

SYSTEMATIC REVIEW

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Stigma and health outcomes in multiple sclerosis: a systematic review

Bradley Powell^{1*}, Roger Mills^{2,3}, Alan Tennant⁴, Carolyn A. Young^{2,3} and Dawn Langdon¹

Abstract

Background Stigma is increasingly recognised as contributing to disability in MS. This systematic review aimed to answer the following question: To what extent is stigma associated with psychological and physical health outcomes in MS?

Methods The inclusion criteria were: scientific publication of original quantitative research in adults with MS and/or Clinically Isolated Syndrome; outcome measures including a measurement of stigma and psychological and/or physical health; peer reviewed articles in the English language. Pubmed, PsycINFO and Science Direct were searched in November 2023. The Joanna Briggs Institute Critical Appraisal Tool was used to assess the methodological quality and risk of bias in all of the identified studies. The following data was extracted: (1) author and publication year, (2) country, (3) design, (4) sample size and demographics, (5) stigma measure, (6) psychological and/or physical health outcomes, 8) key findings.

Results 18 Studies were identified, reporting in total 22,021 adult participants with multiple sclerosis, with individual sample sizes ranging from 33 to 6,670. The review consistently identified stigma to be significantly associated with adverse psychological and physical health outcomes in all 18 identified studies. Over half of all identified studies investigated depression and stigma and over half investigated quality of life and stigma, and a significant association was demonstrated for both of these variables with stigma in all of these studies.

Discussion Limitations are that most studies were Western with primarily white participants. Only variables studied could be reported and therefore only a selective perspective of stigma in MS could be explored. A meta-analysis was not feasible, due to the variety of stigma definitions and measures employed. A model of stigma in MS is presented and possible interventions to manage stigma in MS are discussed. A need for international action to develop a consensus measure of MS stigma and determine the trajectory and causal dynamics of MS stigma is highlighted.

Keywords Stigma, Multiple sclerosis, Health outcomes, Depression, Systematic review

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Background

Multiple Sclerosis (MS) is a progressive, chronic demyelinating disease of the central nervous system, involving degenerative and inflammatory processes, leading to a complex pattern of disability [1]. The worldwide prevalence of MS is over 2.8 million [2]. The mean age of onset in Europe is in the early 30's [3], a time when identity, career and relationships start to flourish. Unfortunately, people with chronic neurological conditions such as MS may experience significant stigma which can compound their disability [4]. Stigma has been described as experiencing “a set of negative and unfair beliefs that a society or group of people have about something” [5]. Social stigma in the context of health is the disapproval of, or discrimination against, an individual or group based on a health condition which differentiates them from other members of a society. Stigmatising attitudes can become internalised, whereby an individual believes the negative beliefs that others hold, impacting their view of themselves in relation to others (for instance, in hearing loss, 6).

Stigma in MS is related to the physical, psychological and social aspects of the disease. Stigma has also been reported in eastern cultures and been associated with reductions in quality of life (QoL) [7]. Cultural stereotypes, which value productivity and personal responsibility, further compound stigma [8]. Stigma is also a likely driver in many social determinants of health (SDOH) in MS [9]. It has been found to be detrimental to health both directly, as a pernicious stressor which triggers adverse cognitive, behavioural, affective, and physiological responses, and indirectly, by preventing access to crucial health-promoting resources such as community participation, employment, and healthcare [4]. In recognition of this, there is a growing literature investigating MS stigma [10–12]. Consequently, clinical opinion acknowledges the need to address stigma in neurological disease and professional groups seeking to address stigma are working with some specific diseases, for example epilepsy [13].

Two previous systematic reviews have explored stigma in MS. Vitturi et al. [14] investigated MS stigma in the workplace, finding that stigma was commonly reported, associated with unemployment, and prevented diagnosis disclosure, despite research indicating diagnosis disclosure is related to work-based adjustment and increased workplace wellbeing [15]. Koutsogeorgou et al. [16] found stigma was associated with the ability to maintain relationships. It is well established that social capital is protective against a range of psychological and physical health outcomes in the general population, and therefore may be of increased importance in MS-populations [3]. It is unclear how stigma is associated with broader psychological and physical health outcomes in MS, and

a further comprehensive systematic review is indicated. The present review therefore aims to answer the following question: To what extent is stigma associated with psychological and physical health outcomes in MS?

