Neurological Sciences (2019) 40:1137–1144
https://doi.org/10.1007/s10072-019-03780-z

ORIGINAL ARTICLE

# Disparity between perceived needs and service provision: a cross-sectional study of Italians with multiple sclerosis

Michela Ponzio[1] · Andrea Tacchino[1] · Concetta Vaccaro[2] · Giampaolo Brichetto[1,3] · Mario Alberto Battaglia[4] · Michele Messmer Uccelli[1]

Received: 29 November 2018 / Accepted: 18 February 2019 / Published online: 27 February 2019


## Abstract

**Background** Assessing the coverage by public or private resources in meeting health-related and social-related needs may be useful for service planning and guide optimization of care, important especially in view of an increase in the prevalence of multiple sclerosis (MS).

**Methods** An ad hoc questionnaire assessed satisfaction of health-related and social care–related needs in a cross-sectional study of 1014 people with MS identified through MS outpatient clinics and local branches and social media channels of the Italian MS Society.

**Results** 87.1% and 79.8% of the responders had experienced at least one health-related or social-related need, respectively. The study demonstrated significant gaps between perceived needs and service provision. Rehabilitation, residential care, and psychological support were most frequently unsatisfied health-related needs, while the more commonly unmet social-related needs were financial support, elimination of architectural barriers, workplace adaptations, and career guidance. The multivariate analysis highlighted that the satisfaction of health-related needs was primarily associated with geographic area of residence. Social-related needs correlated with both clinical and sociodemographic aspects.

**Conclusion** The results provide insight into the range of interventions, care, and support people with MS report to be important to them at different points in their disease trajectory. More emphasis should be put on the inequitable distribution of NHS services in different geographic areas of Italy as well as on particularly fragile subgroups of the MS population (older individuals, and those with higher levels of disability) because the care of these individuals continues to be assumed by the family.

**Keywords** Multiple sclerosis · Perceived needs · Italy

## Background

Multiple sclerosis (MS) is a chronic neurological disease that is highly variable and unpredictable in terms of symptoms and disability progression [1]. Currently, MS affects around 2.3 million people, with as many as 600,000 in Europe [2] and more than 109,000 in Italy (or approximately 1 individual in every 550) [3]. MS usually presents between 20 and 40 years of age and women are more than twice as likely to develop the disease than men [4]. Motor, sensory, and cognitive impairments dramatically impact the family, social, and work lives of individuals with MS [5]. In this context, pharmacological and non-pharmacological treatments attempt to prevent disease progression and manage illness-related complications [6]. In general, the economic effects of MS are mainly due to the cost of medications and personal assistance, often paid as out-of-pocket expenses, hospitalization, and productivity loss [7]. One study in MS suggested that, in order to be effective and better guide service development and resource allocation, health and social services must be based on the needs of patients and their families [8]. It has been further suggested that an examination of needs of individuals from their own perspective is useful in service planning, disease management, and care optimization in MS [9–13]. However, these needs are largely under-considered by the National Health Service

✉ Michela Ponzio
michela.ponzio@aism.it

[1] Scientific Research Area, Italian Multiple Sclerosis Foundation (FISM), via Operai 40, 16149 Genoa, Italy

[2] Fondazione CENSIS, Rome, Italy

[3] AISM Rehabilitation Service, Italian Multiple Sclerosis Society, Genoa, Italy

[4] Department of Life Science, University of Siena, Siena, Italy

in Italy, but are relevant considering the high prevalence of the disease in this country [3].

Therefore, the objectives of the present study were to understand the extent to which the national healthcare system and private-pay resources satisfy the health-related and social-related needs of people with MS in Italy and to assess whether disease, demographic, or other factors correlate with some needs going unmet.

## Methods

### Sample

A cross-sectional study was carried out in Italy during 2017. Participants were identified through MS outpatient clinics and through local branches of the Italian MS Society. Potential subjects were invited to participate in the study through information on the MS Society website, membership contact lists of the local branches of the MS Society, and direct recruitment at MS outpatient clinics. Subjects were randomly invited to participate from local branch contact lists. Subjects were consecutively recruited at MS clinics. Specifically, an MS Society volunteer, stationed at the MS clinic, informed individuals of the study and acquired consent to be contacted later for a telephone interview. Inclusion criterion was a diagnosis of MS [14]. Data were collected using an identical questionnaire either in paper format completed during an in-person interview or through a telephone interview.

