

RESEARCH

Open Access



The subjective wellbeing of people living with Multiple Sclerosis in Australia: insights from the Personal Wellbeing Index

Glen J. Henson¹ , Ingrid van der Mei¹ , Bruce V. Taylor¹ , Suzi B. Claflin¹ , Andrew J. Palmer¹ , Julie A. Campbell^{1*} and Gang Chen^{2†}

Abstract

Objectives Subjective wellbeing has been defined as an individual's personal appraisal of their quality of life. Subjective wellbeing is associated with positive health behaviours and improved coping abilities. This study aimed to investigate the subjective wellbeing of people living with multiple sclerosis (MS), using the novel Personal Wellbeing Index, and make comparisons with the general population.

Methods Cross-sectional data was obtained from the Australian Multiple Sclerosis Longitudinal Study and the How Is Your Life Australian general population study in August–October 2020. Subjective wellbeing was measured as life satisfaction using the Personal Wellbeing Index. This instrument measures life satisfaction globally and in seven life domains, allowing the importance of domain-specific life satisfaction to be explored. Descriptive and multivariable regression analyses were conducted.

Results One thousand six hundred eighty-three MS and 1,021 general population participants entered the study (mean age 52.4 and 58.6; female 79.9% and 52.4%, respectively). For people living with MS the most important life domains were standard of living and achieving in life. The domain of personal health was more influential for people living with MS ($p < 0.01$) than the general population. The life domains most susceptible to MS-related disability were personal health, achieving in life, and community connectedness ($p < 0.01$ for these domains).

Conclusion Personal health and achieving in life are key domains through which the subjective wellbeing of people living with MS is modified. This study recommends the development of interventions to support healthy perceptions of illness and continued employment as paramount in improving the subjective wellbeing of people living with MS.

Introduction

Characteristics of multiple sclerosis

Multiple sclerosis (MS) is a neuroinflammatory/neurodegenerative demyelinating disease of the central nervous system [1, 2]. The symptoms of MS are diverse in substance and protean in severity (ranging from mild to extreme). MS symptoms frequently include fatigue, pain, sensory impairment, incontinence, and motor and cognitive dysfunction [3]. The global prevalence of MS was 2.8 million cases in 2020: a 21.7% increase from 2013 [4]. In Australia, MS prevalence was estimated at

[†]Julie A. Campbell and Gang Chen joint senior authors.

*Correspondence:

Julie A. Campbell

julie.campbell@utas.edu.au; Julie.Campbell@utas.edu.au

¹ Menzies Institute for Medical Research, University of Tasmania, 17 Liverpool St, Hobart, TAS 7000, Australia

² Centre for Health Economics, Monash University, Caulfield East, Victoria, Australia



33,335 cases in 2021 (up from 25,607 in 2017), and is increasing at an accelerating rate [5].

Our group established that the societal health economic burden of MS in Australia was A\$2.45 billion in 2021 [5]. This equates to a mean cost per person with MS per year of A\$73,457. In addition, the annual, per-case cost of MS increases from A\$59,957 for people with mild disability to A\$123,333 for people with severe disability [5].

Subjective wellbeing and the Personal Wellbeing Index

Subjective wellbeing has been defined as an individual's personal appraisal of the quality of their life [6]. While the health-related quality of life of people living with MS has been extensively analysed [3, 7–9], relatively few studies have analysed their broader, subjective wellbeing. Subjective wellbeing is not effectively measured by most conventional health-related quality of life instruments. For example, the EQ-5D-5L multi-attribute utility instrument, used in approximately 63% of health economic evaluations, contains no items relating to subjective wellbeing [10]. Importantly, detailed measurement of subjective wellbeing, often measured through life satisfaction, can help researchers understand the effects of disability and interventions beyond their impacts on levels of physical and psychosocial functioning [11]. Subjective wellbeing, which is often held to be synonymous with happiness [12] or morale, has been linked to health and risk of mortality through a variety of mediators including health behaviours (such as diet, exercise, and sleep) and the ability to cope with stress [13].

A literature review regarding the subjective wellbeing of people living with MS yielded several notable observations. Firstly, relevant studies frequently used small samples ($n < 100$) [14–16]. Secondly, pertinent studies have often chosen to analyse specific psychological contributors (such as gratitude, acceptance of illness, depression, stress, or coping strategies) to global life satisfaction [14–19]. Thirdly, only one study included a general population control group, concluding that global life satisfaction was worse in people living with MS [20]. Lastly, the five-item Satisfaction With Life Scale was used in all identified studies of subjective wellbeing for people living with MS. Importantly, this instrument provides only an aggregate measure of subjective wellbeing as life satisfaction. In contrast, the Personal Wellbeing Index – Adult (PWI-A, hereafter referred to as the PWI) includes both an aggregate measure and seven life domain measures, while also assessing subjective wellbeing through life satisfaction. The multi-dimensional format of the PWI allows researchers to better understand life satisfaction and, therefore, how to improve subjective wellbeing.

Aims of the study

Following our review of the literature, we aimed to investigate the effect of MS-related disability on satisfaction in the PWI's life domains. We also aimed to determine how satisfaction in the life domains influences global life satisfaction, and which life domains are most important, for people living with MS. To understand heterogeneity in life domain importance between people living with MS and the general population, we conducted a comparison. Attainment of these aims was intended to inform interventions that seek to improve the subjective wellbeing of people living with MS.

Methods

Source of study participants

Participants living with MS were sourced from the representative, survey-based Australian Multiple Sclerosis Longitudinal Study (AMSLS; approximately 3,000 active participants, initiated in 2001) [21]. Ninety-six percent of these participants were diagnosed with MS according to the McDonald criteria, with details of the diagnoses of the remaining 4% unconfirmed. Recruitment to the AMSLS is ongoing, with all study participants required to provide informed consent. Ethics Approval for the AMSLS was received from the Tasmanian Health and Medical Human Research Ethics Committee (ethics approval number H0014183).

Participants from the Australian general population were sourced from the How Is Your Life (HIYL) study. This study used an anonymous online survey that was developed on Qualtrics (www.qualtrics.com). HIYL study participants (aged 18 and over) were recruited through the general company Cint (www.cint.com) from among members of its panels. Recruitment used a quota sampling method that was informed by the age and sex distributions in the states and territories of Australia. The study had a target sample size of 1,000 persons. Participants who completed the HIYL survey were provided limited remuneration. Ethics approval for the HIYL was granted by the Monash University Human Research Ethics Committee (project ID 8442).

