Stigma and Health

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The Experience of Stigma and Concealment in Multiple Sclerosis

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Despite a growing acceptance of chronic health conditions, people with multiple sclerosis can experience stigma. We aimed to understand the extent, nature, and predictors of stigma in multiple sclerosis (MS) and to explore how this relates to MS concealment. A mixed-methods cross-sectional survey ($n = 242$), designed with public and patient involvement, was conducted in October–November 2023. MS stigma was measured using a nine-item scale, along with questions on stigma experiences and sources. Hierarchical regression analysis explored sociodemographic, health, and psychosocial predictors of stigma, while reflexive thematic analysis identified stigma experiences described. The hierarchical regression model predicted 70% of variance in stigma scores, with stigma associated with higher loneliness ($\beta = .38$, $p < .001$), lower MS self-efficacy ($\beta = -.21$, $p < .001$), lower self-rated health ($\beta = -.19$, $p < .001$), female gender ($\beta = -.16$, $p < .01$), progressive MS type ($\beta = -.15$, $p < .01$), and greater difficulty in making ends meet ($\beta = -.13$, $p = .01$). Only 10% of participants had never experienced MS stigma, with themes of misunderstanding, isolation/exclusion, unwanted inputs, accessibility struggles, medical disregard, and personal stigma described. Higher anticipated stigma predicted higher levels of MS concealment. Overall openness of individual MS symptoms varied, suggesting that some MS symptoms are more stigmatized than others. Findings highlight how the experience of stigma in MS can take many different forms, with implications for MS disclosure. While certain sociodemographic and health factors put people with multiple sclerosis at risk, interventions that increase MS self-efficacy and reduce loneliness may also reduce stigma. Raising awareness of MS and increasing accessibility of services offer ways in which stigma can be reduced at a societal level.

Clinical Impact Statement

Living with MS can lead to experiences of stigma, which include feelings of being excluded or misunderstood. Fears of stigma can prevent people with MS from being open about their diagnosis and symptoms, precluding them from accessing the support they need. As women and those with progressive MS are at greater risk of stigma, efforts to support these groups are needed. Interventions that increase self-efficacy and reduce feelings of loneliness offer one way in which stigma may be reduced. At a societal level, raising awareness of MS and ensuring that people with MS are not overlooked is also key in tackling stigma.

Keywords: stigma, multiple sclerosis, concealment, disclosure, loneliness

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Due to the sensitive nature of the data collected (e.g., descriptions of stigma in personal and employment contexts) and the fact that participants may be potentially identifiable based on the range of sociodemographic and health characteristics collected in the survey, these data are not publicly available; participants did not consent to the sharing of these data in a public repository.

The authors' positionality statements follow: The authors provide transparency about their backgrounds. With regard to gender, three authors identify as women and one as a man.

Rebecca Maguire is a person living with multiple sclerosis (MS), so she was mindful of this identity in all stages of the research process. The other authors are not living with MS, but one has experience as a family member

continued

Multiple sclerosis (MS) is a neurological condition typically diagnosed in early adulthood (McGinley et al., 2021), affecting almost 3 million people internationally (Walton et al., 2020). Living with MS can give rise to a number of challenges, with impacts on quality of life extensively documented (Kan et al., 2022). While many of the challenges experienced by people with MS (PwMS) can be directly attributed to the range of MS symptoms that can occur, such as fatigue, mobility limitations, cognitive difficulties, and problems with bowel/bladder functioning (Silveira et al., 2021), negative psychosocial impacts are also common (Cowan et al., 2020; Finlayson et al., 2005; Irvine et al., 2009; Mohr et al., 1999). Such impacts include the experience of anxiety and depression, which are higher in PwMS than in the general population (Boeschoten et al., 2017; Fahy & Maguire, 2022; Hanna & Strober, 2020). A less studied psychosocial impact of MS is the experience of stigma, which can lead PwMS to feel stereotyped, excluded, or discriminated against by others (Spencer et al., 2019).

Stigma has long been a topic of interest from theorists and researchers across a number of disciplines, stemming from the work of Goffman (1963), who noted that stigma can enable discrimination, reduce opportunities, and increase social inequalities for those affected. While stigma as a concept is not always clearly defined (Andersen et al., 2022), one widely cited definition comes from Link and Phelan (2001), who stated that stigma occurs when "elements of labeling, stereotyping, separation, status loss and discrimination occur together in a power situation" (p. 367). More recently, other accounts have emphasized how stigma functions as a form of power in the wider cultural and political economy (Tyler & Slater, 2018).

While stigma can be encountered by various groups, the concept of "disability stigma" has gained increasing attention in recent years (Grue, 2016; Tsatsou, 2021; Watson & Larson, 2006). It is now well established that health-related stigma can be encountered by those with a range of chronic health conditions, including MS (Scambler, 2009). Recently, Stangl et al. (2019) developed a Health Stigma and Discrimination Framework that describes how stigmatization in health is a social process influenced by economic, social, and political factors. It follows that one of the main reasons disability stigma exists is due to the barriers (economic, environmental, and cultural) that may be encountered for those affected (Oliver, 2004). In their framework, Stangl et al. (2019) noted how stigma itself can consequently lead to a number of potential health and social impacts, acting as a barrier to engagement in care and health-seeking behaviors in a range of different settings.

A recent narrative review has shown that there is a lack of a consistent definition and understanding of stigma in MS (Winston-Khan et al., 2024). It is often broadly thought to involve three forms: experienced, internalized, and anticipated stigma, all of which may be elevated in PwMS. Experienced stigma, which is sometimes referred to as "enacted stigma," is when discrimination, stereotyping, or prejudice from others is directly experienced, while anticipated stigma is when some form of discrimination, stereotyping, or prejudice is expected or predicted to occur (Earnshaw & Quinn, 2012). In contrast, internalized stigma stems from the individual themselves. For example, Link (1987) noted that internalized stigma occurs when individuals hold negative beliefs or feelings associated with their condition (Earnshaw & Quinn, 2012). In the context of MS, stigma has been conceptualized and measured in a variety of ways. For example, Cook et al. (2016) noted that, in addition to MS involving internalized stigma (i.e., negative feelings about one's own disease) and anticipated stigma (i.e., concerns about biased treatment from others), isolation stigma (i.e., the sense of social isolation due to MS) can also occur. Isolation stigma may be more common in MS than in other conditions, as PwMS may experience exclusion from others due to their disease. Building on these definitions, Cook et al. (2016) developed a 20-item scale to measure these three types of stigma in MS. A shorter nine-item scale omitting internalized stigma (Cadden et al., 2018, Spencer et al., 2019) is used in the present study.