### Materials

An ad hoc questionnaire was developed for the study based on 12 health- and social-related needs previously reported to be relevant for people with MS in Italy [15]. Health-related needs included rehabilitation, psychological support, technical aids, medications, and residential care. Social-related needs included financial support, personal assistance, transportation, elimination of architectural barriers, managing bureaucracy, workplace adaptations, and career guidance. Questions covered sociodemographic (gender, age, education, occupational status, marital status, geographic area of residence) and clinical information (disease duration, disability level). Subjects' level of disability was collected with the self-Expanded Disability Status Scale (EDSS) dichotomized using a cutoff score of 6 (EDSS $< 6$, "low" disability; EDSS $\geq 6$, "high" disability) [16]. The cutoff was chosen because it represents an important functional milestone of clinical disability, signifying the transition from walking independently to requiring unilateral assistance [17].

Subjects were asked to consider the past year and report their perceived needs accordingly. If a need was indicated, subjects were asked to specify if it was unmet or met, and if met, whether by the national healthcare system or by out-of-pocket private services.

### Data analysis

Sociodemographic and clinical information, perceived health- and social-related needs, and need satisfaction are reported using descriptive statistics. Spearman's rank correlation coefficients ($\rho$) were used to examine the relation between health-related and social-related needs with disability level. Logistic regression models were used to determine the association between potential predictors and need satisfaction. Separate regression models were fitted for both health-related and social-related needs. The dependent variable was categorized as 0/1 (unmet/met). Potential predictors included gender (categories: male, female), age, educational level (categories: primary school, high school, university degree), occupational status (categories: unemployed, currently employed), marital status (categories: other, married), geographic area of residence (categories: northern, central, southern Italy), and disease duration in years and level of disability (categories: low, high). The predictors were simultaneously entered in the model. The results are presented as odds ratios (ORs) and 95% confidence intervals. Analyses were performed using Stata Statistical Software, release 15 [18].

## Results

### Sociodemographic and clinical characteristics

The number of subjects who consented to be contacted to participate in the study was 1351. Of these, 337 individuals were subsequently unavailable to proceed with the telephone interview. The total number of study participants was 1014 (75%), of which, 955 responded to the telephone interview. Fifty-nine paper versions of the questionnaire were completed by ad hoc trained volunteers in the home of the subject, due to advanced disability in the majority of cases, requiring a home visit and assistance with completing the questionnaire (86% with EDSS $>= 7$). Study participants' mean age was 49.8 (SD12.8) years (range, 18–85 years), 69.4% of the sample was female, 69.0% had at least a high school–level education, 55.0% of participants were married, and 37.4% were employed. Of the 62.5% who were unemployed, 49.4% were below the standard age of retirement. The distribution of the geographic area of residence was 42.7% northern Italy, 23.9% central Italy, and 33.4% southern Italy. Mean disease duration was 15.3 (SD 10.2) years (range, 0–52 years) and 46.1% of subjects had an EDSS score of $> 6$ (high disability).

### Perceived needs

87.1% and 79.8% of responders had experienced at least one health-related and social-related need, respectively, over the year preceding the study. A significant correlation was found between the level of disability and the number of health-related ($\rho = 0.43$, $P < 0.0001$) and social-related needs ($\rho = 0.60$, $P < 0.0001$). Among health-related needs, rehabilitation was most often reported ($n = 822$, 81.1%), followed by psychological support ($n = 381$, 37.6%), technical aids ($n = 219$, 21.6%), medications ($n = 185$, 18.2%), and residential care ($n = 55$, 5.4%). Among social-related needs, transportation was most often reported ($n = 525$, 51.8%), followed by personal assistance (492, 48.5%), elimination of architectural barriers ($n = 433$, 42.7%), financial support ($n = 360$, 35.5%), managing bureaucracy ($n = 285$, 28.1%), career guidance ($n = 119$, 11.7%), and workplace adaptation ($n = 79$, 7.8%).

### Satisfaction of needs

Among those who reported rehabilitation as a need, 275/822 subjects (33.5%) felt that it was satisfied (NHS, 38.5%; private, 61.5%). Of subjects reporting a need for psychological support, 251/381 (65.9%) felt that their need was satisfied (NHS, 71.3%; private, 28.7%). Eighty-four percent of subjects ($n = 184/219$) felt that the need for technical aids was resolved (NHS, 73.9%; private, 26.1%). Medication needs were satisfied in 72.4% of subjects ($n = 134/185$) (NHS, 77.6%; private, 22.4%) and in 60% reporting a need for residential care ($n = 33/55$) (NHS, 66.7%; private, 33.3%).