Method

Search strategy

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed [17]. Three databases were used: Pubmed, PsycINFO and Science Direct. The search terms ((Multiple sclerosis) OR (clinically isolated syndrome) OR (MS CIS) AND (stigma) AND (adults)) were applied to “title,” “abstract” and “key words”. Search terms were combined using Boolean operators and truncation. The full search was conducted in November 2023. Reference lists of identified papers were also searched.

Eligibility criteria and screening methods

The inclusion criteria were:

- a) Scientific publication of original quantitative research in adults with MS and/or Clinically Isolated Syndrome.
- b) Outcome measures including a measurement of stigma and psychological and/or physical health.
- c) Peer reviewed articles in English language.

Two researchers independently screened all titles and abstracts identified by the search procedure. Selected studies were reviewed against the inclusion criteria. In line with PRISMA guidelines, quality appraisal of identified studies was conducted (See Appendix A for Quality Appraisal Table and Appendix B for Quality Appraisal Summary).

Data extraction

The data were extracted independently by B.P. The key characteristics that were extracted included: (1) author and publication year, (2) country, (3) design, (4) sample size and demographics, (5) stigma measure, (6) psychological and/or physical health outcomes, 8) key findings.

Data synthesis

This systematic review followed the PRISMA statement to ensure complete reporting and transparency in the manuscript [17]. A narrative data synthesis without meta-analysis was performed due to the heterogeneity in outcomes and measures, following the Synthesis Without Meta-analysis guideline [18].

Results

Study identification

The flow diagram (see Fig. 1) illustrates the study eligibility and selection procedure. The search strategy retrieved 412 papers. After removing duplicates, there were 371 papers to be assessed against the inclusion criteria. 18 studies met eligibility criteria and progressed to quality assessment and synthesis phase.

Study characteristics

Included studies were published between 2004 and 2023. In total, there were 22,021 participants, with individual sample sizes ranging from 33 to 6,670. Seven studies were published in the United States (38.9%), and the majority used a cross-sectional design (88.9%, 16 studies). Most of the participants were female, with a percentage that was representative of the MS population (67.74%) [3]. The

mean age of the participants was 50.04 (SD=8.87). Six studies reported ethnicity where most participants were white (75.52%) (See Table 1).

Stigma prevalence

All nine studies that reported on the prevalence of stigma within the sample found the experience of stigma to be common. As stigma scales assess a range of experiences that impact individuals to varying degrees, a person's stigma score is unlikely to be indicative of how adversely those with MS are affected. Thus scoring highly on one item of a stigma scale, (i.e. 'people treat me differently due to my MS'), has been interpreted as experiencing a degree of stigma. Using this classification, the prevalence of stigma in our sample ranged from 19.9% [19] to 85.5% [20]. Tworek et al. [21] defined stigma statistically by designating scores that were two standard deviations above

