



Engagement in volunteering activities by persons with multiple sclerosis in Switzerland

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ABSTRACT

Background: Informal and formal volunteering engagement is a proxy for social integration and may have beneficial effects for physical and mental well-being in persons with multiple sclerosis (pwMS). As literature on the topic among the pwMS is lacking, this study aimed to determine frequency and type of volunteering performed by pwMS and to identify factors associated with volunteering.

Methods: Cross-sectional, self-reported data of 615 pwMS participating in the Swiss Multiple Sclerosis Registry were analyzed using descriptive statistics to determine frequency and type of volunteering engagement. Univariable and multivariable generalized linear models with binomial distribution and log link function were used to identify factors associated with volunteering. Age, sex, employment status and gait disability were added to the multivariable model as fixed confounders. Sociodemographic, health-, work- and daily activity-related factors were included in the analysis.

Results: About one third (29.4%) of participants reported engagement in volunteering activities, most often through charities (16.02%) and cultural organizations (14.36%). In the multivariable model, participants who had a university degree were more likely to volunteer than those with lower level of education (RR = 1.48 95% CI [1.14; 1.91]). The ability to pursue daily activities (as measured by the EQ-5D subscale) was strongly associated with participation in volunteering among pwMS. Compared with pwMS who had no or only slight limitations in daily activities, those with severe problems were markedly less likely to engage in volunteering (RR = 0.41, 95% CI [0.21; 0.80]). Finally, pwMS who reported caring for and supporting their family (i.e., being a homemaker) were more likely to engage in volunteering activities than those who did not (RR = 1.52, 95% CI [1.15; 2.01]).

Conclusion: Nearly one in three pwMS engaged in diverse volunteering activities. Having a university degree, being less limited in daily activities and being a homemaker increased the probability of pursuing volunteering activities. Contingent on individual-level motivations, resources or physical abilities, pwMS who experience challenges in performing daily activities or social barriers should be made aware of barrier-free offers of socially inclusive and volunteering activities, often provided by the national MS societies and health leagues.

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1. Introduction

Employment represents a path to social integration and is associated with higher levels of well-being, quality of life and self-esteem in the general population as well as among persons with multiple sclerosis (pwMS) (Krokavcova et al., 2012; Dorstyn et al., 2019). As multiple sclerosis (MS) progresses and disability accumulates, maintaining regular jobs can become increasingly difficult for pwMS, often leading to the loss of employment (Lehmann et al., 2020; Bishop and Rumrill, 2015). Volunteering can provide a new sense of purpose and usefulness for pwMS (Van Campen and Cardol, 2009).

Volunteering is defined as any activity in which time is given freely to benefit another person, group or cause (Volunteering, 2000). The annual report on volunteering by the Swiss Society for Common Good distinguishes between formal and informal volunteering, the former reflecting unpaid activities in associations or societies, and the latter a direct third-party engagement (Lamprecht et al., 2020).

Almost half (43%) of the adult population in Switzerland pursues formal or informal volunteering activities, often alongside paid work. Such engagements include formal activities in various clubs and societies, charities, churches and informal volunteering activities outside their own household, but within family and friends circles (Lamprecht et al., 2020). Literature on frequency or type of volunteering in which pwMS in Switzerland are engaged is lacking. A recent Europe-wide meta-analysis and a subsequent publication from a longitudinal study confirmed that physical ailments and worsening health condition, such as impaired mobility and depression, are more likely to be barriers to volunteering, than chronic diseases such as heart conditions, diabetes, hypertension, or cancer (Niebuur et al., 2018; Papa et al., 2019). Therefore, it can be hypothesized that pwMS, who often face mobility difficulties and have a higher risk of depression (Feinstein et al., 2014), engage in volunteering less often than the general Swiss population. Furthermore, it remains plausible that not only physical ailments but also the severity of impairments and the degree of mobility and independence may be additional barriers to volunteering, especially for pwMS.

Socioeconomic status indicators, such as education and income, are known to promote participation in volunteering, with education considered the most robust predictor of volunteering in the general population (Son and Wilson, 2017). Available literature provides conflicting evidence on the relationship between sociodemographic factors and volunteering. While a meta-analysis of European volunteers found no differences in volunteering between men and women, there is evidence that men are more likely to volunteer formally and women are more likely to volunteer informally (Niebuur et al., 2018; Helms and McKenzie, 2014; Bundesamt für Statistik BFS, 2021). Similarly, no significant association between age and volunteering was found in Europe (Gil-Lacruz et al., 2017), while in Canada seniors were more likely to volunteer (Hall et al., 2000). Factors that promote volunteering may overlap with those that foster social integration, such as socio-economic status, or language and literacy skills (Gracia et al., 1995).