Sources of data

AMSLS data was sourced from both the 2020 Quality of Life survey (conducted August–October 2020), which included the PWI and the Assessment of Quality of Life – Eight Dimensions (AQoL-8D) multi-attribute utility instrument, and the 2018, 2019, and 2020 Disease Course surveys. The majority of data for AMSLS participants was obtained from the 2020 Quality of Life survey, with additional data regarding education and MS phenotype being collected from the Disease Course surveys. Unique

AMSLS research identifiers were used to link AMSLS data sources. General population data was sourced from the HIYL survey (conducted September–October 2020).

Measures

Participant subgroups

Participants were divided into three subgroups for statistical analysis based on their disease status: 1. people living with MS; 2. the general population without chronic diseases; and 3. the general population with other chronic diseases.

Subjective wellbeing and the Personal Wellbeing Index

The PWI is comprised of one global life satisfaction item and seven life domain items pertaining to standard of living, personal health, achieving in life, personal relationships, personal safety, community connectedness, and future security [22]. The PWI also contains an optional item for religion/spirituality, which is not recommended for use with Australian cohorts [23]. Each PWI item contains eleven levels, being measured on a 0–10 scale. Rasch analysis, which used a sample comprised of Australian and Canadian adults, found that the PWI has excellent psychometric properties [23].

Clinical and sociodemographic measures

Sociodemographic measures included: age (stratified into the categories <45, 45–54, 55–64, 65–74, >74); sex; adverse impacts associated with COVID-19 pandemic (yes, no); education (secondary or less, occupation certificate or diploma, bachelor's degree, postgraduate degree); and the Australian Bureau of Statistics' index of relative socioeconomic advantage and disadvantage (IRSAD) stratified by national quartile (higher scores indicate greater socioeconomic advantage).

Clinical measures included: MS-related disability (mapped from the Patient Determined Disease Steps to the Kurtzke Expanded Disability Severity Scale [EDSS] and categorised as no [EDSS=0.0], mild, [EDSS=1.0–3.5], moderate [EDSS=4.0–6.0], or severe disability [EDSS≥6.5]) [24]; MS-phenotype (relapsing–remitting, secondary progressive, progressive onset); and type of chronic disease (for participants with other chronic diseases). Chronic diseases among the general population were grouped into the following classifications which broadly reflect ICD-10 Codes: psychological; musculoskeletal; respiratory; oncological, endocrinological; cardiovascular; gastrointestinal; neurological; sensory; and other (World Health Organisation, 2015). Importantly, disease duration in the MS subgroup was not controlled for due to its high collinearity with age, which is consequently an effective proxy for time since diagnosis. The effects of disease duration in this subgroup were also captured by MS disability severity.

Statistical analyses

Descriptive analyses

To investigate the relationship between MS-related disability and life satisfaction, global and life domain satisfaction scores were stratified by the MS-related disability levels of no, mild, moderate and severe. To determine the comparability of the with chronic disease and MS subgroups, we compared the distributions of their health state utilities. Health state utilities represent overall health-related quality of life on a zero (death) to one (full health) interval scale. These utilities were obtained using the AQoL-8D, a validated, preference-based measure of health-related quality of life [25]. Specifically, the AQoL-8D generates health state utilities by synthesising survey responses using an Australian-specific algorithm. Means and standard deviations were reported for continuous measures and counts and proportions were reported for categorical measures.

Regression analyses

We adopted two forms of regression analysis to investigate our aims. In our regressions, PWI data was multiplied by ten to aid with ease of reporting. First, linear multivariable regression models (estimated via Ordinary Least Squares) were used to determine how MS-related disability affects satisfaction in the PWI life domains. Second, nonlinear multivariable regression models (estimated using Kernel-Based Regularised Least Squares) were used to investigate associations between life domain-specific and global life satisfaction for people living with MS versus the general population subgroups, thereby determining the relative importance of the life domains. Interaction terms – specified as MS subgroup membership multiplied by the PWI life domains – were used for this purpose. Kernel-Based Regularised Least Squares [26] was utilised as it has been found to generate superior results when modelling the complex relationships between PWI life domains and global life satisfaction [27]. Additionally, life satisfaction variables were standardised in these latter regression models. This aided in accurately estimating the variation in global life satisfaction associated with changes in life domain satisfaction. All models were adjusted for clinical and sociodemographic covariates, including age, sex, socioeconomic status, disability severity, MS phenotype, and type of chronic disease (general population only).

Results

Flow of participants into the study

Figure 1 outlines the flow of participants into the study. Regarding the MS group, 2,513 AMSLS participants were invited to participate in the 2020 Quality of Life Survey and 1,683 participants (67.0%) responded to this