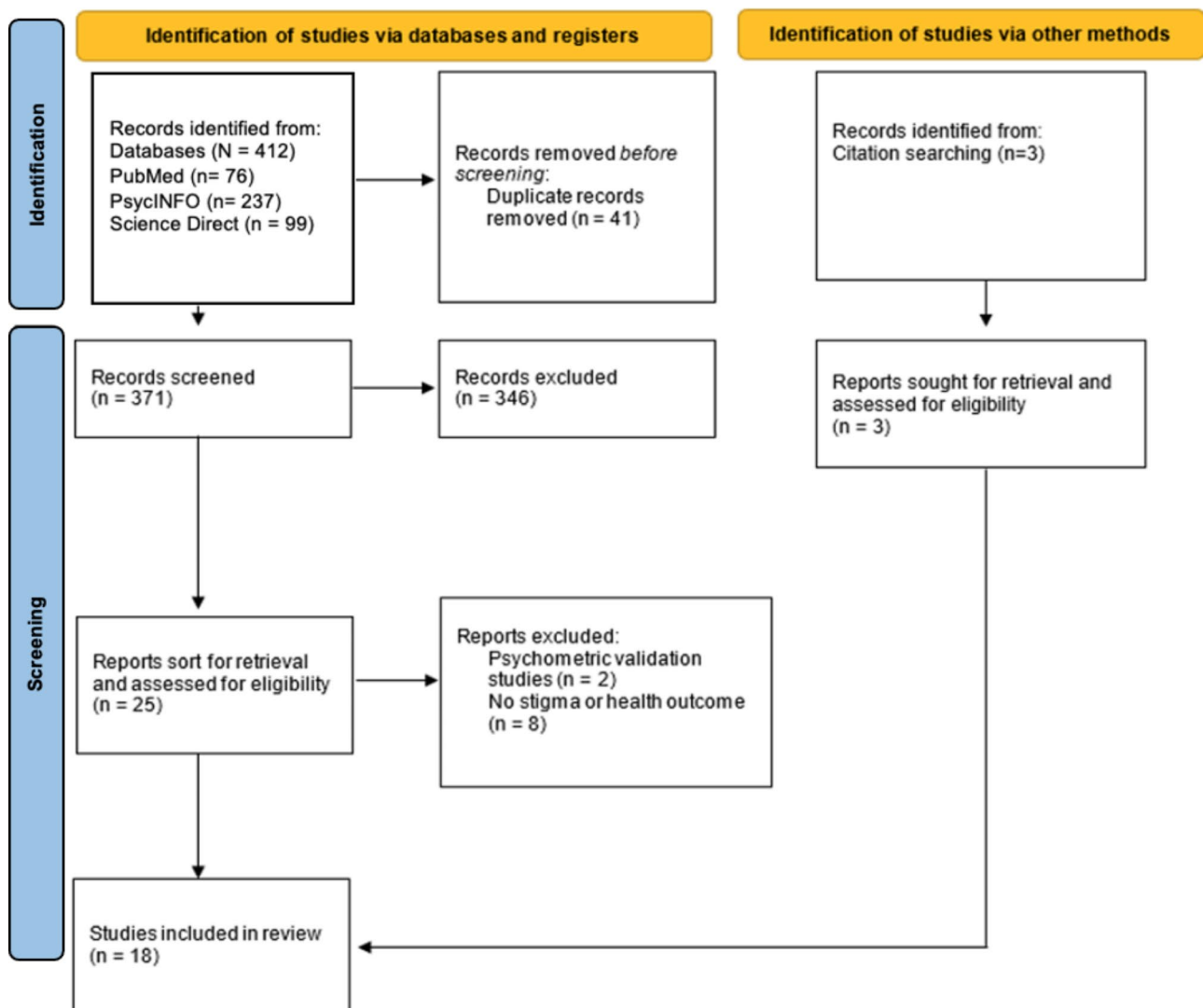


Fig. 1 PRISMA diagram

Table 1 Study characteristics

First Author Year Country Design	N	% Female	Age Mean SD	% White	Stigma Measure	Psychological and/ or Physical Health Outcome Measure	Key Findings
Tworek 2023 USA Cross-sectional	6,670	73.3	60.2 8.9	74.2	Neuro-QoL	Neuro-QoL PROMIS-GH	Patients with the greatest stigma were younger, black, single, younger disease onset, had progressive MS, greater levels of disability, and worse scores across all outcomes.
Pérez-Miralles 2021 Spain Longitudinal	55	64.6	55.8 9.5	NR	SSCI	RBAN BDI-FS MSIS WPAI MSWDQ	Greater stigma associated with increased depression risk, worse depression, poorer cognitive outcome, and higher disease and psychological impact.
Ochoa-Morales 2021 Mexico Cross-sectional	98	57.1	36.3 13.3	NR	KISS	EDSS BDI	Perceived discrimination in patients with multiple sclerosis was associated with earlier disease onset, depressive symptoms, and the lack of caregivers.
Maurino 2020 Spain Cross-sectional	199	60.8	43.9 10.9	NR	SSCI	MSWDQ MSIS	Higher perceptions of stigma were also strongly linked to higher physical and psychological impact on health-related quality of life and greater work difficulties.
Spencer 2019 USA Cross-sectional	6,771	78.4	58 10.5	NR	Nine-items	PDSS	Stigma was associated in general with worse health, negative health behaviours, and a relative lack of resources.
Hategeka 2019 Canada Cross-sectional	530	74.9	50.7 17.3	NR	Four-items	HUIM3	Greater stigma associated with not working and more informal care.
Stevens 2019 USA Cross-sectional	151	66.2	46.1 11.8	73.5	Neuro-QoL	Neuro-QoL PHQ-9 BSQ	Patients with moderate/marked concern body image difficulties were more likely to have greater stigma scores, be female and had higher body mass index values, Patient Health Questionnaire-9 scores.
Cadden 2018 USA Longitudinal	5,369	78.4	58.3 10.2	90.4	Nine-items	NARCOMS-DS	People experiencing higher levels of stigma reported more depression symptoms and were more likely to meet the threshold for clinical depression at both times, even controlling for covariates. Higher levels of stigma also predicted depression at one year follow up.
Broersma 2018 Netherlands Cross-sectional	185	68	60 10.8	NR	SSCI	WHOQoL SoCS EDSS	Stigma highly prevalent but low in severity. Increased limitations resulted in greater stigma. More stigma related to poorer QoL.
Anagnostouli 2016 Greece Cross-sectional	342	67.5	43.1 11.4	NR	SSCI	MSQoL-54	Stigma levels displayed strong negative correlation with all composites of MSQoL-54.
Cook 2016 USA Cross-sectional	53	79	45.8 NR	83	Nine-items	CQ PDSS	Concerns of stigma lead to disease concealment. Isolation stigma associated with disabled work status
Looper 2004 Canada Cross-sectional	33	NR	NR	NR	AoO PSS	SC90-R	Perceived stigma significantly predicts depression.