In health-related research, volunteering is often investigated and was shown to contribute to physical and mental well-being, including better self-reported health, lower mortality, and better coping with one's own disease in various populations (Casiday et al., 2008). While the benefits of volunteering in the elderly population have been studied extensively, finding that volunteering contributes to improved well-being (Griep et al., 2017; Von Bonsdorff and Rantanen, 2011; Kahana et al., 2013), there are very few studies about the potential benefits for persons with chronic diseases. Volunteering was shown to moderate the relationship between chronic diseases such as diabetes, cancer, heart diseases, or hypertension and the resulting functional limitations (Kail and Carr, 2017), as well as between chronic pain and well-being, physical activity, depression, and meaning in life (Salt et al., 2017). Engagement in volunteering was positively related to well-being among the older Swiss adults with a chronic physical disability (Fekete et al., 2020) and among

the older cancer survivors (Heo et al., 2016). Finally, peer volunteering has benefited persons with chronic pain conditions and end-stage renal disease in terms of pain management, depression and purpose in life (Arnstein et al., 2002; Hwan and Hussin, 2022). However, our search did not reveal any studies conducted in the population of pwMS or similar neurological debilitating conditions.

In this study, we aimed to examine engagement in volunteering in adult pwMS living or receiving treatment in Switzerland. More specifically, we aimed to:

- (1) Determine the frequency and type of volunteering activities in which pwMS are involved and compare them to the general population in Switzerland.
- (2) Identify factors associated with volunteering among pwMS. In particular, we aimed to explore associations of mobility, independence, and socio-demographic characteristics including education, citizenship, or living situation with volunteering.

2. Materials and methods

2.1. Study design and participants

This cross-sectional study used data from the Swiss Multiple Sclerosis Registry (SMSR), a nation-wide registry for adult persons with a confirmed MS diagnosis living or receiving treatment in Switzerland (N = 2,277; status quo: April 6th, 2020). The SMSR is a prospective longitudinal study initiated by the Swiss Multiple Sclerosis Society and conducted by the University of Zurich based on the citizen science approach (<https://www.Clinical-Trials.gov> identifier: NCT02980640). PwMS were involved in key aspects of the design of the SMSR surveys such as the selection of specific research topics and the development of the questionnaires. Further details on the SMSR design and recruitment are described elsewhere (Steinemann et al., 2018; Puhan et al., 2018). The SMSR was approved by the Ethics Committee of the Canton of Zurich (PB-2016-00894; BASEC-NR 2019-01027) and all participants signed a written informed consent. The present study focused on volunteering by pwMS and used data on work integration collected in the 18-month follow-up survey, which was first launched in the second half of 2018. Of the 651 participants who responded to the survey, 19 did not answer the question about whether they volunteer and were not included in the present analysis. The analyzed sociodemographic characteristics of the participants were asked in the SMSR baseline survey. A total of 17 persons with missing employment status or sociodemographic variables of interest were excluded from the analysis, resulting in a final sample of N = 615.

2.2. Outcome variable

Engagement in volunteering was self-reported and measured using a multiple-choice question "Are you currently engaged in volunteering activities (e.g., volunteering within an association or a society)?" with "Yes" and "No" as response options, thus enabling for a dichotomous outcome variable. If the response was positive, participants were asked to provide information about the area of volunteering activity and time spent volunteering in an open-text field. Two authors (MM and VvW) independently analyzed the free text and categorized the type of volunteering according to the classification used by the Federal Statistical Office in Switzerland (Freiwilliges Engagement in der Schweiz, 2020). Any disagreements in categorization were resolved by the two coders.

2.3. Variables of interest

The following sociodemographic characteristics were considered: age, sex (male or female), nationality (Swiss or non-Swiss), education level (having a university degree or other), marital status (married or not), having children, living situation (alone, with partner, with family,