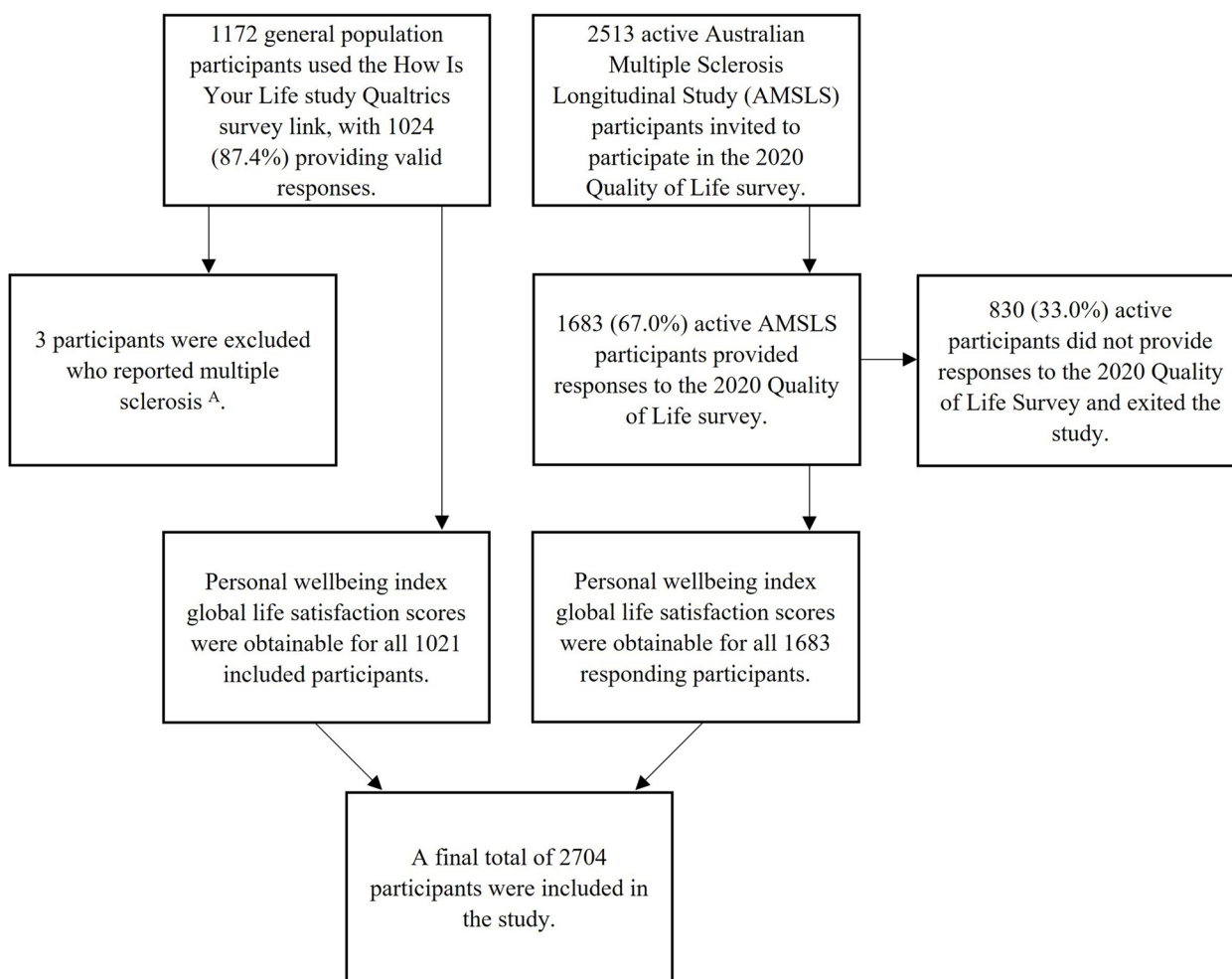


Fig. 1 Flow of participants into the study. Notes: [^] How Is Your Life study participants self-reporting MS were not transferred to the AMSLS dataset as their diagnoses could not be confirmed

survey. Regarding the general population sample, 1,172 people accessed the How Is Your Life study survey link, with 1,024 consenting to participate and providing valid responses (87.4%). Of these respondents, three were excluded as they self-reported having MS.

Participant characteristics

Table 1 displays the sociodemographic and clinical characteristics of the study’s groups. The greatest dissimilarity between the MS and general population groups is their female proportions, with 79.9% of the MS group being female compared to 52.4% of the general population sample. Importantly, this difference is consistent with the presentation of MS, as it disproportionately affects women at approximately a 3:1 ratio [28]. Other differences included a higher proportion of the MS group reporting adverse impacts associated with the COVID-19 pandemic (42.5% compared to 29.4%), and persons in the MS group

being more likely to have a higher socioeconomic status (34.2% versus 25.0% for the fifth socioeconomic status quintile) or a postgraduate degree (17.6% versus 10.6%).

The MS group and other chronic disease groups were considered comparable based on their similar distributions of AQoL-8D health-related quality of life scores (see kernel density estimates in Fig. 2). The chronic disease group was principally represented by persons with psychiatric (24.5%) or musculoskeletal disorders (24.2%). Respiratory (11.8%), endocrinological (11.2%), and cardiovascular (6.8%) conditions were also substantially represented.

Stratifications of Personal Wellbeing Index life domains and global life satisfaction scores by MS-related disability severity

Figure 3 displays the proportions of MS participants with low, medium, and high global life satisfaction stratified by

Table 1 Participant characteristics

Variables	Multiple Sclerosis ^a Group (n = 1683)	How Is Your Life ^b Group (n = 1172)
Age: Mean (SD)	58.6 (11.3)	52.4 (17.0)
Sex: No. (%)		
Male	339 (20.1)	486 (47.6)
Female	1344 (79.9)	535 (52.4)
Education level: No. (%)		
Secondary school or less	429 (25.5)	290 (28.4)
Occupation certificate or diploma	587 (34.9)	362 (35.4)
Bachelor's degree	360 (21.4)	259 (25.4)
Postgraduate degree	296 (17.6)	108 (10.6)
Unknown	11 (0.6)	2 (0.2)
Socioeconomic status by area: No. (%)		
Well below average (first quantile)	194 (11.5)	182 (17.8)
Below average (second quantile)	265 (15.8)	179 (17.5)
Average (third quantile)	306 (18.2)	184 (18.0)
Above average (fourth quantile)	342 (20.3)	219 (21.5)
Well above average (fifth quantile)	575 (34.2)	256 (25.0)
Unknown	1 (0.1)	1 (0.1)
COVID-19-related adversity		
Reported adversity	716 (42.5)	300 (29.4)
Did not report adversity	950 (56.5)	721 (70.6)
Unknown	17 (1.0)	0 (0.0)
Multiple Sclerosis Group Only		
Disability Severity: No. (%)		
No disability	402 (23.9)	
Mild disability	343 (20.4)	
Moderate disability	608 (36.1)	
Severe disability	317 (18.8)	
Unknown	13 (0.8)	
Phenotype: No. (%)		
Relapsing–Remitting	1066 (63.3)	
Secondary Progressive	240 (14.3)	
Progressive Onset	236 (14.0)	
Unknown	141 (8.4)	
How Is Your Life Group Only		
Reporting of Chronic Disease: No. (%)		
Reported chronic disease		602 (59.0)
Did not report chronic disease		364 (35.6)
Unknown		55 (5.4)
Types of Chronic Disease: No. (%)		
Psychiatric		250 (24.5)
Musculoskeletal		247 (24.2)
Respiratory		120 (11.8)
Oncological		28 (2.7)
Endocrinological		114 (11.2)
Cardiovascular		69 (6.8)
Gastrological		13 (1.2)
Neurological		40 (3.9)
Sensory		11 (1.1)
Other		14 (1.4)

^a Multiple sclerosis group sourced from the Australian MS Longitudinal study (AMSLs)

^b How Is your Life Group represents the general population

their MS-related disability severities of no, mild, moderate and severe. The figure shows a clear, dose–response relationship between MS-related disability and reduced life satisfaction. For example, 89.1% of MS participants with no disability reported high life satisfaction, compared to 71.4%, 54.3%, and 47.3% across the increasing levels of disability severity. This relationship is affirmed by Fig. 4, which provides mean life domain scores also stratified by MS-related disability. The relationship is most strongly demonstrated in the life domains of Personal Health, Achieving in Life, and Community Connectedness ($p < 0.01$ for all domains).