Table 1 (continued)

First Author Year Country Design	N	% Female	Age Mean SD	% White	Stigma Measure	Psychological and/ or Physical Health Outcome Measure	Key Findings
Viner 2014 Canada Cross-sectional	630	73.3	51.8 NR	NR	Survey	HUIM3 PHQ-9	Depressed subjects had lower quality of life; an increased frequency of suicidal ideation; and more often reported a negative disease course, high stress, low social support and stigmatization.
Valvano 2016 USA Cross-sectional	128	85	45.5 10.8	56	Nine-items	CFQ HADS MSQoL	Cognitive fusion mediated relationship between stigma and depression, anxiety and quality of life.
Hunter 2023 USA Cross-sectional	143	74.1	49.1 NR	76	TEDS	PROMIS PDQ PDS	Black participants reported greater discrimination and increased anxiety.
Pérez-Miralles 2019 Spain Cross-sectional	55	44.6	55.8 9.5	NR	SSCI-8	MSIS-29 BDI-FS EDSS	Stigma predicted depression. Stigma was highly prevalent, and was associated with QoL and mood in primary progressive MS.
Kalantari 2018 Iran Cross-sectional	305	74.8	35.7% were age 35 or higher	NR	20-items	EDSS Demographics	Stigma was significantly associated with occupation, disease duration, visibility of symptoms, level of disability and economic conditions. 44% hid their disease status and 52.6% believed the disease would stigmatise them in society.
Sharifi 2023 Iran Cross-sectional	223	72.6	37.8 8.3	NR	20-items	MSQOL-54	Social stigma had a significant negative correlation with quality of life.

Footnote. Stigma Measures: Stigma Scale for Chronic Illness (SSCI), King Internalised Stigma Scale (KISS), Researcher made measure (nine-items; four-items; 20-items), Neuro-Quality of Life (Neuro-QoL), Attitudes of Others Scale (AoO), Pain Stigma Scale (PSS), Researcher made survey (Survey), The Everyday Discrimination Scale (TEDS). Health Measures: Patient Reported Outcome Measurement Information System-General Health (PROMIS-GH), Repeatable Battery for the Assessment of Neurological Status (RBAN), Beck's Depression Inventory-Fast Screen (BDI-FS), Multiple Sclerosis Impact Scale (MSIS), Work Productivity and Activity Impairment Questionnaire (WPAI), Multiple Sclerosis Work Difficulties Questionnaire (MSWDQ), Expanded Disability Status Scale (EDSS), Beck's Depression Inventory (BDI), Patient Disease Steps Scale (PDSS), Health Utilities Index-Mark 3 (HUI-M3), Patient Health Questionnaire-9 (PHQ-9), Body Shape Questionnaire (BSQ), North American Research Committee on Multiple Sclerosis – Disease Scale (NARCOMS-DS), Sense of Coherence Scale (SoCs), Concealment Questionnaire (CQ), Symptom Checklist-90 (SC90-R), Cognitive Fusion Questionnaire (CFQ), Hospital and Anxiety Depression Scale (HADS)

the population mean as severe, resulting in 8.31% of their sample reporting a severe degree of stigma. These findings show that the experience of stigma in MS is nuanced and widespread. Two of the 18 studies reported the association of demographic characteristics with MS-stigma. MS-stigma was greater and associated with worse health for participants who were black, single, and younger in age [23]. Black participants were more likely to report discrimination and experience anxiety [22].