with parents, in clinic or residential home). The health-related characteristics considered for the analysis were: self-reported disability status scale (SRDSS), a validated proxy measure for Expanded Disability Status Scale (EDSS) based on 3 multiple-choice questions on mobility and hereafter referred to as EDSS proxy (Kaufmann et al., 2020), health-related quality of life measured by the European Quality of Life 5-Dimension 5-Level version (EQ-5D-5L) and the associated visual analogue scale (EQ-5D VAS) (Herdman et al., 2011; EuroQol Group, 1990), MS type, duration of MS since the onset of symptoms, currently receiving disease-modifying therapy, self-reported fatigue, and self-reported depression. Finally, factors related to performing daily activities, such as ability to drive a car and use public transportation, as well as work-related factors (i.e., current employment status and workload (full- or part-time), caring for family members (i.e., being a homemaker), receiving a disability pension, and having had to change job in the past due to MS) were also considered. Except for the EDSS proxy and EQ-5D scales described above, all variables of interest were obtained by self-report and asked with a single multiple-choice question (e.g., “Have you changed or had to change your job in the last 1-2 years because of MS diagnosis?” with response options of “Yes” and “No”, or “Please indicate the current type of your MS.”, with response options: “Clinically isolated syndrome”, “Relapsing-remitting multiple sclerosis”, “Primary progressive multiple sclerosis”, “Secondary progressive multiple sclerosis”, and “Transition stage”).

2.4. Statistical analysis

To address the first study aim, descriptive statistics were used to compare the sociodemographic and health-related characteristics of pwMS who were volunteering at the time of the survey with those who were not. Categorical data were summarized as percentages, and continuous variables were summarized as median and interquartile ranges. The categories of the volunteering areas or institutions through which volunteering activities were conducted were analyzed descriptively only.

To address the second study aim, the abovementioned variables of interest were assessed in a generalized linear model with binomial distribution and log link function with volunteering as an outcome. Age, sex, employment status, and EDSS proxy were included as fixed confounders. Other variables were added sequentially and maintained in the model if the Akaike Information Criterion (AIC) decreased by 2 points or more. In addition to the variables listed above, a two-way interaction between age (categorized in 5 discrete groups) and having children (yes or no) was tested. The rationale for testing this a priori defined interaction was that young parents may have less time for volunteering activities. However, this interaction did not reach our pre-defined AIC threshold and was therefore not included in the final model.

Statistical analysis was performed using Stata 16 (Stata Corp., College Station TX, USA). No imputation or adjustments for multiple testing were performed.

3. Results

Data of 615 SMSR participants were included in the analysis, 74.5% of whom were female. The median age [interquartile range] was 51 years [42, 60] and the median MS duration was 11 years [5, 19]. Most of the participants (63.9%) had relapsing-remitting MS (RRMS), 21.2% had primary or secondary progressive MS, while the remainder had clinically isolated syndrome (CIS) or reported experiencing a transition between RRMS and SPMS. Overall, 181 (29.4%) participants were engaged in volunteering.

Characteristics of the study population are given in Table 1, stratified by engagement in volunteering. Age distribution was similar in the two compared groups. Of 458 women in total, 126 (27.5%) volunteered, whereas 55 out of 157 (35%) men reported volunteering. Women were slightly less represented in the group that volunteered (69.6%) than in

Table 1
Study population, stratified by engagement in volunteering engagement.