Among those who perceived transportation as a need, 248/525 subjects (47.2%) reported the need satisfied (NHS, 54.8%; private, 45.2%). For those needing personal assistance, 289/492 subjects (58.7%) reported that the need was resolved (NHS, 26.3%; private, 73.7%). Of subjects who reported the need for the elimination of architectural barriers, 74/433 (17.1%) were satisfied (NHS, 35.1%; private, 64.9%). Financial support needs were resolved through the NHS for 39 of 360 subjects (10.8%). A need related to help with managing bureaucracy was satisfied in 150 of 285 subjects (52.6%) (NHS, 78.7%; private, 21.3%). Needs related to career guidance and workplace adaptation were satisfied in 43 of 119 (36.1%) (NHS, 88.4%; private, 11.6%) and 21 of 79 subjects (26.6%) (NHS, 61.9%; private, 38.1%), respectively.

Figures 1 and 2 show whether or not a need was perceived to have been met and provide the source of need satisfaction related to satisfied needs.

### Correlations between the satisfaction of needs and other factors

The satisfaction of a perceived need for rehabilitation was more likely in subjects with the highest level of education (university degree vs. primary school) (OR = 1.73, $P = 0.015$). The geographic area of residence negatively influenced the satisfaction of needs related to psychological support (OR = 0.45, $P = 0.004$), technical aids (OR = 0.15, $P < 0.001$), and medications (OR = 0.41, $P = 0.050$) for subjects living in southern Italy and for psychological support for subjects living in central Italy (OR = 0.55, $P = 0.043$) (Table 1). Satisfying a need for technical aids was less probable for subjects currently employed vs. unemployed (OR = 0.24, $P = 0.017$). Transportation needs were less likely to be satisfied in subjects who were married (OR = 0.43, $P < 0.001$). Satisfaction of a need for financial support was more frequent for subjects with a higher level of disability (OR = 2.56, $P = 0.031$). The need for personal assistance was more likely to be satisfied in older subjects and those with a longer disease duration (OR = 1.02, $P = 0.041$ and OR = 1.02, $P = 0.028$, respectively). Career guidance was more frequently a met need for subjects who were currently employed (OR = 3.34, $P = 0.013$). Workplace adaptation was significantly less likely to be satisfied for subjects living in central vs. northern Italy (OR = 0.15, $P = 0.018$) (Table 2).

## Discussion

The objectives of the present study were to understand the extent to which the national healthcare system and private-pay resources satisfy the health-related and social-related needs of people with MS in Italy and to assess whether disease, demographic, or other factors correlate with some needs going unmet. This study included a large sample of subjects geographically varied and sampled from across the disease trajectory through different sources. Consistent with the complexity and progression of the disease, subjects experienced several health-related and social-related needs concurrently. As expected, a higher level of disability resulted in an increase in needs. The unmet needs identified in this study were similar to those reported in previous studies [19–21].

The present study demonstrates significant gaps between perceived needs and service provision, for both health-related and social-related needs. Although it has been recognized for decades that rehabilitation is beneficial for individuals with MS, it continues to be a highly unmet need in Italy [22–24]. In the present study, subjects with a higher level of education were more likely to report a rehabilitation need as being satisfied. If level of education can be considered a proxy of socioeconomic status, it could in part explain this correlation, since over 25% of more highly educated subjects paid for rehabilitation out-of-pocket [25]. Comprehensive rehabilitation is not widely available in Italy, particularly through the NHS. Based on anecdotal information, Italians with MS are fortunate enough to live near MS Society rehabilitation centers located exclusively in northern Italy, access non-MS