Stigma and psychological outcomes

All nine studies which explored stigma and depression reported significant associations, regardless of measurement method (all $p < .001$) [4, 12, 21, 23–28]. People reporting perceived discrimination were more likely to report depressive symptoms ($p < .001$) [27]. There were two longitudinal studies. A one-year longitudinal study

found greater Stigma Scale for Chronic Illness (SSCI) scores at baseline were associated with higher risk of developing depression ($p = .007$) and incidence of moderate to severe depression ($p = .003$) [28]. Stigma was also found to explain 35% of the variance in depression ($p < .001$), and predicted likelihood of being clinically depressed at one year follow up ($p < .001$) [12].

All eight studies which assessed stigma and QoL reported significant associations, again, despite the utilisation of different measures. Lower stigma was associated with greater QoL, the relationship was mediated by mood symptoms [21, 29, 30]. Demographic variables also mediated these associations, with stigma being associated with QoL irrespective of disability levels [19]. Greater depression was associated with increased stigma and poorer QoL [26]. Cognitive fusion, being attached to ones thoughts, mediated the relationship between

stigma and QoL, with greater cognitive fusion reducing QoL when stigma is present [25]. Stigma was also associated with greater anxiety ($p < .001$) [21], lower attention, processing speed and memory ($p < .001$) [28], and body image disturbances ($p < .02$) [31].

Physical health and participation

Nine studies explored the association of stigma with physical health and participation. Perceived stigma was associated with earlier disease onset but not objective physical disability [27]. Tworek et al. [21] found greater disability assessed via the patient reported Patient Disease Steps Scale (PDSS) was associated with increased stigma, as well as being younger at symptom onset, younger in age, being black and single. Similar findings were reported by Spencer et al. [20], who used the PDSS and found greater patient reported disability was associated with increased anticipation of stigma experiences. Additionally, they found that the longer people had lived with MS, the less stigma they felt. Broersma et al. [29] also found that greater levels of self-reported disability were related to increased stigma, although people

who reported their lives 'made sense and were coherent' experienced less stigma and self-reported less disability. Hategeka et al. [23] found greater stigma was associated with requiring more informal care and unemployment, both indicators of poorer physical health. Cook et al. [32] found that those with MS who concealed their disease status due to anticipating stigma were more likely to be unemployed, suggesting stigma alone contributes to unemployment. This may be explained by those with internalised stigma beliefs choosing not to disclose their disease status due to concerns they may be discriminated against, which means colleagues lack understanding about their condition and are unable to make work adjustments.

Conceptualising stigma

From these findings it is possible to hypothesise an initial conceptual model of stigma, to be tested in future research (Fig. 2). It includes those domains relevant to public health interventions [13], and those associated with potential cognitive and behavioural approaches for the individual, which have been shown to be effective in