Associations between MS-related disability and Personal Wellbeing Index life domain scores in multivariable regression models

Figure 5 details the associations between MS-related disability severity and the life domains of the PWI. These associations were obtained from linear multivariable regression models. While satisfaction in all life domains was significantly and negatively associated with MS-related disability, MS-related disability was found to have the greatest impact on personal health (test for trend -10.11 , $p < 0.01$), achieving in life (trend -8.44 , $p < 0.01$), and community connectedness (test for trend -8.46 , $p < 0.01$), mirroring the results obtained through stratification. Noting that each life domain was measured on a 0 to 100 scale, severe disability was associated with 27.04-, 24.45-, and 23.78-point decreases in the above life domains, respectively ($p < 0.01$ for all associations).

Differences in the relative importance of Personal Wellbeing Index life domains for people with MS

Table 2 shows the associations between life domain satisfaction and global life satisfaction for people living with MS and the general population subgroups with and without other chronic diseases. Estimates presented in Table 2 represent the average of the marginal effects of the life domains on global life satisfaction and were therefore interpreted as demonstrating strength of association. Satisfaction in the life domains of standard of living (0.210, $p < 0.01$) and achieving in life (0.219, $p < 0.01$) was most strongly associated with global life satisfaction, for people living with MS. Also important were personal health (0.157, $p < 0.01$) and personal relationships (0.165, $p < 0.01$). Satisfaction in the other life domains (personal safety, community connectedness, and future security) was shown to be of relatively low importance in determining global life satisfaction for people living with MS.

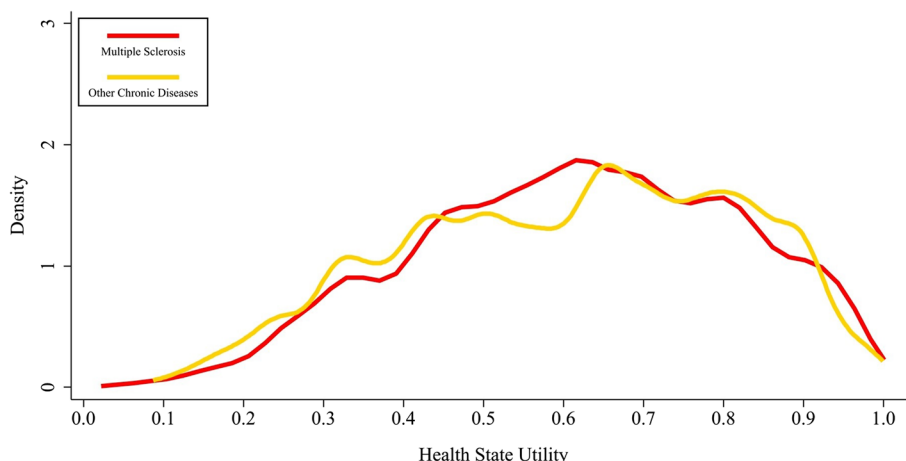


Fig. 2 Kernel density estimates to compare health state utilities between the multiple sclerosis and the chronic disease samples. Notes: Health state utilities are generated by synthesising answers to surveys through scoring algorithms. These algorithms provide survey respondents with scores on a zero (death) to one (full health) interval scale which are representative of their overall health related quality of life. The chart shows that the distribution of health state utilities in the MS and other chronic disease subgroups were similar. This indicates that the two subgroups comprised persons with similar levels of disability severity

The life domains of standard of living, personal health, achieving in life, and personal relationships ($p < 0.01$) were found to be more important for people living with MS than the general population, based on the coefficients of the interaction terms. Of these life domains, the greatest proportional difference in contribution to global life satisfaction was associated with personal health. However, the magnitude of these differences was generally small compared to the total associations between the life domains and global life satisfaction. Additionally, removing the life-domain satisfaction variables from the nonlinear model relating to people living with MS only precipitated very strong associations between MS-related disability severity and general life satisfaction (mild; -8.18 , $p < 0.01$; moderate; -15.10 , $p < 0.01$; severe; -21.03 , $p < 0.01$). In the presence of life-domain satisfaction, MS-related disability severity became insignificant (data not shown).

Discussion

Our study expanded on previous research by studying life domain-specific satisfaction for people living with MS using the PWI. This contrasts with previous studies of subjective wellbeing for people living with MS that have focused mainly on global life satisfaction measured using the Satisfaction With Life Scale [14–18, 20]. We identified that satisfaction in the life domains of achieving in life, personal health, and community connectedness was most susceptible to MS-related disability severity. We also found that satisfaction in the life domains of standard of living

and achieving in life had the strongest associations with global life satisfaction for people living with MS. Satisfaction in the life domains of personal health and personal relationships was also a substantive determinant of global life satisfaction. Satisfaction in other life domains (personal safety, community connectedness, and future security) was not strongly associated with global life satisfaction.

As explained above, satisfaction in the achieving in life and personal health life domains was strongly and negatively associated with MS-related disability. In turn, satisfaction in these life domains explained substantial variation in global life satisfaction for people living with MS. The life domains of achieving in life and personal health, therefore, represent domains upon which subjective wellbeing interventions might be exercised to improve the health and happiness of people living with MS. Such interventions would supplement other care for people living with MS.

Relative importance of PWI life domains

Overall, the strength of association (and thus relative importance) between the seven life domains and global life satisfaction did not differ greatly between our Australian MS and general population groups. However, the personal health domain was moderately more important for people living with MS. Note that the differences in the estimates of average marginal effect, relating to the MS group across the models presented in Table 2, were statistical artefacts and therefore inconsequential. Similar artefacts were present in another, multinational PWI