In a recent systematic review, Powell et al. (2024) illustrated that, regardless of measures used, stigma in MS can be pervasive. For example, one study found that stigma in interpersonal encounters is common for PwMS (Grytten & Måseide, 2006), with social and internalized stigma noted as a key concern in qualitative research (Pourhaji et al., 2023). Another study suggested that 57% of PwMS had experienced stigma due to their MS at least once (Grothe et al., 2022), although the exact prevalence varies across studies depending on the measures used. Earlier research suggests that stigma in MS may be lower than that experienced by patients of other neurological conditions (Molina et al., 2013), while a recent large-scale analysis (n = 11,634) suggested that 18% of PwMS experienced moderate or severe stigma (Ghajarzadeh et al., 2024). Here, stigma was found to be more common in those with higher levels of disability, a finding echoed in earlier work (Kalantari et al., 2018).

Beyond the extent of disability experienced, stigma in MS may also be influenced by the *way* in which disability is manifested. For example, while some PwMS exhibit "visible" disabilities (e.g., needing to use a mobility aid), many more experience what can be termed "invisible" disabilities (e.g., fatigue, pain, cognitive difficulties). In the wider healthcare literature, the occurrence of invisible disabilities has been shown to lead to additional challenges (Joachim & Acorn, 2000). Notably, people with invisible disabilities may experience ableism both from themselves and from others (Kattari et al., 2018), potentially leading to higher levels of anticipated stigma. This sense of ableism may even apply to health care professionals (HCPs), with a systematic review suggesting that workplace ableism in health care settings is common (Lindsay et al., 2023).

Regardless of physical health status, the experience of stigma can lead to a number of negative impacts for those affected (Winston-Khan et al., 2024). For example, PwMS who experience high levels of stigma are at heightened risk of depression (Cadden et al., 2018; Janssens et al., 2003). In addition, fear of stigma from others (i.e., anticipated stigma) may prevent PwMS from being open about their diagnosis, with relationships between stigma and MS

of a person with MS. Rebecca Maguire led the conceptualization of the study and played a key role in the development of the methodology, project administration, data curation, formal analysis, supervision, and writing. Aisling Ahern was involved in project administration, data curation, and formal analysis. Sowmya Shrivastava assisted in the project conceptualization and methodology development. All authors were involved in writing and editing the article.

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concealment documented (Cook et al., 2016). On a practical level, failing to disclose an MS diagnosis due to anticipated stigma may prevent PwMS from accessing the support they need, such as reasonable accommodations in the workplace (Vitturi et al., 2022). This may be more likely for those who experience invisible symptoms, which can be associated with an increased "burden of proof." Research in this field highlights that challenges in the workplace can be common for individuals with invisible disabilities (Norstedt, 2019; Santuzzi et al., 2014), with many people choosing to conceal their conditions from others (Ysasi et al., 2018). Even for those who are open about their MS, anticipated stigma in relation to certain invisible symptoms may deter PwMS from disclosing such symptoms to others, limiting their access to health care and social supports.

While previous research has explored the extent and consequences of stigma in MS, few studies have examined the nature and predictors of this stigma in detail. A more focused analysis of stigma experienced by PwMS may help to raise awareness of the associated challenges and help to identify potentially modifiable factors that can be targeted to decrease stigma in MS. For example, the associations between stigma and psychosocial factors, in addition to health and sociodemographic factors, have not been explored in depth. Factors such as MS self-efficacy (i.e., the belief or confidence in one's ability to overcome the challenges associated with one's MS; Rigby et al., 2003) and MS acceptance (i.e., the extent to which one has come to terms with one's MS; Stuifbergen et al., 2008) have been shown to associate with psychological well-being in other settings (Bradson & Strober, 2024; Fahy & Maguire, 2024; Van Damme et al., 2016; Wilski et al., 2019), but their relationships with stigma, after controlling for likely sociodemographic and health risk factors, are unclear. In addition, the potential role of loneliness (i.e., the lack of relational and social connectedness and feelings of isolation; M. E. Hughes et al., 2004) in stigma merits attention, given that feelings of loneliness are often elevated in PwMS (Balto et al., 2019).

In this mixed-methods study, led by public and patient involvement (PPI), we aimed to (a) explore the nature of stigma in MS, (b) determine if there are certain groups of PwMS who are more likely to experience stigma than others, and (c) examine whether there are certain modifiable factors that may help reduce the experience of stigma. As a secondary aim, we wished to examine the degree to which PwMS conceal their diagnosis and symptoms from other people and to establish links between stigma and MS concealment.

Method

Design and Recruitment

The study took the form of a mixed-methods online cross-sectional survey, with responses collected using Qualtrics (Qualtrics, Provo, Utah). The survey was designed and led by a person with MS, with additional PPI input from four PwMS. This PPI panel, whose members were given a small gratuity for their involvement, was recruited in collaboration with MS Ireland (a community organization to support those affected by MS in Ireland). The PPI panel helped shape the survey design over the course of two meetings in July and September 2023. In the first meeting, R.M. and S.S. presented the background to the project, along with the key research questions to be addressed. The PPI panel provided feedback on the overall aims of the project while also reflecting on their own experiences of stigma. Potential measures that could be used in the project were discussed, including consideration of the best ways to measure stigma. In the second meeting, following circulation of a draft survey protocol, the format of the survey was agreed.

Study recruitment took place during October–November 2023. This was carried out in collaboration with MS Ireland, who circulated the call on their social media channels as well as through the lead author's public social media account. To be eligible, participants were required to have a diagnosis of MS, to be aged 18 years or over, and to be fluent in English. Interested parties were directed to the study information sheet and were required to provide informed consent prior to participating. The study received ethical approval from Maynooth University Social Research Ethics Subcommittee (ref: SRESC-2023-37037).

Participants

In total, 242 PwMS took part in the survey. Participants mainly came from the United Kingdom (n = 99, 41%), Ireland (n = 65, 27%), and the United States (n = 49, 20%), ranging in age from 24 to 74 years (M = 48; SD = 10.06). Almost all were Caucasian (n = 230, 95%), with 5% (n = 12) identifying as LGBTQ+. In line with MS population norms, most participants (n = 188, 78%) identified as female. Most (n = 185, 77%) were in a relationship. Overall, the sample had high levels of education, with two thirds holding an undergraduate or postgraduate degree (n = 161, 66%). While most were employed either full-time (n = 92, 38%) or part-time (n = 45, 19%), many reported being unemployed or unable to work due to health problems (n = 34, 14%). Further details on the demographic breakdown of the sample can be seen in Table 1 and at the beginning of the results section.

Measures

The survey comprised a mixture of validated scales and researcher-devised questions, categorized as follows: (a) sociodemographic measures, (b) health status measures, (c) stigma-related measures, (d) MS concealment-related measures, and (e) psychosocial measures, specifically measures of MS control self-efficacy, MS acceptance, and loneliness. As part of the survey, three open-ended questions were included that asked participants about their experiences of stigma and disclosure of MS. Details of all the measures used in the survey are elaborated on below.