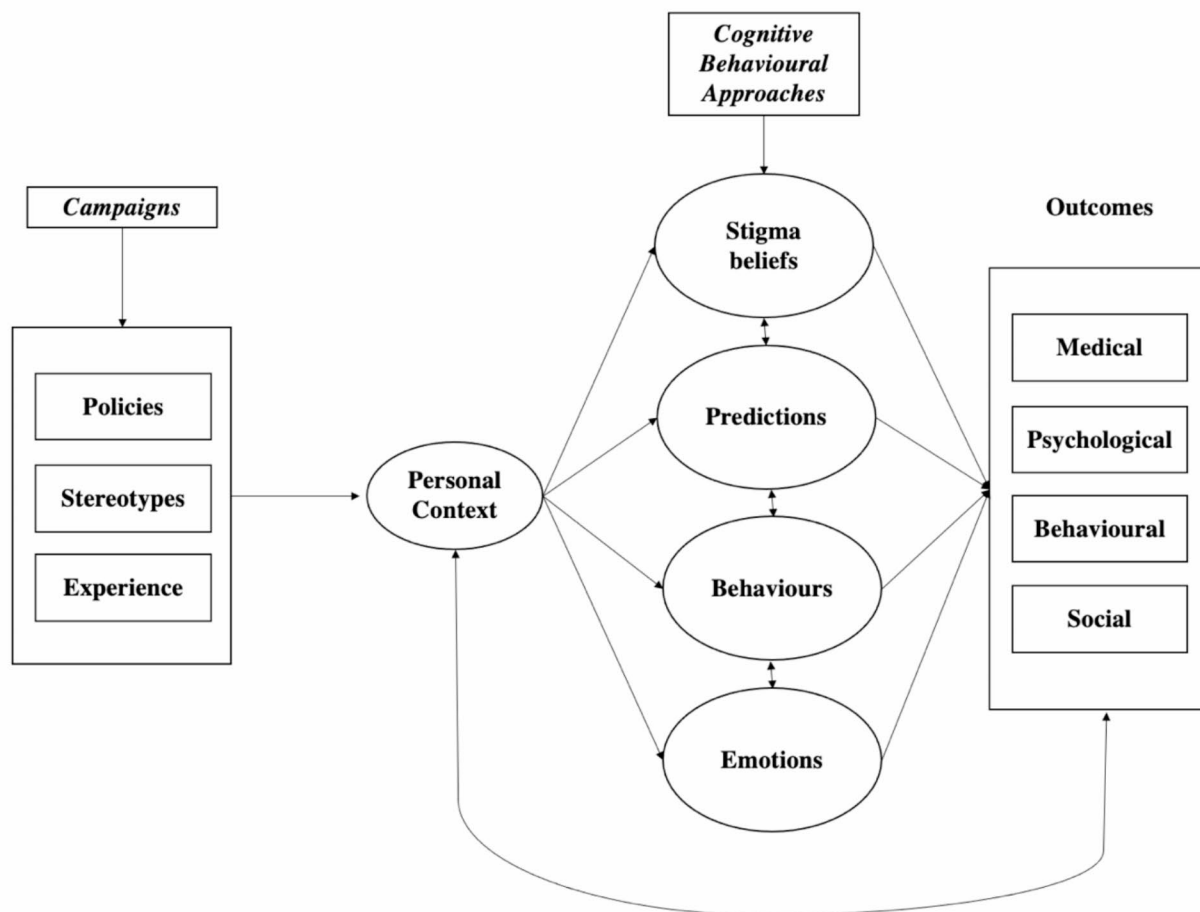


Fig. 2 MS-stigma model

reducing stigma in other conditions [37]. It is consistent with the earlier reported study identifying the different aspects of stigma [6]. Namely the impact of social stigmas on self-stigma (enacted stigma); the effect of emotions on self-stigma (felt stigma), and other factors that impact self-stigma [33].

The tentative model was created based upon the papers identified from the systematic review of the literature. We mapped each outcome reported in the included studies to either psychological or physical health outcomes. Many studies also reported additional outcomes and these medical, behavioural, and social outcomes were included to provide a comprehensive view of stigma in MS. Whilst there was little assessment of personal characteristics associated with stigma, aside from Tworek et al. [21] and Hunter et al. [22], personal context was incorporated within the model, to represent social determinants of health which impact the experience of stigma and associated health outcomes [9].

Discussion

This review consistently identified stigma to be significantly associated with adverse psychological and physical health outcomes in the 18 identified studies with a total sample of 22, 021 participants. This provides empirical support for the pervasive nature of stigma for those with MS. The stigma experience varied in intensity, with the majority experiencing mild to moderate levels. Greater stigma was associated with worse depression, QoL, anxiety, and body image difficulties. Two longitudinal studies found stigma predicted increased depression incidence, and stigma was found to be worse for those with certain demographic characteristics, such as younger age, ethnicity, and disease status. Depression was the most investigated health outcome in this review (nine studies). This may reflect the significant burden of depression for MS, and the association of depression with increased suicide risk [34]. Greater self-reported physical impairments were found to be associated with increased stigma; however, this was not the case with the objective physical disability measure. This highlights the importance of understanding an individual's experiences as well as objective health indicators.