	No volunteering activities	Volunteering activities
N (%)	434 (100%)	181 (100%)
Age categories, N (%)	—	—
18-35	65 (15%)	23 (12.7%)
36-45	89 (20.5%)	36 (19.9%)
46-55	129 (29.7%)	55 (30.4%)
56-65	88 (20.3%)	44 (24.3%)
66 and older	63 (14.5%)	23 (12.7%)
Female sex, N (%)	332 (76.5%)	126 (69.6%)
Swiss Citizenship, N (%)	401 (92.4%)	174 (96.1%)
Highest education level, N (%)	—	—
Other level	225 (51.8%)	71 (39.2%)
University degree	209 (48.2%)	110 (60.8%)
Civilian status, N (%)	—	—
Not married	191 (44%)	75 (41.4%)
Married	243 (56%)	106 (58.6%)
Has children, N (%)	250 (57.6%)	114 (63%)
Living situation, N (%)	—	—
With spouse/partner	202 (46.5%)	69 (38.1%)
With family	118 (27.2%)	60 (33.1%)
Living alone	91 (21%)	40 (22.1%)
Living with parents	22 (5.1%)	12 (6.6%)
In clinic / residential home	1 (0.2%)	0 (0%)
MS type, N (%)	—	—
RRMS ¹	272 (62.7%)	121 (66.9%)
PPMS ²	54 (12.4%)	17 (9.4%)
SPMS ³	86 (19.8%)	36 (19.9%)
CIS ⁴ / Transition stage	22 (5.1%)	7 (3.9%)
EDSS⁵ proxy	—	—
0-3.5	292 (67.3%)	131 (72.4%)
4-6.5	109 (25.1%)	43 (23.8%)
≥7	33 (7.6%)	7 (3.9%)
Currently receiving DMT⁶, N (%)	290 (66.8%)	120 (66.3%)
Experiencing fatigue, N (%)	292 (67.3%)	120 (66.3%)
Experiencing depression, N (%)	69 (15.9%)	20 (11%)
Ability to drive a car, N (%)	—	—
Yes, standard vehicle	292 (68.5%)	136 (75.1%)
Yes, modified vehicle	24 (5.6%)	13 (7.2%)
No	75 (17.6%)	26 (14.4%)
No driver's license	35 (8.2%)	6 (3.3%)
Able to use public transport, N (%)	357 (84.2%)	167 (92.3%)
Employment status (paid work), N (%)	—	—
Not working	136 (31.3%)	63 (34.8%)
Part-time	154 (35.5%)	64 (35.4%)
Full-time	77 (17.7%)	32 (17.7%)
Retirement age	67 (15.4%)	22 (12.2%)
Caring for family members, N (%)	214 (50.1%)	108 (59.7%)
Disability insurance benefits, N (%)	—	—
No benefits	267 (61.5%)	122 (67.4%)
Partial benefits	68 (15.7%)	21 (11.6%)
Full benefits	99 (22.8%)	38 (21%)
Had to change work previously because of MS, N (%)	82 (18.9%)	27 (14.9%)
Health-related quality of life index⁷, median [IQR]	80 [54; 90]	80 [65; 90]
EQ-5D-subscale: problems pursuing in daily activities, N (%)	—	—
No or slight problems	263 (60.6%)	132 (72.9%)
Moderate problems	114 (26.3%)	40 (22.1%)
Severe or very severe problems	57 (13.1%)	9 (5%)
EQ-5D-subscale: selfcare (washing or dressing), N (%)	—	—
No or slight problems	372 (85.7%)	170 (93.9%)
Moderate problems	39 (9%)	6 (3.3%)
Severe or very severe problems	23 (5.3%)	5 (2.8%)
Median [IQR] years since MS onset	11 [5, 19]	12 [5, 20]

¹ = Relapsing remitting MS ² = Primary progressive MS ³ = Secondary progressive MS ⁴ = Clinically isolated syndrome ⁵ = Expanded disability status scale ⁶ = Disease modifying therapy ⁷ = As measured with EQ-5D visual analog scale

the group that did not volunteer (76.5%). Participants who volunteered had a university degree more often than pwMS who did not volunteer (60.8% vs. 48.2%). Almost one third (30.26%) of the Swiss nationals and 7 out of 40 (17.5%) non-Swiss study participants reported volunteering. While volunteers and those who did not volunteer had equal health-related quality of life as measured by EQ-5D, the EQ-5D daily activities subscale differed: 72.9% of the group that volunteered reported no or only slight problems, compared with 60.6% among those who did not engage in volunteering. Furthermore, severe gait disability (as measured by the EDSS proxy ≥ 7) was observed more frequently in the group that reported no volunteering engagement (3.9% vs. 7.6%).

As shown in Fig. 1, most of the volunteering engagement in pwMS was in the field of social work and within different associations, notably in the field of culture. However, a large diversity in volunteering activities was observed. Additionally, 36 (19.9%) participants who volunteered did not indicate the type of activities in which they were engaged, or the associations in which they volunteered do not fall into any of the categories defined. This was the case with, for example, fan clubs or dog sports clubs. Finally, 20 (11.0%) volunteers participated in MS support group activities.

Table 2 illustrates point estimates [95% confidence intervals] from univariable (left column) and multivariable (right column) log binomial regression models. None of the four fixed confounding variables (age, sex, current employment status and workload, EDSS proxy) in the multivariable model were statistically significantly associated with volunteering. Participants who had a university degree were more likely to volunteer than those who had a lower education level (RR=1.48; 95% CI [1.14; 1.91]). The ability to pursue daily activities (as measured by the EQ-5D subscale) was strongly associated with volunteering among pwMS. Compared with pwMS who had no or only slight impairments in daily activities, those with moderate (RR=0.72, 95% CI [0.52; 1.00]) or severe problems (RR=0.41, 95% CI [0.21; 0.80]) were less likely to engage in volunteering. Furthermore, pwMS who reported caring for their family (i.e., being a homemaker) were also more likely to engage in

volunteering activities (RR = 1.52, 95% CI [1.15; 2.01]). No other variable reached our pre-defined AIC criterion for inclusion in the multivariable model.