Sociodemographic Background and Health Status

The survey first included questions on sociodemographic background (specifically, questions were asked on country of residence, gender identity, age, ethnicity, LGBTQ+ status, relationship status, education, and employment status). Also, as a measure of financial status, a single item asked how easy it was for participants to make ends meet on a scale of 1 (*very easily*) to 6 (*with great difficulty*). Scores were later recoded so that lower scores represented a greater difficulty in making ends meet.

Five measures of health status were taken, including type of MS (relapsing remitting MS [RRMS], secondary progressive MS [SPMS], primary progressive MS [PPMS], or other) and years since diagnosis. The Patient Determined Disease Steps (PDDS) scale was used as a

Table 1
Descriptive Statistics for Sample

Categorical variable	*N*	%
Country of residence		
United Kingdom	99	40.91
Ireland	65	26.86
United States	49	20.25
Canada	13	5.37
Other	15	6.20
Missing	1	0.41
Gender		
Male	53	21.90
Female	188	77.69
Nonbinary/third gender	1	0.41
Missing		
Ethnicity		
White/Caucasian	230	95.04
Black/African/Caribbean	3	1.24
Mixed ethnicity	4	1.65
Other	5	2.07
Missing		
LGBTQ+ member		
Yes	12	4.96
No	229	94.63
Unsure	1	0.41
Missing		
Relationship status		
Married/cohabiting	178	73.55
In a relationship, not cohabiting	7	2.89
Single	49	20.25
Separated/divorced	5	2.07
Widowed	2	0.83
Missing	1	0.41
Education status		
Primary education	5	2.07
Secondary education	54	22.31
Undergraduate degree	83	34.30
Postgraduate degree	78	32.23
Other	17	7.02
Missing	5	2.07
Employment status		
Full-time employed	92	38.02
Part-time employed	45	18.60
Self-employed	6	2.48
Retired	41	16.94
Unemployed or unable to work	34	14.05
Looking after home/family	11	4.55
Other	7	2.89
Missing	6	2.89
Types of MS		
Relapsing remitting MS	154	63.64
Secondary progressive MS	33	13.64
Primary progressive MS	27	11.16
Other	4	1.65
Unsure	10	4.13
Missing	14	5.79
Requirement for care		
Yes	62	25.62
No	161	66.53
Missing	19	7.85

Continuous variable	*M*	*SD*	Range	% Missing
Age (years)	47.55	10.058	24–74	2.89%
Time since diagnosis (years)	10.80	8.756	0–43	9.09%
Ease of making ends meet	4.12	1.281	1–6	0.41%
Disability (PDDS)	3.74	2.226	1–8	9.09%
Self-rated health	2.76	1.023	1–5	7.02%
Total stigma	3.08	0.970	1.11–5	12.40%

(*table continues*)

Table 1 (*continued*)

Continuous variable	*M*	*SD*	Range	% Missing
Anticipated stigma	3.11	0.979	1–5	10.74%
Isolation stigma	3.05	1.186	1–5	11.57%
MS concealment (DISCO-MS)	2.53	0.840	1.25–4.69	14.42%
Concealment behavior	2.53	0.823	1.31–4.69	19.42%
Emotional concomitants	2.48	1.203	1–5	13.64%
Disclosure approach changed	3.60	1.146	1–5	12.40%
MS control (MSSE)	60.74	21.748	12–100	24.38%
MS acceptance	30.31	6.736	11–46	19.83%
Loneliness (UCLA-3)	5.85	2.016	3–9	20.25%

Note. MS = multiple sclerosis; LGBTQ+ = lesbian, gay, bisexual, transgender, queer or questioning; PDDS = Patient Determined Disease Steps; DISCO-MS = Disclosure and Concealment in MS Survey; MSSE = Multiple Sclerosis Self-Efficacy; UCLA-3 = three-item University of California, Los Angeles Loneliness Scale.

proxy measure of disability (Learmonth et al., 2013), with scores ranging from 1 (*minimal disability*) to 9 (*bedridden*). Participants were also asked if they required care from others in carrying out their daily activities (yes or no). Self-rated health was measured using a single-item scale, with five options for participants to rate their health ranging from "excellent" to "poor."

Stigma

MS stigma was measured in several different ways. First, a nine-item stigma scale (Cadden et al., 2018) was used to measure anticipated and isolation stigma. Here, participants rated their agreement with each item (e.g., "People who know that I have MS treat me differently") on a scale of 1 (*not true at all*) to 5 (*very true*). An average stigma score was calculated with good reliability in the sample (Cronbach's $\alpha = .877$).

In addition, participants were simply asked how frequently they experienced stigma because of their MS on a 5-point scale ranging from 1 (*never*) to 5 (*always*). They were also asked, if it was applicable to them, to rate the frequency with which stigma was experienced from various sources (e.g., family, friends, employers, romantic partners, HCPs, other PwMS). Finally, an open text question gave participants an opportunity to elaborate on examples of stigma they had experienced. Specifically, participants were asked, "If you would like to, please share examples of the type of stigma you have experienced."

Concealment and Disclosure of MS

The extent to which participants conceal their MS diagnosis was measured using a 16-item subscale from the Disclosure and Concealment (DISCO) in MS Survey (Kever & Leavitt, 2022). This includes items that assess the frequency of concealment behavior (e.g., "In general, I talk openly about my MS") and the emotional concomitants of concealment (e.g., "I feel sad that I have to keep my MS a secret from some people in my life"), rated on a scale from 1 (*never*) to 5 (*always*). Scores were averaged, with higher scores indicative of higher levels of MS concealment. This scale had good reliability in the sample (Cronbach's $\alpha = .892$).

The extent of specific symptom concealment was also evaluated by asking participants to rate how open they were to others about the MS symptoms they experienced (if applicable to them) on a scale of 1 (*never*) to 5 (*always*). The list of symptoms included was based on those reported by the National Health Service (https://www.nhs.uk/conditions/multiple-sclerosis/symptoms/), with participants given an option to report other symptoms if they wished.

An additional question asked if participants had changed their approach to telling people about their MS or MS symptoms since diagnosis on a scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Participants were also given an opportunity to elaborate on the reasons for their response to this question in an open-text response. Specifically, they were asked, "If you would like to, please explain how and why your approach to telling people about your MS has or hasn't changed since your diagnosis." Participants were also asked (if applicable to them) to provide examples of positive or negative experiences of MS disclosure. Specifically, they were asked, "If you would like to, please explain the positive or negative experiences you have had following disclosure of your MS or symptoms to others."

