double vision. So obviously I had to give up work and arrive home to my mother and be like 'mammy help will yah I can't live on my own anymore, I need my mammy' [laughs]'. [Nancy]

Participants also spoke of how they did not openly discuss their diagnosis with family members. Participants believed that by discussing their medical needs, family members may perceive and treat them differently. This would negatively impact their relationships.

> 'But even my family I don't really tell them. I don't and it's probably this thing of disclosure with people and I, you know you're constantly kind of battling trying to hide [pause]'. [Ronan]

The strain of maintaining work demands can result in unhealthy life choices which may have negative implications on health. One participant discussed how they have developed unhealthy working habits resulting in completing work out of hours. This participant felt that they had to overcompensate their work abilities to continue to be respected by peers.

> *'I was there six months because I was doing late nights, I was still working at four o'clock in the night, which I will be doing in the next few weeks, I will still be working at four o'clock at night, they could get an email from me or a text message so they know well that I throw everything at it if something needs to be done, so'. [Fintan]*

Finally, one participant emphasized the importance of maintaining balance in daily life, enabling successful engagement in all aspects of participation.

> *'When you do find a way of managing it that works for you, it definitely makes life a lot easier. It's about finding balance, really balance is the key word. It's actually true. If you keep the balance in the middle, it's a lot easier'. [Nancy]*

Discussion

The results from this study indicate that individuals' experiences of disclosing or not disclosing MS in the workplace is subjective based on personal circumstances. Participants may be forced to disclose due to the impact of symptoms and for some the decision to disclose was taken from them by others. In this study participants discussed the negative consequences to employment experiences as a result of their symptoms. The experiences of participants' disclosure status were both positive, negative, and a mixture of both. Participants were often forced to disclose because of the severity of symptoms experienced. In this study participants emphasized the need for recognizing and understanding the symptoms they experience. D'Arcy (2012) reported the need for individuals to have insight into their diagnosis and understanding of associated symptoms. This is fundamental to support engagement in employment.

Environmental barriers and restricted accessibility negatively impacted productivity for participants in this study. The importance of accommodations was outlined in terms of enabling equal opportunities with peers. This was achieved through open communication and understanding of individual requirements to enable participation (Krause et al., 2013). Physical aids supported workplace engagement for some participants, and their importance in terms of safety and comfort were discussed. Poor environmental supports inhibit performance, yet a very large proportion of employers fail to provide their employees with reasonable accommodations (Roessler et al., 2011).

Participants in this study discussed altering workplace demands and responsibilities to support the retention of roles and enable feasible workloads. Meade et al. (2016) found that adapting

workloads enabled individuals to fulfil job demands. The study highlighted the need for reduced job demands when necessary to prevent relapses (Meade et al., 2016). Morse et al. (2013), supported this emphasizing the need for restructuring employment roles, facilitating reduced employment demands as individuals' abilities to multi-task may be impaired. Cancelliere et al. (2016) considered factors impacting work for individuals with a range of illnesses including MS and of the 56 articles reviewed, findings implied that unrealistic expectations of employers had a negative impact on likelihood of being employed.

Half of the participants in this study had limited or no control over their disclosure status. For some this was a factor of being based in a small community. Mattarozzi and colleagues (2015) found that within families, disclosure often happened without the consent of the individual with MS, but this was not reported to the same extent in the context of work. Participants outlined the impact work relationships with fellow colleagues have on their work performance. There was apprehension associated with possible discrimination from colleagues in many interviews which has also been found in other studies looking at potential consequences of disclosure in the workplace (Kirk-Brown et al., 2014). Runrill et al. (2013) emphasized the need for colleagues' knowledge of MS to increase, supporting the implementation of accommodations and input into problem-solving processes. Discrimination from both employers and colleagues can be a factor which results in loss of employment (Li et al., 2016).

Negative workplace experiences resulted in restricted social participation outside the work environment for some participants in this study. Dennison et al. (2009) explored the impact of psychologically adjusting to MS emphasizing the need for social roles, which was also highlighted by participants in this study. Schwarkz and Gronemann (2009) suggested that social supports are necessary to decrease loneliness which can have negative implications on participation. The importance of maintaining a balanced routine which enables healthy lifestyle choices was discussed in this study. The need for work-life balance is essential for employment retention (Forslin et al., 2018) for people with MS. Some participants in this study discussed how they found it challenging to maintain their roles and fulfil personal needs including sleeping and maintaining a balanced diet. Bøe Lunde et al. (2012) discussed the association between psychological burden and poor sleeping routines and the importance of treatment for this. This study found maintaining a work-life balance incorporating self-care and socialization is essential to reduce the stress associated with employment.