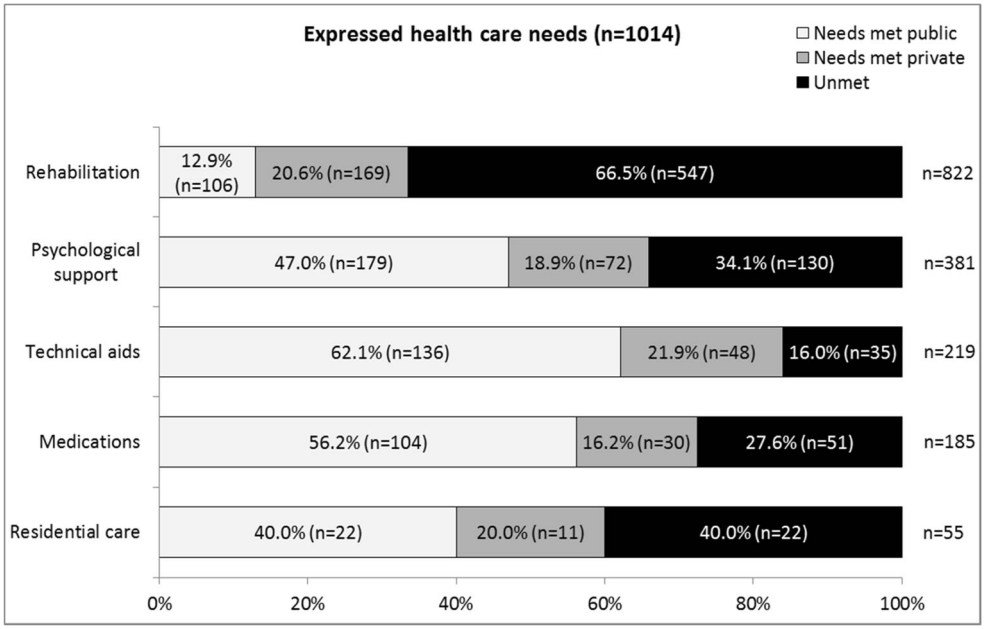


**Fig. 1** Satisfaction of health-related needs. The bar chart describes the proportion of subjects who reported health-related needs and the proportion who did and did not have their needs met; the numbers next to the graph bars represent the number of subjects that have reported the specific need regardless of the level of satisfaction

specialist rehabilitation through the NHS, pay out-of-pocket, or go without. Forty-six percent of subjects had a significant level of disability (EDSS ≥ 6), a stage of MS when rehabilitation is essential for managing the impact of the disease [26]. This was an unmet need for 68% of subjects and is certainly a cause for concern.

Residential care, although expressed as a need by a relatively small number of subjects, represents an important unmet need in MS (40%). The profile of this subgroup, compared to the complete sample, is of older individuals (mean 54.3 (± 11.2) years vs. 49.5 (± 12.9) years, $P = 0.0060$) who are more disabled (78.2% vs. 21.8%, $P < 0.001$), a potentially fragile subgroup of the MS population. In Italy, the care of these individuals is typically assumed by the family, perhaps in part due to the fact that appropriate care facilities for non-elderly disabled individuals in Italy are non-existent [27, 28].

Considering that mood disorders are frequently associated with MS, it is expected that psychological support is a frequently reported need [29]. In the present study, 66% of subjects reported this need as unmet. This was correlated with geographic area of residence and subjects living in central or southern Italy were significantly less likely to have access to psychological support. This result underlines an inequitable distribution of NHS services related to the psychological