MS Control, Acceptance, and Loneliness

Three psychosocial measures hypothesized to be associated with MS stigma were included in the survey. First, the control subscale of the Multiple Sclerosis Self-Efficacy Scale short version (Chiu & Motl, 2015) was used. Here, participants rated their confidence in managing various aspects of MS (e.g., "How confident are you that you can regulate your activity so as to be active without aggravating your MS?") on a 10-point scale ranging from 10 (*very uncertain*) to 100 (*very certain*). Total scores were standardized, giving rise to a possible range of 0–100, with higher scores representing higher levels of MS control self-efficacy. MS acceptance was measured by the acceptance of chronic conditions scale (Stuifbergen et al., 2008), with 10 items (e.g., "I've come to terms with my MS") rated on a scale of 1 (*strongly disagree*) to 5 (*strongly agree*). Items were summed to give a total acceptance score ranging from 10 to 50, with higher scores indicating a greater level of MS acceptance. Loneliness was measured using the three-item University of California, Los Angeles Scale (M. E. Hughes et al., 2004), with possible scores from the three questions (e.g., "How often do you feel that you lack companionship?") rated on a three-point scale (options ranging from "hardly ever" to "often"). Total scores ranged from 3 to 9, with higher scores representing higher levels of loneliness. Reliability for all these scales was high, with Cronbach's α ranging from .799 (MS acceptance) to .930 (Multiple Sclerosis Self-Efficacy).

Analysis

A mixture of qualitative and quantitative analytic approaches was adopted to address the study aims. Descriptive statistics were calculated for the categorical and continuous measures, and, following binary recoding of relevant sociodemographic variables, a hierarchical regression analysis was conducted to explore the role of (a) sociodemographic factors (gender, age, education, employment status, ease of making ends meet, and relationship status), (b) health factors (MS type, time since diagnosis, PDDS, self-rated health, and requirement for care), and (c) psychosocial factors (loneliness, MS acceptance, and self-efficacy) in predicting stigma. Spearman's rho correlations were conducted to examine relationships between the variables. Associations between stigma and concealment were investigated using linear regression.

Separately, reflexive thematic analysis (Braun & Clarke, 2019) was used to identify themes from the open-text questions on stigma experiences and MS disclosure (including how participants' approach to disclosure had changed and positive and negative experiences of disclosure). This analysis involved six phases: (a) familiarization with the data, (b) data coding, (c) generation of initial themes, (d) development of themes, (e) refinement of themes, and finally (f) writing up the results. The coding and creation of initial themes was developed by one author and subsequently refined and developed with input from another author.

Reflexivity

We are aware that our background and perspectives may have influenced various aspects of the research process, particularly as one author is a woman living with MS. In conjunction with input from the PPI panel, this experience shaped the overall design of the project and influenced decisions regarding the measures used. While we feel that this was an important strength of the research, we also took steps to mitigate any potential biases that may have occurred with this approach. For example, the qualitative analysis was conducted by an author with no experience of MS, with the themes refined and discussed with input from the author with lived experience of MS. In order to ensure the trustworthiness of the qualitative data, the preliminary themes were presented to a wider sample of PwMS, who validated these findings before finalizing.

Results

Descriptive Statistics

As referenced above, descriptive statistics for the sample can be seen in Table 1. In terms of health status, most of the sample reported having RRMS ($n = 154$, 64%), with a quarter having either SPMS ($n = 33$, 14%) or PPMS ($n = 27$, 11%). Time since diagnosis ranged from less than a year to 43 years ($M = 10.8$, $SD = 8.75$), with PDDS scores ranging from 1 to 8 ($M = 3.74$, $SD = 2.23$). Just over a third (39%) reported mild levels of disability (PDSS 1–2), a quarter (26%) reported moderate levels of disability (PDSS 3–4), while the remainder (36%) needed some form of assistance with walking or required the use of a wheelchair (PDSS 5–8). Just over a quarter of the sample ($n = 62$, 26%) reported requiring care from others. The mean self-rated health score of 2.76 ($SD = 1.02$) suggests that, on average, participants felt they had "good" health. Nevertheless, 40% reported either "poor" or "fair" health, while just 25% reported having "very good" or "excellent" health. Separately, on average, participants reported a good ability to make ends meet ($M = 4.12$; $SD = 1.28$).

University of California, Los Angelos scores suggest that the sample experienced moderate levels of loneliness ($M = 5.86$; $SD = 2.02$). Multiple Sclerosis Self-Efficacy scores also indicate a moderate level of self-efficacy ($M = 60.74$; $SD = 21.75$), with MS acceptance scores reasonably high ($M = 30.31$; $SD = 6.74$).

Stigma

Scores on the stigma scale ranged from 1 to 5, with the mean score of 3.08 ($SD = 0.97$) suggesting that the experience of stigma was common. This was true both for experiences of anticipated ($M = 3.11$, $SD = 0.98$) and isolation ($M = 3.05$; $SD = 1.19$) stigma. Most participants reported experiencing at least some stigma in relation to MS since their diagnosis, with just 10% ($n = 22$) indicating that they had never experienced any stigma. In contrast, 21% reported "often" or "always" experiencing stigma (see Supplemental Figure S1).

When asked about the sources of their stigma, stigma from oneself was rated most highly, followed by (for those participants to whom it applied) stigma when dating, from employers, and from colleagues. Other PwMS were the least likely source of stigma reported (see Figure 1). In addition to the options provided, participants were given the opportunity to share other sources of stigma that they had experienced. Some participants referred here to having experienced stigma from strangers, in retail settings, from the media, and in local and national policies.

Predictors of Stigma

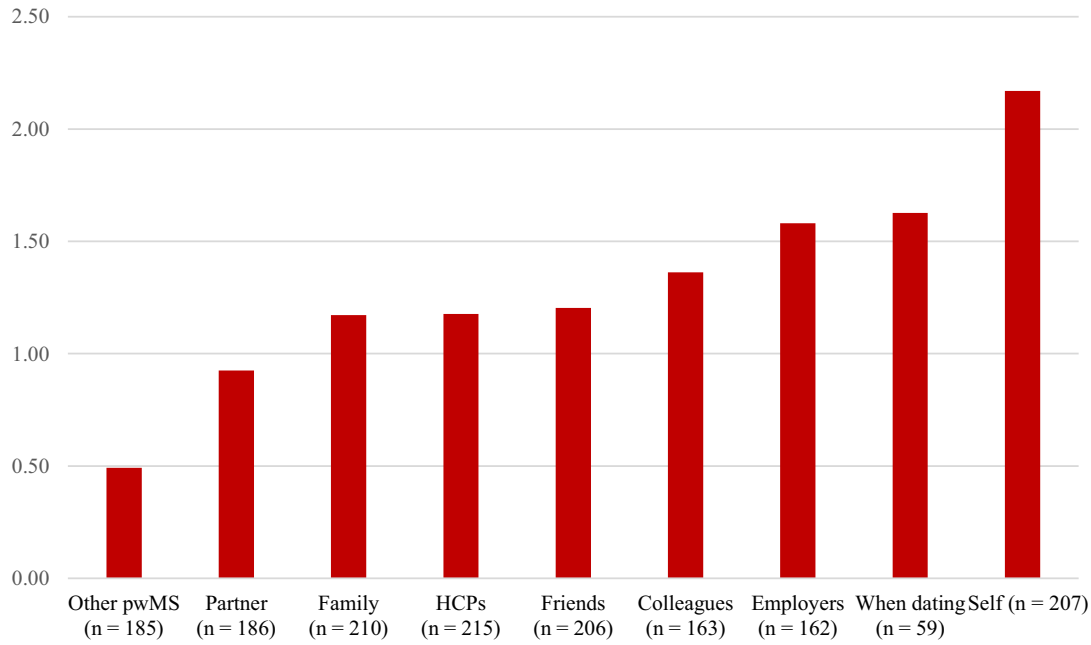
A hierarchical regression analysis was conducted to explore the role of (a) sociodemographic factors, (b) health factors, and (c) psychosocial factors in predicting stigma, as shown in Table 2. Prior to this, Spearman's rho correlations were conducted to investigate the relationships between these measures (see Supplemental Table S1). This analysis revealed no multicollinearity between the variables included, with assumptions of linearity and homoscedasticity also met.