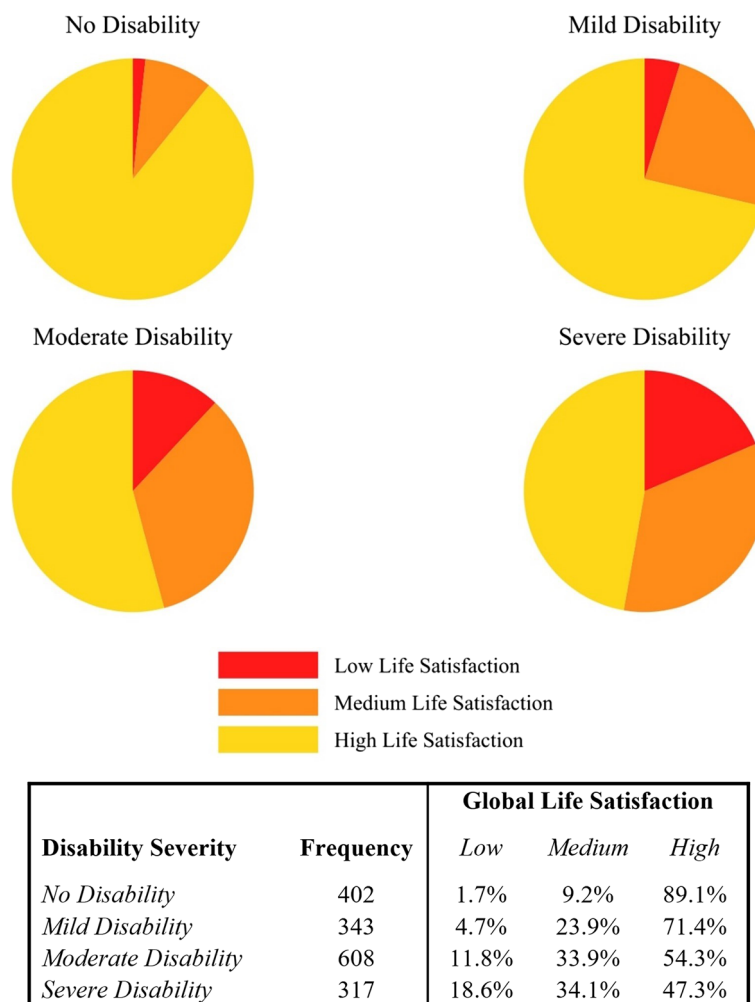


Fig. 3 Personal Wellbeing Index global life satisfaction scores stratified by disability severity for the MS subgroup. Notes: Life satisfaction was defined in the following way: Low < 4, 4 < Medium < 6, High > 6

study which conducted an analogous analysis for persons with heart disease [29].

Our result largely aligned with the findings of the aforementioned multinational PWI study, which compared people living with heart disease to the healthy public ($n = 2703$ from six countries: Australia, Canada, Germany, Norway, the UK and the USA) [29]. However, it concluded that personal health was of substantially greater importance to people living with heart disease ($0.152, p < 0.01$), and that achieving in life was significantly less important ($-0.120, p < 0.05$) [29]. The reason for these conflicting outcomes could be cultural differences between our Australian participants and the multinational study’s non-Australian participants ($n = 2289$ [84.7%]), as well as differences in the provision of health services and the life satisfaction profile of people living with heart disease.

Some of the observed heterogeneity in strength of association may have resulted from the intrinsic

characteristics of web-based cohorts, which can report lower mean health state utilities than the broader general public [30]. That the strength of association between global and life domain satisfaction differed less among the general population subgroups (data not shown), than between the MS subgroup and the general population subgroups, indicates that this may have been the case. Despite this potential for heterogeneity, we nevertheless observed no large differences in relative life domain importance between the subgroups.

MS-related disability may negatively impact satisfaction with achieving in life by affecting employment

We found that MS-related disability severity was strongly and negatively associated with satisfaction in the achieving in life domain. Cessation of employment may be an important pathway by which MS-related disability affects satisfaction with achieving in life and consequently global life

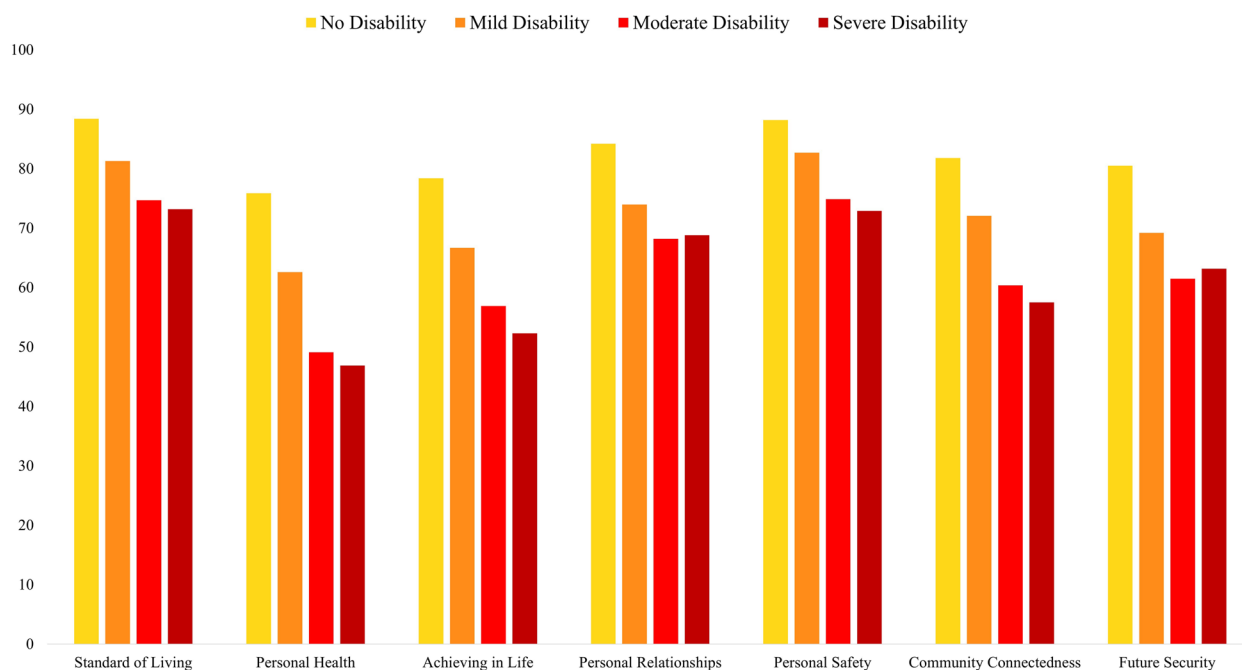


Fig. 4 Mean Personal Wellbeing Index life domain scores for the multiple sclerosis subgroup stratified by disability severity. Notes: Higher scores indicate greater satisfaction

satisfaction. This could be explained by the fact that MS is most frequently diagnosed in people between the ages of 20–40 [1, 31]. People within this age group are expected to be in the prime of building and consolidating their careers.

In support, a recent systematic review identified unemployment as a consistent contributor to reduced wellbeing for people living with MS [32], with other investigations linking MS-related disability severity to workplace redundancy [33, 34]. Another study found that 43% of people with MS who leave the workforce do so within three years of diagnosis [35]. Moreover, a large study ($n \approx 8500$) identified that only approximately 42% of people living with MS are employed at any given time [36]. This proportion of employment stands in stark contrast to an expected 90–96% employment rate prior to diagnosis [34].