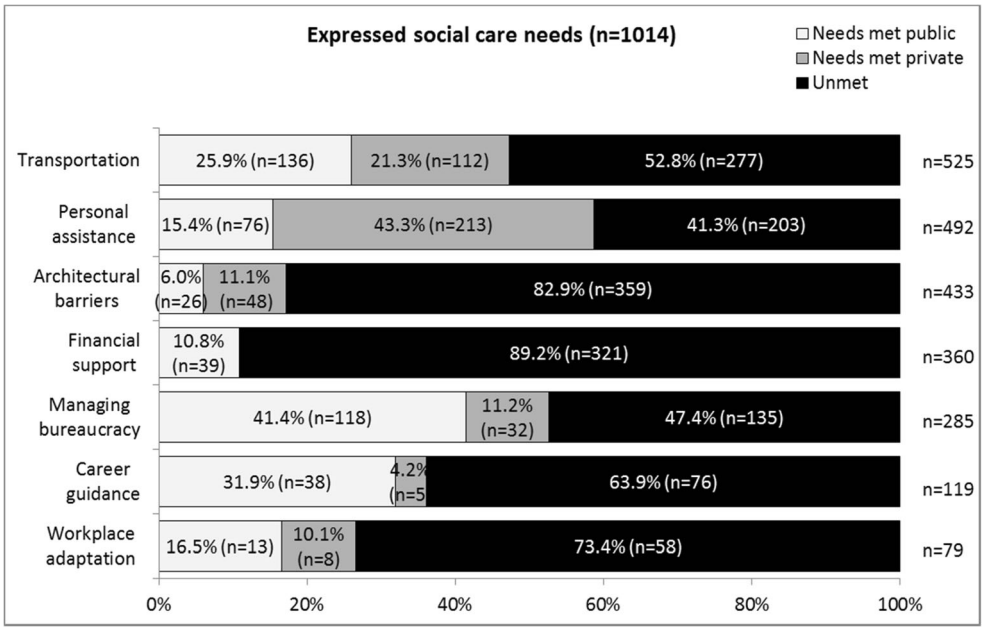


**Fig. 2** Satisfaction of social-related needs. The bar chart describes the proportion of subjects who reported social-related needs and the proportion who did and did not have their needs met; the numbers next to the graph bars represent the number of subjects that have reported the specific need regardless of the level of satisfaction

**Table 1** Factors associated with met health-related needs

| | Variables | Rehabilitation OR (95% CI) | Psychological support OR (95% CI) | Access to technical aids OR (95% CI) | Access to drugs OR (95% CI) | Residential care OR (95% CI) |
|---|---|---|---|---|---|---|
| Frequency of the need, *n* | | 822 | 381 | 219 | 185 | 55 |
| Gender | Male | 1 | 1 | 1 | 1 | 1 |
| | Female | 0.92 (0.67–1.27) | 1.07 (0.64–1.80) | 1.31 (0.58–2.94) | 0.84 (0.40–1.80) | 0.47 (0.11–2.06) |
| Age in year | | 1.00 (0.99–1.02) | 0.99 (0.94–1.01) | 0.97 (0.92–1.01) | 1.02 (0.98–1.06) | 0.99 (0.91–1.06) |
| Educational level | Primary school | 1 | 1 | 1 | 1 | 1 |
| | High school | 1.20 (0.85–1.70) | 1.10 (0.65–1.85) | 1.33 (0.54–3.28) | 1.80 (0.81–3.99) | 1.22 (0.27–5.56) |
| | University degree | *1.73 (1.11–2.69) | 0.93 (0.46–1.85) | 1.50 (0.43–5.18) | 1.00 (0.38–2.66) | 0.56 (0.04–7.60) |
| Occupational status | Unemployed | 1 | 1 | 1 | 1 | 1 |
| | Currently employed | 0.98 (0.68–1.42) | 1.40 (0.82–2.39) | *0.24 (0.07–0.77) | 0.54 (0.22–1.30) | 3.57 (0.31–41.03) |
| Marital status | Other | 1 | 1 | 1 | 1 | 1 |
| | Married-Yes | 0.98 (0.72–1.33) | 0.91 (0.57–1.44) | 0.67 (0.30–1.50) | 0.78 (0.38–1.61) | 0.49 (0.12–2.03) |
| Geographic area of residence | Northern Italy | 1 | 1 | 1 | 1 | 1 |
| | Central Italy | 1.04 (0.71–1.51) | *0.55 (0.31–0.98) | 2.06 (0.42–10.02) | 1.17 (0.48–2.86) | 0.95 (0.10–9.32) |
| | Southern Italy | 1.26 (0.89–1.79) | *0.45 (0.26–0.78) | *0.15 (0.05–0.40) | *0.41 (0.17–1.00) | 0.65 (0.12–3.52) |
| Disease duration in years | | 1.00 (0.99–1.02) | | 1.02 (0.98–1.07) | 0.97 (0.93–1.01) | 1.00 (0.92–1.08) |
| Level of disability (EDSS) | Low disability | 1 | 1 | 1 | 1 | 1 |
| | High disability | 0.80 (0.57–1.13) | 1.18 (0.70–1.99) | 0.99 (0.28–3.47) | 1.37 (0.61–3.05) | 0.12 (0.01–1.90) |

*OR*, adjusted odds ratio; *CI*, confidence interval; *EDSS*, expanded disability status scale; *$P < 0.05$