Block 1 of the regression model, which comprised gender (female vs. other), age, relationship status (in a relationship vs. other), education status (primary/secondary vs. third level), employment status (employed vs. other), and ease of making ends meet, significantly predicted 30.3% of the variance in stigma scores, $F(6, 174) = 12.187$, $p < .01$, adjusted $R^2 = 0.278$. Block 2, which included time since diagnosis, MS type (RRMS vs. PPMS/SPMS/other), PDDS, self-rated health, and requirement for care, was also significant, explaining an additional 21.3% of the variance in stigma scores, $F(11, 174) = 15.83$, $p < .001$, adjusted $R^2 = 0.213$. Finally, Block 3, which included loneliness, MS acceptance, and MS control self-efficacy, also significantly contributed to the model, explaining a further 18.4% in the variance of stigma scores. Overall, the final model predicted 70% of variance in stigma scores, $F(14, 174) = 26.69$, $p < .001$, adjusted $R^2 = 0.67$.

In order of magnitude, significant predictors were loneliness ($\beta = .38$, $p < .001$), self-efficacy ($\beta = -.21$, $p < .001$), self-rated health ($\beta = -.19$, $p < .001$), gender ($\beta = -.16$, $p < .01$), MS type ($\beta = -.15$, $p < .01$), and ease of making ends meet ($\beta = -.13$, $p = .01$). Specifically, higher levels of loneliness, lower self-efficacy, poorer

Figure 1

Mean Frequency of Stigma Experienced From Various Sources



Note. Scores ranged from 0 (*never*) to 4 (*always*) with those who selected "not applicable" excluded. pwMS = people with multiple sclerosis; HCPs = health care professionals. See the online article for the color version of this figure.

self-rated health, being female, having progressive forms of MS, and a greater difficulty in making ends meet were all independently associated with greater stigma (see Table 2).

Reflexive Thematic Analysis of Stigma Experiences

Sixty-seven participants provided examples of stigma they experienced. These responses were categorized into six themes (see Table 3).

Misunderstandings and Misconceptions

A number of participants described how others simply did not understand MS, which often led to misconceptions about the condition, especially if they did not look "sick." For example, one participant noted that "most people do not understand MS, that is the biggest problem of stigma."

Related to this, many noted how they were not believed by family, friends, and employers (e.g., "A colleague once laughed at me when I said I had MS! they assured me that I was mistaken as if I had MS I 'would be in a wheelchair'"). This seemed particularly common for those with invisible symptoms, leading to the perception that others thought they were "faking it."

Struggle for Recognition

Many participants described experiences of isolation or exclusion. Some noted how they had been excluded from various groups and activities due to their MS, with others reporting that they had been ignored. For example, one participant noted how their friend "stopped speaking to me when I told her I'd MS," while another reported that "… people exclude me from events citing my disability." In addition, being overlooked for opportunities was reported by some, including opportunities for progression in the workplace. The need to prove oneself was also mentioned by some participants, whether that be a requirement for them to justify their ability to carry out certain tasks or to prove that they could continue to work in spite of their MS.

Unwanted Inputs

Some participants reported stigma in the form of unwanted inputs from others. For example, a number of participants reported feeling patronized by other people. One noted how offers for help were not always welcomed ("I find that people decide to help you, or you need help, when you don't it doesn't feel nice"), while another reported that people talked to them like they were going to "die soon." Feeling judged by others was also common, including being stigmatized for using disabled parking spots. One participant reported feeling judged "on how I walk asking why I need a walking stick why I'm not drinking." Negative comments from others, including the inappropriate use of humor, were also not welcomed.

Accessibility Struggles

On a more practical level, some participants described the difficulties they had in accessing various accommodations as examples of stigma (e.g., one noted how they felt like "an inconvenience for requesting anything to accommodate my condition"). Another participant suggested that they felt discriminated against by having to pay higher rates of insurance, while one feared financial dependency.

Table 2
Hierarchical Regression Analysis Investigating Predictors of Stigma

Variable	β	*p*	*t*	*B*	*SE*	CI 95% *LL*	CI 95% *UL*
Step 1: Sociodemographic factors							
Gender (0 = female; 1 = other)	−0.159**	.001	−3.465	−0.370	0.107	−0.582	−0.159
Age	−0.104	.068	−1.840	−0.010	0.005	−0.021	0.001
Education (0 = primary/secondary; 1 = third level)	0.001	.975	0.031	0.003	0.107	−0.207	0.214
Employment status (0 = employed; 1 = other)	0.096	.068	1.840	0.191	0.104	−0.014	0.397
Ease of making ends meet	−0.133*	.010	−2.601	−0.101	0.039	−0.177	−0.024
Relationship status (0 = not in relationship; 1 = in relationship)	−0.001	.984	−0.020	−0.002	0.108	−0.216	0.212
			R^2 change = 0.303 Adjusted R^2 = 0.278				
Step 2: MS and health factors							
Time since diagnosis	0.049	.337	0.963	0.005	0.006	−0.006	0.016
MS type (0 = RRMS; 1 = SPMS/PPMS/ other)	−0.149**	.008	−2.667	−0.307	0.115	−0.534	−0.080
PDDS	0.084	.235	1.191	0.036	0.031	−0.024	0.097
Self-rated health	−0.189**	.001	−3.284	−0.179	0.055	−0.287	−0.071
Care requirement (0 = requires care; 1 = does not require care)	−0.076	.143	−1.470	−0.164	0.111	−0.383	0.056
			R^2 change = 0.213 Adjusted R^2 = 0.484				
Step 3: Psychosocial factors							
Loneliness (UCLA-3)	0.376***	.000	6.490	0.181	0.028	0.126	0.236
MS acceptance	−0.084	.136	−1.497	−0.012	0.008	−0.028	0.004
MS self-efficacy (MSSE control)	−0.208**	.002	−3.175	−0.009	0.003	−0.015	−0.004
			R^2 change = 0.184 Adjusted R^2 = 0.674				

Note. MS = multiple sclerosis; RRMS = relapsing remitting MS; SPMS = secondary progressive MS; PPMS = primary progressive MS; PDDS = Patient Determined Disease Steps; UCLA-3 = three-item University of California, Los Angeles Loneliness Scale; MSSE = Multiple Sclerosis Self-Efficacy; *SE* = standard error; CI = confidence interval; *LL* = lower limit; *UL* = upper limit.
* $p < .05$. ** $p < .01$. *** $p < .001$.