The review identified a range of stigma-health associations in MS. The significant association between MS depression and stigma could be explained by the negative processing bias in depression attributing negative experiences as indicative of stigma (i.e. a confirmation bias) [35]. This may also explain the finding that the self-reported level of disability of those with MS is associated with increased stigma [23, 35], whereas there were mixed findings regarding an association of objective measurement of disability and stigma [26, 36]. Valvano et al. [25] found cognitive fusion, the process of being 'attached' to

one's thoughts, mediated the association between stigma and depression and QoL, which provides evidence for the role of cognition in perpetuating the experience of stigma. This also suggests cognitive interventions may reduce the association of stigma on health.

There are a range of depression symptoms that may contribute to the sense that someone is being stigmatised. For instance, those who experience low motivation due to their depression may have an increased likelihood of becoming isolated, which could be perceived as evidence of being stigmatised [30]. Moreover, those with MS have reported that neurologists may not prioritise the psychological consequences of their illness, which reinforce stigmatising beliefs [37]. Depression also predicts low QoL [38], which may explain the association between stigma and quality of life. QoL is defined as a person's perception of their position in life, in the context of the culture and value systems in which they live in [39]. This is conceptually similar to the original definition of stigma, being 'socially discredited' [40]. Broersma et al. [28] found sense of coherence (an ability to respond to stress and capacity to employ adaptive behaviours) was associated with less stigma, greater QoL and less reporting of physical limitations. It is therefore hypothesised that cognitive and behavioural approaches may be efficacious for stigma management in MS. Such approaches have demonstrated effectiveness in MS for stress management [41]. There is also a growing evidence base for third-wave cognitive-behavioural approaches for MS such as mindfulness-based interventions [42, 43]. There is a strong literature of such approaches for other long-term conditions [44].

The review also highlights the multi-level experiences of stigma for people with MS. Tworek et al. [21] demonstrated how an individual's demographic characteristics were associated with MS-stigma and could potentially be a protective or predisposing factor for the experience of stigma, depending on an individual's characteristics and circumstances. Maurino et al. [19] highlighted how work-based policies can result in greater work difficulties, and that these were associated with increased stigma and poorer health outcomes. Cook et al. [32] illustrated how stigma can manifest interpersonally, through the behaviour of disease concealment. Disease concealment which may result from trying to avoid stigma in the workplace, perpetuates structural and individual stigma by preventing accommodations to support those with MS.

The model in Fig. 2 does suggest cognitive-behavioural interventions addressing stigma experiences may be helpful [37]. For example, a person with MS may report an internalised stigma belief such as 'I will never find a partner because of my MS' [45]. Such a belief will negatively influence their attention, behaviours, and emotions. For example, by perceiving neutral experiences negatively and as evidence that people do not find them

attractive and thus choose to actively not seek relationships. However, this belief can be challenged by identifying those with MS who are actively dating, happily married and have children. In addition, those who report anticipating stigma, and therefore avoid potentially stigmatising experiences, can be supported in testing out the validity of their predictions to assess whether the extent they believe they will be stigmatised is accurate. Such experiments have the potential to reduce the belief that they will anticipate stigma [46]. Awareness of an individual's cognitions, adjunct to a behavioural experiment approach, could be employed to help defuse stigma related thoughts resulting from stigmatising policies, stereotypes, and experiences. Campaigns led by third sector organisations can also be employed to make policies more inclusive, to tackle societal stereotypes and inform others as to how to avoid contributing to a stigmatising experience. A direct assessment of the impact associated with the stigma that an individual is experiencing can indicate which intervention may target the maintaining factors [47].

The review also found stigma to be significantly associated with physical health. Greater physical health concerns may be more visible to others, increasing an individual's vulnerability to stigma [48]. Future research would benefit from employing longitudinal designs to understand the relationship between stigma and disability as time progresses. Such a relationship could be hypothesised given that stigma in MS can result in reduced physical activity over time, as people begin to avoid potentially stigmatising experiences. Reduction in physical activity is known to exacerbate physical health difficulties [49], highlighting a vicious cycle that those with MS can be supported to manage.

Strengths and limitations of review

To the authors knowledge, this is the first review to assess the impact of stigma on health outcomes in MS. It addresses an area which is currently high priority among service users, researchers, social media regulators, and government ministers, aligning with key debates in the field [50]. The review followed PRISMA guidance [17], and the large sample size with male to female gender ratio representative of MS increases the validity of this review [3]. Previously psychological outcomes have been neglected in MS [51], here the inclusion of psychological and physical health outcomes provides a comprehensive assessment of the reported associations of stigma within MS. The synthesis of findings provides suggestions for the management of stigma and future research.