4. Discussion

This cross-sectional registry study investigated the frequency and type of volunteering among 615 pwMS in Switzerland, focusing on sociodemographic-, health-, work- and daily activity-related factors associated with volunteering. Our study showed that almost one third of the pwMS volunteered, despite possible physical and cognitive difficulties due to MS. However, the observed frequency of volunteering among the pwMS is lower in comparison to the general population in Switzerland, where almost every second person volunteers (). It could be speculated that this discrepancy is due to the physical constraints in pwMS, as it was previously described that functional limitations and physical ailments are negatively associated with volunteering (Niebuur et al., 2018).

Volunteering was most commonly pursued within cultural and charitable organizations. This was not surprising, given the vast number of volunteering organizations associated with charitable causes. Volunteering in sports associations, which is by far the most popular volunteering activity among Swiss men (; Bundesamt für Statistik BFS, 2021), tends to be less popular among Swiss pwMS, which is most probably explicable by the physical constraints in pwMS. Volunteering in the MS-related activities was frequently mentioned by study participants, indicating a strong and supportive local MS community fostered by the Swiss MS Society, as well as the existence of forms of volunteering activities specifically tailored to pwMS.

While sex was not significantly associated with volunteering in our study, women were slightly less often represented among the volunteers. In contrast to the general population in Switzerland, where 41.4% of men and 44.0% of women volunteer, the percentage of male study participants who volunteered (35.0%) was somewhat higher compared

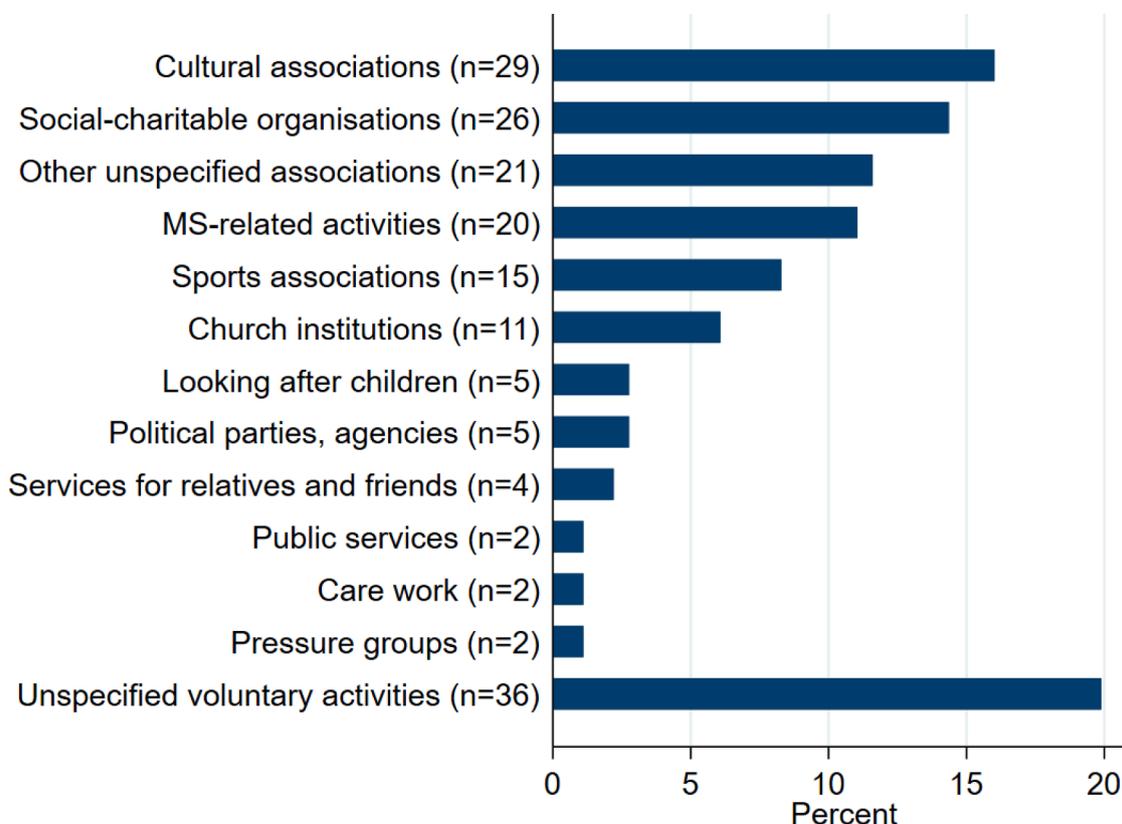


Fig. 1. Distribution of different volunteering activities among all persons engaged in volunteering (N =181). Multiple categories per person were possible.