Resultantly, interventions that assist people living with MS to remain in employment could substantially improve the subjective wellbeing of people living with MS. Such interventions may involve flexible methods of employment, enhanced workplace ergonomics, and sustained occupational therapy [36]. Respectively, these could take the forms of working from home arrangements, installation of mobility assisted bathroom cubicles, ramps and handrails, and government subsidisation of counselling services for working people living with MS.

MS-related disability severity may negatively impact satisfaction with personal health through perceptions of illness

As expected, MS-related disability severity was strongly associated with reduced satisfaction with personal health. Consider that MS is an incurable disease, involving unpredictable symptoms and inexorable disease progression (in a proportion of cases), which can strip an individual of their independence [2, 37]. Given the uncertainty of outcomes in MS, due to the heterogeneous nature of its clinical course, it may be that people living with MS are particularly prone to negative perceptions of illness that reduce their satisfaction with their health. Notably, negative perceptions of illness have been found to substantially impact wellbeing [38].

The literature supports the view enunciated above. For instance, 90% ($n = 18$) of the papers included in a recent systematic review concluded that there was a significant association between illness perceptions and health-related quality-of-life outcomes for people living with MS [39]. Another paper identified that illness perceptions in people living with MS were driven by illness coherence (understanding of MS) and determinism in perspectives on MS, among other factors [40]. Therefore, combatting negative perceptions of illness, perhaps by increasing or encouraging access to counselling and peer-support groups, could enhance the subjective wellbeing of people living with MS. In addition, cognitive-behavioural

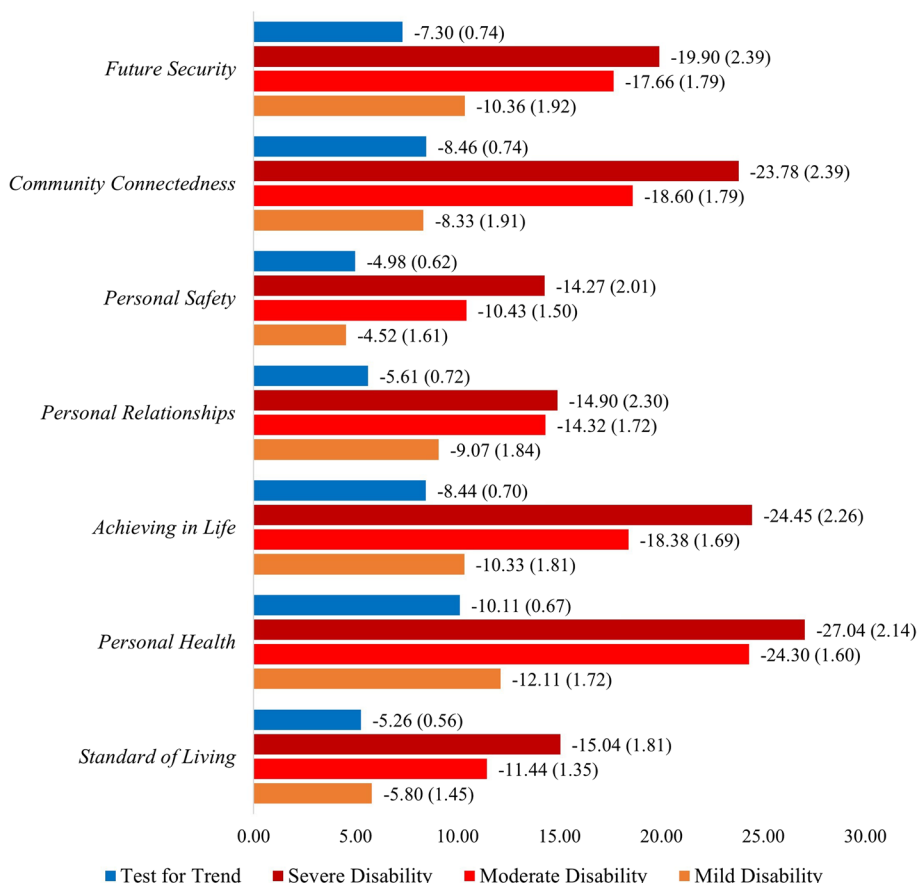


Fig. 5 Negative associations between multiple sclerosis-related disability and Personal Wellbeing Index life domains, obtained through multivariable linear regression. Notes: Data are presented as coefficient (standard deviation); no MS-related disability was the base category. A separate, linear multivariable regression model was estimated (via Ordinary Least Squares) for each life domain. Regressions controlled for age, sex, education level, and socioeconomic status (via the Index of Relative Socioeconomic Advantage and Disadvantage), multiple sclerosis phenotype, and self-reported COVID-19-related adversity. All results were significant at the 0.01 level

therapy and psycho-educational programs have previously been suggested as potential interventions [40].

Strengths and limitations

This study’s key strength was its use of the novel and validated PWI, which facilitated the examination of satisfaction in key life domains. Investigation of domain-specific life satisfaction allowed the study to explore beyond summary measures of subjective wellbeing and innovatively identify life domains that may be preferentially targeted by MS-specific subjective wellbeing interventions. The study also benefited from a large, representative sample of people living with MS from the AMSLS, which provided statistical power and internal validity. Study results may be generalisable to other comparable MS populations with similar standards of living and health systems.

An important limitation was that the disability severity of people with chronic diseases in the general population

cohort was not known. However, we showed that the distributions of health state utilities across both the chronic disease and MS groups were very similar. This implies that the two groups were comparable.

Another potential limitation was no adjustment in the MS-specific regression analyses for disease duration and level of care. As stated in the methods, disease duration was not included in this study as it is highly collinear with age. Importantly, this implies that age is an effective proxy for disease duration, with additional information regarding disease duration being captured by disability severity (this was confirmed by our co-authoring MS neurologist, BVT). Level of care, which may influence subjective wellbeing, was not included as relevant data were not available. However, a recent study indicated that satisfaction with treatment was not strongly associated with subjective wellbeing [41]. Therefore, the exclusion of this variable is not a major limitation.