Limitations include the heterogeneity of stigma measurement within the review, however, the inclusion of all stigma measures was appropriate due to the paucity of published research investigating stigma in MS. As the

evidence develops, future systematic reviews may benefit from focussing upon specific stigma measures and their impact upon psychological and physical health. An additional limitation is the exclusion of grey literature from this review, possibly introducing a selection bias into the findings reported. Similarly, 16 of the 18 included studies were conducted in Western cultures, limiting generalisations to other cultures and religious contexts. There may have also been a recruitment bias, with stigma experience influencing who would volunteer [52]. Research participants sometimes reported more than one personal characteristic associated with stigma, such as being disabled, black and/or unemployed, as well as having MS. Available data does not allow us to segregate which factors are contributing most to the perceived stigma. We were only able to report variables which had been investigated in the identified studies, resulting in a selective overview. A further limitation of the review is the absence of a meta-analysis. This was not viable, due to the heterogeneity of methodology and measures across studies. The variation therefore required a narrative synthesis opposed to a quantitative analysis [17], highlighting that consensus is needed as to how to measure stigma (as well as depression) in MS.

Clinical and research implications

This review highlights the need for healthcare professionals to understand and support the management of stigma for those with MS, particularly for groups who are most vulnerable, to protect health outcomes. Given that there was little examination of personal characteristics associated with stigma within the identified papers, future research examining stigma in the context of social determinants of health could further develop the conceptual model. The findings corroborate the voices of those with MS who suggest the psychological impact of the disease is often overlooked [20]. Thus, healthcare professionals should be alert to specific patient profiles most vulnerable to stigma to provide targeted treatment that addresses stigma and the attendant risks. For some people stigma declines with age [20], possibly due to gaining experience of living with MS and increasing acceptance of the condition [55]. This provides evidence of increased resilience to stigma and the importance of supporting stigma resilience in the early stages of illness. Notwithstanding, for others stigma may increase, which may reflect the larger impact of increased physical disability and reduced life opportunities [1]. Life adjustments may also be made that reduce the likelihood of entering stigmatising situations, such as avoiding busy places. However, limiting social contact (and increasing social isolation) will reduce physical conditioning and frequency of mood elevating situations [43]. As such, those with MS should be supported to develop adaptive coping strategies, which could

include psychoeducation, mindfulness, cognitive restructuring, and behavioural experiments [44, 53]. Given the widespread nature of stigma, third sector organisations should partner with governments to reduce stigmatising attitudes in society, by developing awareness raising campaigns [54].

The international MS community needs to take concerted action to address stigma [13]. An international research initiative involving those with MS to share their experiences of stigma is also essential to produce a consensus definition. Internationally validated measures should also be agreed and funded (e.g. as in HIV) [55]. More comprehensive, longitudinal studies are required, to understand stigma vulnerability and resilience. Interventions incorporating cognitive and behavioural approaches to help manage stigma should be evaluated [37, 43, 56, 57].

Conclusion

This systematic review provides a comprehensive synthesis of the known associations between stigma and both psychological and physical health outcomes in individuals with MS. The review's findings reveal several key insights into the impact of stigma. Stigma is a widespread occurrence among individuals with MS, affecting a significant portion of the representative population studied. The intensity of such stigma varies, with most experiencing it at mild to moderate levels. Furthermore, the review shows that stigma is significantly associated with a range of negative psychological and physical health outcomes in individuals with MS. These outcomes include depression, reduced QoL, physical health and participation. In conclusion, this systematic review highlights the pervasive impact of stigma on the lives of those with MS and underscores the urgency of addressing this issue to improve their health outcomes and overall wellbeing.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12883-024-03853-3>.

Supplementary Material 1

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Author contributions

BP – searches, data extraction, first draft of manuscript. RM – project conception, critical review of manuscript. AT – project conception, critical review of manuscript. CAY – project design, supervision, critical review of manuscript. DL – project design, lead supervision, research governance, manuscript writing and overview.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

All authors have seen and agreed the final manuscript and consent to publication.

Competing interests

The authors declare no competing interests.

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