Table 2

Log binomial model with volunteering (“Yes” or “No”) as outcome variable. Risk ratios [95% confidence intervals] not including the null value of 1 are printed in boldface. The abbreviation “n.d.” denotes variables that were not included in the multivariable analysis based on our pre-defined AIC criterion.

	Univariable risk ratio [95% confidence interval]	Multivariable risk ratio [95% confidence interval]
Age categories	—	—
18-35	Refs.	Refs.
36-45	1.10 [0.71; 1.72]	1.09 [0.70; 1.69]
46-55	1.14 [0.76; 1.73]	1.12 [0.73; 1.71]
56-65	1.28 [0.83; 1.95]	1.36 [0.86; 2.15]
66 and older	1.02 [0.62; 1.68]	1.12 [0.65; 1.95]
Female sex (vs. male sex)	0.79 [0.61; 1.02]	0.76 [0.58; 1.01]
Swiss Citizenship (vs. other citizenship)	1.73 [0.87; 3.43]	n.d.
Having a university degree (vs. other education level)	1.44 [1.12; 1.85]	1.48 [1.14; 1.91]
Married (vs. not married)	1.08 [0.84; 1.38]	n.d.
Has children (vs. no children)	1.17 [0.91; 1.51]	n.d.
Living situation	—	—
With spouse/partner	Ref.	n.d.
With family	1.32 [0.99; 1.77]	n.d.
Living alone	1.20 [0.86; 1.67]	n.d.
Living with parents	1.35 [0.82; 2.22]	n.d.
MS type	—	—
RRMS ¹	Refs.	n.d.
PPMS ²	0.78 [0.50; 1.21]	n.d.
SPMS ³	0.96 [0.70; 1.31]	n.d.
CIS ⁴ / Transitional form	0.78 [0.40; 1.52]	n.d.
EDSS⁵ proxy	—	—
0-3.5	Refs.	Refs.
4-6.5	0.91 [0.68; 1.22]	1.06 [0.76; 1.47]
≥7	0.57 [0.28; 1.12]	0.83 [0.41; 1.69]
Currently receiving DMT⁶ (vs. not)	0.98 [0.76; 1.27]	n.d.
Experiencing fatigue (vs. not)	0.97 [0.75; 1.26]	n.d.
Experiencing depression (vs. not)	0.73 [0.49; 1.10]	n.d.
Ability to drive a car	—	—
Yes, standard vehicle	Refs.	n.d.
Yes, modified vehicle	1.11 [0.70; 1.75]	n.d.
No	0.81 [0.57; 1.16]	n.d.
No driver's license	0.46 [0.22; 0.98]	n.d.
Able to use public transport	1.81 [1.11; 2.96]	n.d.
Employment status	—	—
Not working / retired	Refs.	Refs.
Part-time	0.99 [0.76; 1.31]	0.92 [0.66; 1.27]
Full-time	0.99 [0.71; 1.40]	0.91 [0.59; 1.41]
Caring for family members (vs. not)	1.35 [1.05; 1.73]	1.52 [1.15; 2.01]
Disability insurance benefits	—	—
No benefits	Refs.	n.d.
Partial benefits	0.75 [0.50; 1.12]	n.d.
Full benefits	0.88 [0.65; 1.20]	n.d.
Had to change work previously because of MS	0.81 [0.57; 1.16]	n.d.
Health-related quality of life index⁷	1.04 [0.98; 1.11]	n.d.
EQ-5D subscale: daily activities	—	—
No or slight problems	Refs.	Refs.
Moderate problems	0.78 [0.58; 1.05]	0.72 [0.52; 1.00]
Severe or very severe problems	0.41 [0.22; 0.76]	0.41 [0.21; 0.80]
EQ-5D subscale: selfcare (washing or dressing)	—	—
No or slight problems	Refs.	n.d.
Moderate problems	0.43 [0.20; 0.90]	n.d.
Severe or very severe problems	0.57 [0.25; 1.27]	n.d.

¹ = Relapsing remitting MS ² = Primary progressive MS ³ = Secondary progressive MS ⁴ = Clinically isolated syndrome ⁵ = Expanded disability status scale ⁶ = Disease modifying therapy ⁷ = As measured with EQ-5D visual analog scale

to the percentage of women who volunteered (27.5%) (). However, existing literature on the relationship between sex and volunteering in the general population is conflicting. Krause and Rainville (2018) found no differences in secular volunteering involvement, and similar findings emerged from a meta-analysis of longitudinal studies in the European population (Niebuur et al., 2018). Contrary to this, in neighboring Germany men were found more likely to engage in volunteering coordinated by an organization, i.e., formal volunteering, while women volunteered informally more often, providing direct help to the individuals (Helms and McKenzie, 2014). Similar finding is observed in the Swiss general population, when distinction is made between formal and informal volunteering engagement (). The difference in the proportion of volunteers between the two sexes in our study and in the Swiss general population could be due to the fact that our analysis of the frequency of volunteering did not distinguish between informal and formal volunteering, and women may not have recognized their informal volunteering engagements as volunteering.