This study was limited by the number of participants recruited. Although a diversity of experiences was seen through the interviews, the topic is complex and additional interviews would provide

further insight into participants' experiences of workplace disclosure. The interview guide was developed for the study and may have omitted essential questions unbeknown to the researcher. The development of the guide was completed through exploring literature on this topic (Grytten & Maseide, 2005; Kirk-Brown & Van Dijk, 2014) but a clear limitation was that there was no stakeholder involvement in the creation of the topic guide which would have been important to ensure the relevance and appropriateness of the questions asked. The researcher did, however, complete pilot interviews with four individuals to establish time requirements, structure, and accessibility of information.

Uncertainty related to disclosure makes it challenging for individuals to feel confident in their environment and uncertain about the implications on their employment position. Findings suggested that disclosure facilitated accommodations including physical and restructuring of roles enabling employment retention but could also cause strained relationships with colleagues and employers. Participants who had open communication with employers reported receiving supports enabling role engagement while others discussed the burden associated with concealing MS.

Disclosure status is a diverse topic and is influenced by multiple personal and workplace factors. Individuals should be supported to disclose in a manner which is appropriate to their needs. There is a need for therapists and employers to collaborate, facilitating successful work (re)integration (Cancelliere et al., 2016). Further supports should facilitate employers to understand how the work environment should be to be adapted to enable and maintain positive work roles. Physical and psychological support is key to success in the workplace for people who disclose their diagnosis and those who choose not to.

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Appendix A

Interview Topic guide:

1. Can you please tell me your name and length of time diagnosed? What is your current employment and disclosure status? What sub-type of MS do you have?

2. Describe to me what your job role was before your diagnosis?

3. Describe to me your current job role? **OR**
   Describe your job role after your diagnosis?

4. Explain to me the reasons you choose to disclose/ not disclose your diagnosis.

5. Explain to me the experience of disclosing/ not disclosing your Multiple Sclerosis to your employer and management.

6. Can you explain to me your experience of disclosing your diagnosis to other employees and staff within your workplace?

7. Do you feel your work relationships have changed in any way since being diagnosis?

8. Was your experience of disclosing/ not disclosing your diagnosis of Multiple Sclerosis positive, negative or a mix of both?
   Why was this the case?
   Does this have any impact on the work you do now?

9. Is there anything else you would like to say? Do you have any questions?

Prompts to assist the interviews:

1. "Tell me more"
2. "What do you mean by that"
3. "Can you describe this to me"
4. "Why was that"
5. "How did that impact you"
6. "Were there any other reasons for this?"
7. "Was that challenging?"
8. "Were you confident in doing this?"
9. "Can you give me an example of a time where that was the case?"

Table One: Example of Thematic Mapping: Theme Two Accommodations

Theme	Example of Code	Supporting Quote
Accommodations This theme refers to supports in place in the work environment which promote workplace participation and implications of supports.	Environmental Supports	*"When I come into work there's a step down and when you're walking you might trip"*.
	Comfort of Role	*"I feel able to say to people, 'look it', especially if I only have two or three on a tour, 'do you mind if I sit down for a minute?"*
	Sharing Job Demands	*"It's relaxed a bit now cause I job share with another girl now, since I got ill."*
	Reduced Work Demands	*"I organise workshops and stuff like that, but the pressure it's off really."*
	Refusal of Physical Environmental supports	*"They even offered to put in a lift. No, I said I will crawl up that stairs before anyone does anything to make me different."*
	Stigma of Aids	*"I have all these things for like opening my jar.. You carry them to work and you're afraid in case they fall out of your bag."*

Table Two: Participant Demographic Details

Participant	Gender	Disclosure Status	Years since diagnosis	Employment status
"Jane"	Female	Not disclosed colleagues; Disclosed manager	10 years	Part-time
"Ronan"	Male	Not disclosed manager; Disclosed colleagues	2.5 years	Full-time
"Nancy"	Female	Full disclosure	5 years	Part-time seasonal work
"Fintan"	Male	Full disclosure	8 years	Full-time
"James"	Male	Full disclosure	27 years	Not employed
"Lisa"	Female	Full disclosure	4 years	Part-time