Table 2 Associations between Personal Wellbeing Index life domains and global life satisfaction

All results are presented in the form: Coefficient (SD)	Multiple Sclerosis (MS)		Multiple Sclerosis versus No Chronic Disease		Multiple Sclerosis versus Other Chronic Disease	
Standard of Living	0.210	(0.018)^a	0.170	(0.014)^a	0.165	(0.013)^a
Personal Health	0.157	(0.014)^a	0.096	(0.013)^a	0.112	(0.012)^a
Achieving in Life	0.219	(0.016)^a	0.197	(0.013)^a	0.204	(0.013)^a
Personal Relationships	0.165	(0.016)^a	0.149	(0.013)^a	0.111	(0.012)^a
Personal Safety	0.038	(0.017)	0.025	(0.014)	0.041	(0.013)^a
Community Connectedness	0.072	(0.016)^a	0.047	(0.013)^a	0.069	(0.013)^a
Future Security	0.048	(0.016)^a	0.045	(0.013)^a	0.079	(0.013)^a
Interaction Terms						
MS * Standard of Living			0.052	(0.015)^a	0.062	(0.016)^a
MS * Personal Health			0.054	(0.012)^a	0.046	(0.013)^a
MS * Achieving in Life			0.045	(0.013)^a	0.047	(0.015)^a
MS * Personal Relationships			0.030	(0.014)	0.050	(0.015)^a
MS * Personal Safety			0.002	(0.014)	-0.012	(0.015)
MS * Community Connectedness			0.013	(0.013)	-0.001	(0.015)
MS * Future Security			0.002	(0.013)	-0.028	(0.015)
R^2	0.804		0.802		0.801	

All regressions were conducted using Kernel-Based Regularised Least Squares. The estimates represent the average marginal effect of the life domains on global life satisfaction. Estimates under the subtitle *interaction terms* refer to the differences in the contributions of the life domains to global life satisfaction attributable to multiple sclerosis subgroup membership, as opposed to membership in the indicated general population subgroup. Regressions controlled for age, sex, education level, and socioeconomic status (via the Index of Relative Socioeconomic Advantage and Disadvantage) and self-reported COVID-19-related adversity. Differences in estimates of average marginal effect for the MS group, across the three models, are statistical artefacts and therefore inconsequential. Bolding indicates significance at the 0.05 level

^a indicates significance at the 0.01 level

Conclusions

This study provides evidence that satisfaction with achieving in life and personal health are paramount contributors to global life satisfaction for people living with MS, and that these life domains are very susceptible to MS-related disability. Resultantly, subjective wellbeing interventions for people living with MS should focus on these life domains. This novel use of life satisfaction data in identifying targets for interventions demonstrates the utility and translatability of studies relating to subjective wellbeing. Our findings will support a patient-centred approach to health care for people living with MS with respect to their unique subjective wellbeing needs.

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12955-024-02278-3>.

Supplementary Material 1

Acknowledgements

The authors thank the participants, staff and volunteers of the Australian Multiple Sclerosis Longitudinal Study, and the participants of the How Is Your Life study.

Authors' contributions

Concept and design: GH, GC, JC, lvdM, BT; Acquisition of data: lvdM, JC, GC; Analysis and interpretation of Data: GH, JC, GC, lvdM, BT, SC; Drafting of the manuscript: GH and JC; Critical revision of the paper for important intellectual content: all authors; Statistical analysis: GH, GC, JC, lvdM, BT; Provision of study materials or patients: lvdM, GC; Obtaining funding: lvdM, BT, AP, JC; Administrative, technical, or logistic support: lvdM, GC; Supervision: lvdM, BT, SC, JC.

Funding

This study was supported by Dr Julie Campbell's MS Research Australia Research Fellowship (grant number 19-0702).

Availability of data and materials

The Australian Multiple Sclerosis Longitudinal Study data that support the findings of this study are available from MS Australia, but restrictions apply to the availability of these data, which were used under licence for the current study. However, data is available upon reasonable request from the Corresponding Author with permission from MS Australia. The How Is Your Life dataset, analysed during the current study, is available from the corresponding author on reasonable request and with permission from Monash University.

Declarations

Ethical approval and consent to participate.

Ethics Approval for the Australian Multiple Sclerosis Longitudinal Study was received from the Tasmanian Health and Medical Human Research Ethics Committee (ethics approval number H0014183). Ethics approval for the How Is Your Life Study was granted by the Monash University Human Research Ethics Committee (project ID 8442).

Consent for publication

Informed consent was obtained from all participants included in the study.

Competing interests

The authors declare no competing interests.