The frequency with which various age categories were represented among volunteers did not allow us to discern any particular pattern, nor was age associated with the likelihood of volunteering. This is contrary to the Swiss general population, where a steady increase in volunteering engagement is observed with increasing age, until late life (75 years of age and over) (Griep et al., 2017). However, such a trend would hardly be expected among the pwMS, considering that disability-related limitations accumulate over time.

Education is considered one of the most robust factors associated with volunteering. In the resource theory, education is seen as a human capital that enables volunteering resources, such as skills, time, or financial means, while also allowing for a stronger social network through which individuals are more likely to engage in volunteerism (Son and Wilson, 2017, 2012; Wilson and Musick, 1997). In line with these findings, the study participants who had a university degree were significantly more likely to volunteer than those who did not, reflecting similar trends in the Swiss population ().

It is well known that immigrants are less likely to volunteer (Hall et al., 2000; Cappelletti and Valtolina, 2015), due to language and cultural barriers, as well as discrimination (Cappelletti and Valtolina, 2015). According to national statistics, 23.3% of foreigners living in Switzerland volunteer, compared to 48.7% of the Swiss nationals (Bundesamt für Statistik BFS, 2021). Therefore, we would have expected the possession of Swiss citizenship to be positively associated with volunteering. Indeed, only 17.5% of non-Swiss study participants reported volunteering, while nearly one third (30.26%) of the Swiss nationals volunteered. However, the citizenship variable did not meet our AIC-based criteria for inclusion in the multivariable model. On the other hand, volunteering can also be seen as a means of faster social and cultural integration into the new country (Handy and Greenspan, 2009). Interestingly, although education was significantly associated with volunteering and differences in frequency of volunteering were observed between groups with and without Swiss citizenship, full- or part-time employment, which is often influenced by education and citizenship (Raggi et al., 2016; Laganà, 2011), was not significantly associated with volunteering in our study.

In their meta-analysis of longitudinal cohort studies in the general population, Niebuur et al. (2018) found a negative relationship between functional limitations and volunteering. In addition, they found that socioeconomic status determined participation in volunteering. In our study, worse EDSS proxy, five different EQ-5D subdomain questions, limitations in the use of public transport, and the lack of ability to drive a car were considered proxies for functional limitations. However, of all these variables, only the question on the EQ-5D subdomain “Problems in pursuing daily activities” met the AIC criterion for multivariable model

inclusion (in addition to the EDSS proxy, which was a fixed confounder).

Persons who reported care for their family were more likely to pursue volunteering. The interpretation of this finding is complex and may touch upon at least three dimensions: first, pursuing housekeeping tasks imply the physical abilities to do so. Second, it may be a proxy for reduced or no formal, paid work and thus potentially more time for volunteering engagements. Third, it may reflect social or altruistic attitudes and values that make persons more amenable to other altruistic engagements, such as volunteering. Of note, our multivariable analysis includes variables that control for the first two proposed effects, namely EDSS proxy, as a measure of gait disability, the EQ-5D activity sub-domain and employment status, thus leveraging credence for the third hypothetical explanation.

Finally, several variables in the multivariable model were only nominally associated with volunteering in an expected way. For example, full-time employment or worse EDSS proxy were negatively, but statistically insignificantly associated with volunteering. However, since part-time employment was reported much more frequently than full-time employment, lack of free time to pursue volunteering due to full-time employment may have presented less of a barrier to volunteering in the surveyed group of pwMS.

4.1. Practical and research implications

Our findings suggest that nearly one in three pwMS engage in diverse types of formal and informal volunteering. The lack of clear association between volunteering activities and physical impairment or health-related quality of life was somewhat surprising. A previous SMSR study found that the employment and job retention were strongly associated with MS-related symptoms and impairments (Lehmann et al., 2020). The absence of analogous findings in our study may be explained by the fact that many pwMS were involved in MS-related activities or peer support, which are actively supported and promoted by the Swiss MS Society.