Medical Disregard

Perhaps surprisingly, some participants noted how they had experienced stigma from HCPs, including not being taken seriously. Others noted the problem of HCPs misattributing symptoms to MS that may have had another underlying cause (e.g., menopause).

Personal Stigma

Some participants noted how their own lack of confidence impacted their engagement in activities. Several stated that they had not disclosed their MS due to their own stigma or fear of stigma from others. For example, one participant noted how they had "told very very few people about my diagnosis mostly due to fear of stigma."

MS Concealment and Disclosure

Experiences of MS concealment varied, with scores on the DISCO scale ($M = 2.53$; $SD = 0.84$) suggesting that, while some participants were very open about their MS, others had not disclosed their condition to others. Participants varied in their levels of openness about specific symptoms (see Figure 2). For instance, while just 31% reported "never" or "seldom" being open about mobility problems or fatigue, a far higher proportion reported "never" or "seldom" being open about sexual (90%), bowel (80%), and bladder (71%) problems. High proportions of participants also reported a lack of openness about mental health (67%) and cognitive problems (55%). Regardless of symptoms, very few participants reported "always" being open about them, suggesting that, even if PwMS are open about their MS diagnosis, they are still unlikely to reveal to others the specific impacts of that diagnosis.

Separately, just over half of participants (58%) reported that their approach to telling people about their MS or symptoms had changed since diagnosis, with only 16% disagreeing (the remainder neither agreed nor disagreed). To provide further context to these answers, participants were asked to elaborate on why their approach had or had not changed, with these responses analyzed using the process of reflexive thematic analysis. Of the respondents who answered this question ($n = 99$), many reported how they were now more open about their diagnosis, often due to having gained an increased acceptance of MS and/or a greater understanding of what this involved. A small number, however, noted that they had to be more open for reasons outside their control (e.g., COVID-19, or through the development of more visible disabilities). Many of those who

Table 3
Stigma Themes

Theme	Subtheme	Example quotes
Misunderstandings and misconceptions	Others do not understand	"I think most people do not understand MS, that is the biggest problem of stigma."
		"I've had a few strangers tell me I'm too pretty and young to need mobility aids. I've had family tell me if I walked more, my ability would improve."
		"People feeling embarrassed or not knowing what to say if i tell them I have MS. People assuming i should look more disabled than i do."
		"When I have told people I have MS I have had several people say 'Well, you'll be in a wheelchair then.'"
	Not being believed	"A colleague once laughed at me when I said I had MS! they assured me that I was mistaken as if I had MS I 'would be in a wheelchair.'"
		"My boss thought I was faking my symptoms because of the relapsing/remitting nature of it. 'My friend asked- do you even need that cane? Why do you sometimes have it and sometimes you don't?'"
		"I believe that some of my family members either think I don't have MS or I am making it up … … they are not really interested in seeing or asking how I am. It is rather silly, as I look and behave normally and so they cannot see what potential difficulties I may have."
		"Its more because i 'look' ok that people react negatively if i need help, like Im somehow faking it, and negativity in their perspectives."
	The problem with invisible and fluctuating symptoms	"You did 'whatever' yesterday so you can today."
		"It's the ignorance of the disease is what gets to me. 'Hows your aches and pains' 'Are you better today' people don't realise it's more than aches and pains and it lasts longer than one day and you're fixed, if only!! I think a lot of people are confusing the disease either with similar ones or they just don't have a clue what it is."
Struggle for recognition	Social isolation	"Friend stopped speaking to me when I told her I'd MS."
		"I've had people exclude me from events citing my disability."
		"Broken confidence in work place has led to increased isolation."
		"Friends and family often not including me in activities given their view of my difficulties. They are helpful but often subconsciously exclude me."
		"Not invited because they think it would be too much for me"
		"Being ignored—people speak to my carer not me."
	Being overlooked for opportunities	"Opportunities are simply not offered."
		"I am 'handy' to have around but professional progression is now not possible."
		"I don't feel at work I would go for promotions as I would be stagmised[sic] due to my MS."
		"My mom doesn't ask me for help anymore. She always calls my sister."
	Need to prove oneself	"Have to prove fitness to drive even though i have no impairment."
		"Having to explain why I can't do something as quickly or efficiently as an able bodied person."
		"At work … . both myself a[n]d my colleagues believe all people with MS have cognitive deficits. I am constantly paranoid that my cognition or personality is changing and feel I have to prove I can do my job just as well as I've always been able to despite my MS often to my detriment as I push beyond my fatigue limits."
Unwanted inputs	Feeling patronized	"… strangers needing to tell me want to pray for me or pray over me."
		"… talking to me like i will die soon"
		"I find that people decide to help you, or you need help, when you don't it doesn't feel nice. It would be better if they would ask if you need something etc."
		"whilst dating, coming across men who have 'a kink' for a disability."
		"Society Attitude"

(*table continues*)

Table 3 (*continued*)