Received: 10 March 2024 Accepted: 29 July 2024

Published online: 30 September 2024

References

- McGinley MP, Goldschmidt CH, Rae-Grant AD. Diagnosis and treatment of multiple sclerosis: a review. *JAMA*. 2021;325(8):765–79.
- Thompson AJ, Baranzini SE, Geurts J, Hemmer B, Ciccarelli O. Multiple sclerosis. *Lancet*. 2018;391(10130):1622–36.
- Zhang Y, Taylor BV, Simpson S Jr, Blizzard L, Campbell JA, Palmer AJ, et al. Feelings of depression, pain and walking difficulties have the largest impact on the quality of life of people with multiple sclerosis, irrespective of clinical phenotype. *Mult Scler*. 2021;27(8):1262–75.
- Walton C, King R, Rechtman L, Kaye W, Leray E, Marrie RA, et al. Rising prevalence of multiple sclerosis worldwide: Insights from the Atlas of MS, third edition. *Mult Scler*. 2020;26(14):1816–21.
- Campbell J, van der Mei I, Taylor B, Palmer A. Health economic impact of MS in 2017: an interim update of prevalence, costs and costs of illness from 2017 to 2021. 2023. Commissioned Report for MS Australia. https://www.msaustralia.org.au/wp-content/uploads/2023/02/health-economic-impact-of-multiple-sclerosis-in-australia-in-2021_final.pdf.
- Diener E, Lucas RE, Oishi S. Advances and open questions in the science of subjective well-being. *Collabra Psychol*. 2018;4(1).
- Campbell JA, Jelinek GA, Weiland TJ, Nag N, Neate SL, Palmer AJ, et al. SF-6D health state utilities for lifestyle, sociodemographic and clinical characteristics of a large international cohort of people with multiple sclerosis. *Qual Life Res*. 2020;29(9):2509–27.
- Makowiecki K, Stevens N, Cullen CL, Zarghami A, Nguyen PT, Johnson L, et al. Safety of low-intensity repetitive transcranial magnetic stimulation for people living with multiple sclerosis (TAURUS): study protocol for a randomised controlled trial. *Trials*. 2022;23(1):626.
- Kobelt G, Thompson A, Berg J, Gannedahl M, Eriksson J, MSCOI Study Group, et al. New insights into the burden and costs of multiple sclerosis in Europe. *Mult Scler*. 2014;23(8):1123–36.
- Campbell JA, Hensher M, Neil A, Venn A, Otahal P, Wilkinson S, et al. An Exploratory Study: A head-to-head comparison of the EQ-5D-5L and AQL-8D for long-term publicly waitlisted bariatric surgery patients before and 3 months after bariatric surgery. *Pharmacoecon Open*. 2018;2(4):443–58.
- Ma BH, Badji S, Petrie D, Llewellyn G, Chen G. Social interventions to support people with disability: A systematic review of economic evaluation studies. *PLoS ONE*. 2023;18(1):e0278930.
- Diener E. Subjective well-being. The science of happiness and a proposal for a national index. *Am Psychol*. 2000;55(1):34–43.
- Ong AD. Pathways linking positive emotion and health in later life. *Curr Dir Psychol Sci*. 2010;19(6):358–62.
- Ryan KA, Rapport LJ, Sherman TE, Hanks RA, Lisak R, Khan O. Predictors of subjective well-being among individuals with multiple sclerosis. *Clin Neuropsychol*. 2007;21(2):239–62.
- Koltuniuk A, Pytel A, Kulik A, Rosinczuk J. The role of disease acceptance, life satisfaction, and stress perception on the quality of life among patients with multiple sclerosis: A Descriptive and Correlational Study. *Rehabil Nurs*. 2021;46(4):205–13.
- Aşiret GD, Özdemir L, Maraşlıoğlu N. Multipl Skleroz Hastalarında Umutsuzluk, Depresyon Ve Yaşam Doyumu. *Türk Nöroloji Dergisi*. 2014;20(1):1–6.
- Pakenham KL. Investigation of the coping antecedents to positive outcomes and distress in multiple sclerosis (MS). *Psychol Health*. 2006;21(5):633–49.
- Lee B. A serial mediation model of gratitude on life satisfaction in people with multiple sclerosis: the intermediary role of perceived stress and mental health symptoms. *Mult Scler Relat Disord*. 2022;58:103421.
- Nosrati R, Momeni KH, Mazdeh M, Karami J. The relationship between psychological capital and acceptance of the disease with life satisfaction in patients with multiple sclerosis. *J Health Care*. 2018;20(2):114–22.
- Delle Fave A, Bassi M, Allegri B, Cilia S, Falautano M, Goretti B, et al. Beyond disease: happiness, goals, and meanings among persons with multiple sclerosis and their caregivers. *Front Psychol*. 2017;8:2216.
- Taylor BV, Palmer A, Simpson S Jr, Lucas R, NZMSPS Group, Simmons RD, et al. Assessing possible selection bias in a national voluntary MS longitudinal study in Australia. *Mult Scler*. 2013;19(12):1627–31.
- International Wellbeing Group. Personal Wellbeing Index. 5th ed. Melbourne: Australian Centre on Quality of Life, Deakin University; 2013.
- Misajon R, Pallant J, Bliuc AM. Rasch analysis of the Personal Wellbeing Index. *Qual Life Res*. 2016;25(10):2565–9.
- Kobelt G, Berg J, Atherly D, Hadjimichael O. Costs and quality of life in multiple sclerosis: a cross-sectional study in the United States. *Neurology*. 2006;66(11):1696–702.
- Richardson J, Iezzi A, Khan MA, Maxwell A. Validity and reliability of the Assessment of Quality of Life (AQoL)-8D multi-attribute utility instrument. *Patient*. 2014;7(1):85–96.
- Ferwerda J, Hainmueller J, Hazlett CJ. Kernel-Based Regularized Least Squares in R (KRLS) and Stata (krls). *J Stat Softw*. 2017;79(3):1–26.
- Chen G, Bulamu NB, McGrane E, Richardson J. Measuring the wellbeing of cancer patients with generic and disease-specific instruments. *Cancers (Basel)*. 2023;15(4):1351.
- Orton SM, Herrera BM, Yee IM, Valdar W, Ramagopalan SV, Sadovnick AD, et al. Sex ratio of multiple sclerosis in Canada: a longitudinal study. *Lancet Neurol*. 2006;5(11):932–6.
- Gao L, Moodie M, Chen G. Measuring subjective wellbeing in patients with heart disease: relationship and comparison between health-related quality of life instruments. *Qual Life Res*. 2019;28(4):1017–28.
- Maxwell A, Ozmen M, Iezzi A, Richardson J. Deriving population norms for the AQoL-6D and AQoL-8D multi-attribute utility instruments from web-based data. *Qual Life Res*. 2016;25(12):3209–19.
- Palmer AJ, van der Mei I, Taylor BV, Clarke PM, Simpson S Jr, Ahmad H. Modelling the impact of multiple sclerosis on life expectancy, quality-adjusted life years and total lifetime costs: Evidence from Australia. *Mult Scler*. 2020;26(4):411–20.
- Gil-Gonzalez I, Martin-Rodriguez A, Conrad R, Perez-San-Gregorio MA. Quality of life in adults with multiple sclerosis: a systematic review. *BMJ Open*. 2020;10(11):e041249.
- Raggi A, Covelli V, Schiavolin S, Scaratti C, Leonardi M, Willems M. Work-related problems in multiple sclerosis: a literature review on its associates and determinants. *Disabil Rehabil*. 2016;38(10):936–44.
- Strober L. Determinants of unemployment in multiple sclerosis (MS): The role of disease, person-specific factors, and engagement in positive health-related behaviors. *Mult Scler Relat Disord*. 2020;46:102487.
- Jones N. Global MS Employment Report 2016. MS International Federation; 2016. Commissioned Report for MS International Federation. <https://www.msif.org/wp-content/uploads/2016/05/Global-MS-Employment-Report-2016.pdf>.
- Julian LJ, Vella L, Vollmer T, Hadjimichael O, Mohr DC. Employment in multiple sclerosis exiting and re-entering the work force. *J Neurol*. 2008;255(9):1354–60.
- Timkova V, Mikula P, Fedicova M, Szilasiova J, Nagyova I. Psychological well-being in people with multiple sclerosis and its association with illness perception and self-esteem. *Mult Scler Relat Disord*. 2021;54:103114.
- Petrie KJ, Jago LA, Devcich DA. The role of illness perceptions in patients with medical conditions. *Curr Opin Psychiatry*. 2007;20(2):163–7.
- Luca M, Eccles F, Perez Algorta G, Patti F. Illness perceptions and outcome in multiple sclerosis: a systematic review of the literature. *Mult Scler Relat Disord*. 2022;67:104180.
- Bassi M, Falautano M, Cilia S, Goretti B, Grobberio M, Pattini M, et al. Illness perception and well-being among persons with multiple sclerosis and their caregivers. *J Clin Psychol Med Settings*. 2016;23(1):33–52.
- Lee HA, Poon N, Dolan P, Dolan A, Darzi A, Vlaev I. Patients' subjective well-being: Determinants and its usage as a metric of healthcare service quality. *J Health Psychol*. 2024;0(0):13591053241246932.

Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.