Studies in persons with other chronic diseases, such as diabetes, heart conditions, cancer or chronic pain and chronic disability, report a beneficial effect on general well-being and quality of life in persons who volunteer (Kail and Carr, 2017; Salt et al., 2017; Heo et al., 2016; Arnstein et al., 2002; Hwan and Hussin, 2022). Although some of these studies describe improvement in symptoms such as pain after volunteering, it remains largely unclear whether volunteers are able to engage in these activities because they are in good health, or whether volunteering truly leads to improvements in well-being. While we were unable to investigate such potential, beneficial effects in our study, it is plausible that they exist in pwMS as well. Therefore, providing opportunities and support for volunteering engagements by pwMS may not only lead to a contribution to society and further social integration, but can also improve the personal well-being of pwMS.

At the same time, imposing implicit or explicit pressure on pwMS to volunteer must be avoided. Individuals with a high symptom burden or impaired ability to pursue daily activities may lack the physical or mental resources to engage in volunteering activities. Also, volunteering should not be seen as a substitute for paid work, and increased efforts to retain pwMS in the primary labor market remain critical to improving the social integration and financial stability of persons with MS. A previous analysis of the same study population emphasized the importance of adequate job resources (e.g., autonomy or social support) and well-adjusted management of job demands (e.g., time pressures) as critical factors for job retention (Lehmann et al., 2020).

In terms of opportunities to engage in volunteering activities, regional support groups, organized and offered by MS societies, can play an important role. Furthermore, many pwMS try to maintain their social and cultural activities after the diagnosis. Therefore, societies, clubs, or charitable and non-profit organizations also play an important role in the integration of pwMS and should be supported by the private sector and by political decision makers.

4.2. Study limitations

This study has several limitations. All information is based on self-reported data, which may be prone to reporting biases such as under-reporting or social desirability. Furthermore, since the survey did not use a strict definition of volunteering, participants were free to decide for themselves what they understood by volunteering. On the other hand, this openness may have provided a better overview of the types of volunteering engagements. Follow-up studies, possibly also qualitative, could build on these findings and further explore, for example, the barriers and facilitators as well as the benefits of volunteering engagements. Due to the cross-sectional design of our study, no conclusions could be drawn on the causal relationships between volunteering and variables of interest.

5. Conclusion

Nearly one in three pwMS engaged in diverse volunteering activities, many of which promote social integration. The factors associated with volunteering among pwMS were similar to those in the general population. Having a university degree, being able to pursue daily activities and being a homemaker were positively associated with pursuing volunteering activities. Contingent on individual motivation, resources and physical abilities, persons with more severe impairments, and reduced mobility (both in terms of gait problems and impaired ability to use private and public transport) may benefit from additional information and support efforts to advertise and enhance accessibility to volunteering.

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CRediT authorship contribution statement

Mathias Mettler: Conceptualization, Methodology, Investigation, Formal analysis, Writing – original draft, Writing – review & editing. **Mina Stanikić:** Conceptualization, Methodology, Investigation, Writing – original draft, Writing – review & editing. **Urban Schwegler:** Writing – review & editing, Investigation. **Chloé Sieber:** Writing – review & editing, Investigation. **Vladeta Ajdacic-Gross:** Writing – review & editing, Investigation. **Stephanie Rodgers:** Writing – review & editing, Investigation. **Christina Haag:** Writing – review & editing, Investigation. **Chiara Zecca:** Writing – review & editing, Investigation. **Pasquale Calabrese:** Writing – review & editing, Investigation. **Susanne Kägi:** Writing – review & editing, Investigation. **Irene Rapold:** Writing – review & editing, Investigation. **Viktor von Wyl:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – original draft, Writing – review & editing, Supervision.

Declaration of Competing Interest

Mina Stanikić reports employment by Roche branch in Serbia, Roche d.o.o., from February 2019 to February 2020. The employer of Chiara Zecca receives support for advisor activities, speaking or grants from Celgene, Genzyme, Lilly, Merck, Novartis, Roche, and grants from Abbvie, Almirall, Biogen Idec, Celgene, Genzyme, Lilly, Merck, Novartis, Roche, Teva Pharma. Pasquale Calabrese has received honoraria for speaking at scientific meetings, serving at scientific advisory boards and consulting activities from Abbvie, Actelion, Almirall, Bayer-Schering, Biogen, EISAI, Lundbeck, Merck Serono, Novartis, Sanofi-Aventis and Teva. He also receives research grants from the Swiss Multiple Sclerosis Society (SMSG), and the Swiss National Research Foundation. Mathias Mettler, Urban Schwegler, Chloé Sieber, Vladeta Ajdacic-Gross,

Stephanie Rodgers, Christina Haag, Susanne Kägi, Irene Rapold and Viktor von Wyl declare no competing interests.

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