Theme	Subtheme	Example quotes
	Feeling judged	"Judging me on how I walk asking why I need a walking stick why I'm not drinking."
		"I have a blue badge for parking and because I was able to walk getting out of the car I was followed all the way into the lift in the shopping centre I have also had people pass remarks at me as I get out or into the car this makes me avoid using the spaces in certain scenarios."
		"Scowls and verbal complaints using a scooter in a store or parking in a handicap space happen the most."
	Negative comments from others	"Making fun of how I walk or my word forgetfulness."
		"People make comments about physical appearance and say inappropriate discriminative things in conversation about awareness and general life."
		"Just comments, probably intended to be humorous but only serve to highlight how noticeable my disability is."
Accessibility struggles	Lack of accommodations	"An inconvenience for requesting anything to accommodate my condition."
		"My previous employer was especially bad at fulfilling their responsibilities."
	Financial discrimination	"Was refused a medical card and disability allowance due to partner's income. In my view this risks financial dependency and potentially financial abuse for some people. Those will long term illness deserve financial independence."
		"Have to pay higher health and travel insurance"
Medical disregard	Not being taken seriously	"Doctors didn't believe me and put my symptoms down to 'teenage anxiety' and now I am often told I am 'too young' for my ms to be so bad."
		"In a&e for falls, there seems to be little concern over what i might need to support my recovery from falls."
	Not everything is due to MS	"HCP put everything down to my MS when actually it could be menopause eg cognitive changes"
		"I had surgery about five years ago and my physical ability went significantly downhill since then. Be[c]ause of the MS diagnosis, my health concerns about the restriction of movement due to adhesions is largely brushed aside by medics. Any issue is explained away by MS diagnosis, when it really feels like something else is being completely missed. Very frustrating."
Personal stigma	Lack of confidence	"By far the biggest stigma I have experienced is the one from myself. It presents itself in a general lack of confidence in abilities which has impacted in many areas of my life, particularly professionally."
		"It is more stigma I add on myself. I feel like sometimes I don't try things or put myself out there, kind of a 'what's the point' attitude"
		"I am my own worst enemy in this department. Nobody else could ever come close."
	Fear of stigma	"I have told very very few people about my diagnosis mostly due to fear of stigma."
		"Did not disclose my diagnosis at work for this reason."
		"I feel very scared about being out in my wheel chair. In the days of using my stick I would fould[sic] it up and put in a bavk[sic] pack when in public."

Note. MS = multiple sclerosis; HCP = health care professional.

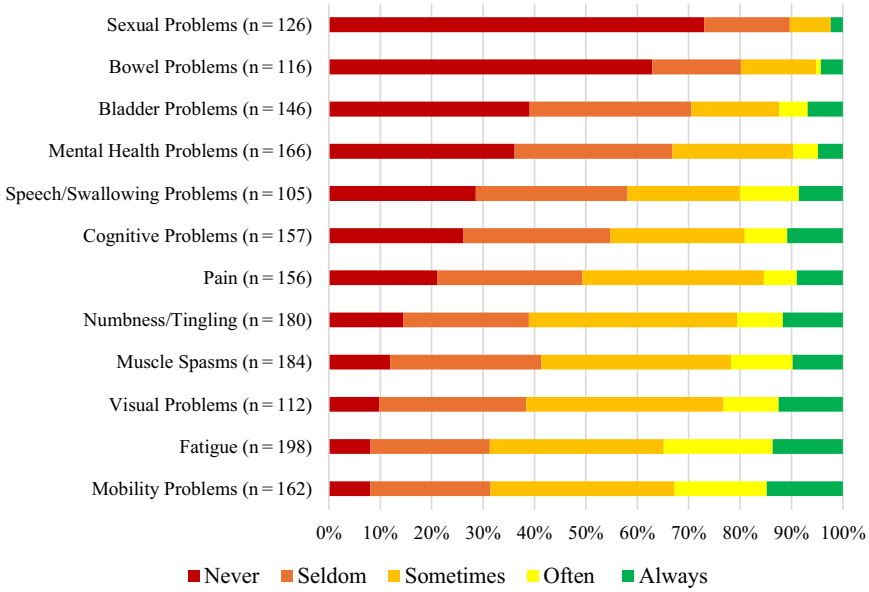
reported being less open than before cited negative experiences with others (e.g., from friends, colleagues, or partners), which led them to have a more cautious approach to disclosure. A number of other participants indicated that they had always been open, while a handful noted how they continued to conceal their diagnosis (see Supplemental Table S2 for further details).

A separate question asked participants to give examples of positive or negative experiences they had following disclosure of MS (if applicable to them). Using reflexive thematic analysis, 29 of these responses were coded as positive, with far more ($n = 75$) coded as negative. Positive subthemes included experiences of empathy/understanding, support, and inclusivity from others, while negative subthemes included experiences of people disengaging, feelings of being pitied, or not being taken seriously by others. In addition, some participants gave examples of work-based discrimination that they had experienced following disclosure (see Supplemental Table S2 for details).

In line with expectations, linear regression analysis found stigma to be associated with concealment, $F(2, 188) = 12.582$, $p < .001$,

Figure 2

Level of Openness About Specific Symptoms (Excluding Participants Who Reported That They Did Not Experience This Symptom)



Note. See the online article for the color version of this figure.

with stigma scores predicting 12% of the variance in concealment scores on the DISCO scale. Higher anticipated stigma, but not isolation stigma, was a significant predictor of higher concealment ($\beta = .40$, $p < .001$).

Discussion

This study aimed to explore the extent, nature, predictors, and consequences of stigma in MS. Our findings have revealed that the experience of stigma among PwMS is common and can manifest in different ways, with potential implications for MS disclosure. This work builds and expands upon recent literature by revealing the factors that increase the likelihood of stigma in MS. Specifically, our quantitative analysis has shown how a combination of sociodemographic, health, and psychosocial factors associate with stigma, while our qualitative analysis helps to explain why this may be the case. Taken together, the integration of both quantitative and qualitative results indicates ways in which the stigma experienced by PwMS may be reduced.

Building on recent research suggesting that stigma is more likely in those with higher levels of disability (Ghajarzadeh et al., 2024), we have shown that PwMS with poorer self-rated health and those living with progressive MS are more likely to experience stigma than those with RRMS. Living with progressive MS has previously been demonstrated to negatively impact quality of life (Yalachkov et al., 2019; Zhang et al., 2020). The results from our qualitative analysis suggest that the experience of stigma may present an additional challenge for this cohort. For example, some participants noted how they experienced stigma as a result of using mobility aids (which are more likely to be needed in those with progressive MS), with some reporting that they felt "judged" for the way that they walked or for needing to use disabled parking spaces. However, consistent with wider literature in the area of invisible disabilities (Joachim & Acorn, 2000; Kattari et al., 2018), the open-text responses also reveal that, conversely, some of those dealing with invisible symptoms experienced stigma because they did not "appear" ill to others. While this implies that the type of stigma experienced may differ depending on the progression of MS and the nature of disabilities, it is also clear from the qualitative analysis that stigma is often manifested due to a lack of understanding and awareness from others as to what MS involves.

While most of the sociodemographic factors examined in our model did not independently predict stigma, one notable exception was gender. Specifically, participants identifying as female had a greater risk of experiencing stigma than other genders, implying that the development of interventions specifically designed to reduce stigma in women living with MS may need to be considered. Some of the open-ended responses suggest examples of the type of stigma that may be experienced by women. For example, one female respondent described how she was labeled as "too pretty" to need mobility aids, highlighting possible intersections between gender and stigma in the context of MS. In citing stigma from HCPs, another participant noted how symptoms caused by the menopause may be incorrectly misinterpreted as stemming from MS. This is consistent with the finding that women with MS are more likely to be subjected to "medical gaslighting" (Horne et al., 2023), which could be regarded as a form of stigma exhibited by HCPs.

Aside from gender, the other notable sociodemographic predictor of stigma in our model was financial stability. The fact that higher stigma was present in those who had a greater difficulty in making ends meet suggests that certain cohorts of PwMS who are financially vulnerable may experience stigma as a further challenge. Given that PwMS are

at an increased risk of unemployment (Messmer Uccelli et al., 2009), a fact which was also reflected in the demographic characteristics of our sample, the likelihood of struggling to make ends meet (and subsequently experiencing stigma) may be enhanced in this population.

After controlling for the sociodemographic and health-related factors described above, the most significant predictors of stigma in our model were psychosocial factors. Perhaps unsurprisingly, loneliness had the strongest associations with stigma here, suggesting that those PwMS who feel lonely were also more likely to feel stigmatized. This was also evident from the qualitative analysis, with "struggle for recognition" being a dominant theme. Within this theme, many instances of isolation stigma were apparent. For example, many participants reported how their friends or family excluded them because of their MS. As regards disclosure, many participants similarly reported how people "disengaged" when they told them about their MS. Conversely, perceptions of support and empathy from others were key in leading to positive experiences of disclosure and possibly less stigma due to increased social support. It follows that one potential intervention to reduce feelings of stigma in MS may be the introduction of peer support. A growing body of evidence has suggested that peer support interventions can enhance well-being in PwMS (Gerritzen et al., 2022; Ng et al., 2013), with literature in other populations suggesting that peer support may reduce stigma (Burke et al., 2019). The potential of such interventions in reducing stigma is also hinted at by our finding that other PwMS were the least likely source of stigma reported by participants. This compares to more frequent reports of stigma from other sources, notably in employment contexts and when dating. Peers with MS may offer a "safe space" for discussing concerns and experiences of living with MS, which may not be widely understood by those not living with the condition.

The other key psychosocial factor showing strong relationships with stigma in our model was MS self-efficacy. A large body of evidence has shown how self-efficacy is predictive of a number of health and psychological outcomes in MS (A. J. Hughes et al., 2015; Motl et al., 2013; Riazi et al., 2004; Schmitt et al., 2014). Our findings imply that the promotion of self-efficacy is one way in which MS stigma can be tackled at an individual level. This can also be seen in the qualitative analysis, where the subtheme "lack of confidence" was a key aspect of personal stigma. While there is clearly a need to reduce MS stigma at a societal level, our findings highlight the need to reduce self-stigma, given that this was the most frequently reported source of stigma among participants. Interventions specifically focused on reducing self-stigma in other populations have been developed with some success (Yanos et al., 2015), though this has not been a focus of MS interventions to date. Also, while MS acceptance was not found to independently associate with stigma in our model, findings of the qualitative responses suggest that an increased acceptance of MS has the potential to reduce self-stigma.

A secondary aim of this study was to explore the extent to which participants concealed their MS from others and how fears of stigma may explain this concealment. Consistent with previous research (Cook et al., 2016; Kever & Leavitt, 2022; Leavitt & Kever, 2022; Vitturi et al., 2022), we demonstrated that anticipated stigma is linked to concealment of MS, with the open-text responses revealing how participants' attitude toward MS disclosure was connected to the stigma they expected to experience from others. While, at times, lack of openness about their diagnosis was due to anticipated stigma, it is also evident from the qualitative analysis that, for some participants, direct experience of stigma led to a change in approach to disclosure. Reports of being pitied or (conversely) not being taken seriously were cited as negative experiences relating to MS disclosure, which could also be considered instances of stigma.

While many participants reported some level of disclosure of their MS diagnosis to others, we showed that people varied in how open they were about different MS symptoms. Aside from the perhaps unsurprisingly low levels of reported openness regarding sexual, bowel, and bladder problems, it is also notable that few participants were open about their cognitive and mental health problems. Given that cognitive difficulties are common in MS (Benedict et al., 2020), with impacts on employment and quality of life (Gil-González et al., 2020), failing to disclose these symptoms may compound the challenges for PwMS. This further highlights the stigma associated with "invisible" disabilities. Regardless of symptoms, few participants reported "always" being open about them, suggesting that even if PwMS are open about their MS diagnosis with others, they are unlikely to reveal the various impacts that this diagnosis has on their lives. While in some cases MS concealment can be a protective mechanism for PwMS (Cook et al., 2017), failure to disclose MS, particularly in employment contexts, may result in PwMS not getting the support they need.

Strengths and Limitations

A key strength of this study is that it was conceptualized and led by a person with MS with further PPI input sought on the design and implementation of the study by a panel of four other people with MS. This meant that the project was driven by patient priorities, with questions designed to best capture the issues deemed most important to PwMS in relation to stigma and disclosure. Equally, it is possible that the patient-led nature of this project may have introduced some bias into the interpretation of the findings. To counter this, a member of the research team who did not have MS led aspects of the qualitative analysis, with further efforts to counter potential biases made through review and discussion of the findings. While both quantitative and qualitative measures of stigma were obtained in order to develop a comprehensive understanding, the cross-sectional nature of the design precluded the directionality of relationships between stigma and the other variables from being assessed. Also, while qualitative data were gathered in the form of open-text responses, more in-depth interviews might have revealed greater detail on the nature of the stigma experience.

Constraints on Generality

While the sample is largely in line with what would be expected based on population norms for PwMS (e.g., in terms of gender breakdown and MS types), the fact that 95% of participants identified as Caucasian suggests that other ethnicities were underrepresented. As the group was a predominately Western English-speaking and highly educated sample, results cannot be generalized to PwMS of other nationalities. Finally, as data collection was conducted online, the views of PwMS who may have limited access to the internet or those with low levels of technological literacy cannot be known.

Recommendations for Future Research

While this study has given some insight into the experiences of stigma and disclosure among PwMS, further research is needed to continue to explore and understand the complexities of this experience. Future qualitative research should attempt to explore the nature of stigma in more detail, including considerations of the various types of stigma that may manifest in MS. Given that we have shown that many PwMS report changing their approach to disclosure over time, longitudinal research would be particularly valuable to track the factors influencing disclosure decisions, as well as showing how the experience of stigma relates to disclosure decisions over time. Finally, in light of the constraints on generality noted above, future research should seek to explore stigma and interventions that reduce it in a representative sample of PwMS, with particular efforts made to target marginalized cohorts of this population.

Conclusions

While current supports and interventions for PwMS are typically aimed at mitigating the physical impact of the disease, our findings highlight the challenges that stigma can present for people living with the condition. Efforts should be directed at reducing stigma, along with reducing other psychosocial impacts of MS. We have highlighted a variety of factors that put PwMS at risk of greater stigma and have suggested various strategies for reducing this risk.

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