**Table 2** Factors associated with met social-related needs

| Variables | | Transportation OR (95% CI) | Financial support OR (95% CI) | Architectural barriers OR (95% CI) | Personal assistance OR (95% CI) | Managing bureaucracy OR (95% CI) | Career guidance OR (95% CI) | Workplace adaptation OR (95% CI) |
|---|---|---|---|---|---|---|---|---|
| Frequency of the need, *n* | | 525 | 360 | 433 | 492 | 285 | 119 | 79 |
| Gender | Male | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| | Female | 1.08 (0.73–1.59) | 0.55 (0.67–1.14) | 0.97 (0.57–1.64) | 1.68 (1.10–2.56) | 0.79 (0.48–1.32) | 0.59 (0.24–1.48) | 0.44 0.13–1.46() |
| Age | | 1.01 (1.00–1.03) | 0.99 (0.95–1.02) | 1.02 (0.99–1.05) | *1.02 (1.00–1.04) | 1.01 (0.98–1.03) | 1.01 (0.96–1.07) | 0.95 (0.88–1.02) |
| Education | Primary school | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| | High school | 0.94 (0.63–1.39) | 1.58 (0.75–3.37) | 1.43 (0.79–2.57) | 0.99 (0.65–1.51) | 1.11 (0.64–1.92) | 0.92 (0.33–2.56) | 1.83 (0.42–7.93) |
| | University degree | 1.43 (0.81–2.53) | 0.73 (0.19–2.88) | 1.37 (0.63–2.98) | 1.59 (0.87–2.88) | 0.90 (0.44–1.85) | 1.22 (0.37–4.07) | 2.73 (0.55–12.55) |
| Occupational status | Unemployed, other | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| | Currently employed | 0.98 (0.59–1.62) | 0.38 (0.13–1.13) | 1.19 (0.58–2.45) | 1.43 (0.86–2.38) | 0.95 (0.52–1.74) | *3.34 (1.28–8.67) | 0.69 (0.18–2.65) |
| Marital status | Other | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| | Married-Yes | *0.43 (0.30–0.63) | 0.78 (0.38–1.60) | 0.99 (0.58–1.68) | 0.60 (0.40–0.88) | 0.92 (0.56–1.50) | 2.17 (0.90–5.25) | 1.74 (0.50–6.04) |
| Geographical area of residence | North Italy | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| | Central Italy | 0.89 (0.56–1.42) | 1.15 (0.49–2.70) | 0.73 (0.35–1.50) | 0.77 (0.48–1.25) | 1.02 (0.55–1.87) | 1.62 (0.57–4.64) | *0.15 (0.03–0.72) |
| | South Italy | 0.92 (0.60–1.40) | 0.56 (0.23–1.33) | 1.32 (0.74–2.36) | 0.90 (0.58–1.39) | 1.40 (0.77–2.55) | 2.12 (0.71–6.36) | 0.41 (0.08–2.05) |
| Disease duration | | 1.01 (0.99–1.03) | 1.00 (0.96–1.04) | 1.01 (0.98–1.04) | *1.02 (1.00–1.05) | 0.98 (0.95–1.01) | 1.01 (0.96–1.08) | 1.01 (0.94–1.10) |
| Level of disability (EDSS) | Low disability | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| | High disability | 1.49 (0.96–2.32) | *2.56 (1.09–6.02) | 1.69 (0.77–3.71) | 0.91 (0.57–1.45) | 1.26 (0.69–2.30) | 0.66 (0.25–1.77) | 1.97 (0.52–7.41) |

*OR*, adjusted odds ratio; *CI*, confidence interval; *EDSS*, expanded disability status scale; *$P < 0.05$

health of people with MS. One's geographic area of residence also influenced the satisfaction of other needs related to MS, including medications, technical aids, and workplace adaptions. These results are consistent with an earlier report that found that the availability of information about services, access to services, and appropriateness of services varied with geography and were conspicuously worse in the south than the north [21]. The role of geography has been documented in multi-country studies as well. According to a report of the Organisation for Economic Co-operation and Development (OECD), variation in healthcare across geographic areas in Italy is a cause for concern. Wide variation suggests that whether or not you will receive a particular health service depends to a great extent on the region where you live within the country [30].

Transportation was the most frequently reported social-related need. It includes assistance getting to the workplace and to medical visits and difficulties accessing public transportation. For subjects with a higher level of disability with this need, it was unmet in half the cases. An unmet transportation need was significantly more frequent in married subjects. This may be due to the fact that it is assumed that the family is responsible for managing the needs of the person with MS, thus resulting in services provided through the NHS being available in a very limited way.

Financial support was unmet for approximately 90% of subjects who reported it as a need, primarily subjects with a higher level of disability. Individuals with documented disability are entitled to public benefits in Italy. Nevertheless, public financial assistance appears to be insufficient in meeting expenses related to living with a chronic progressive disease like MS, particularly if the individual is no longer in the workforce.

Personal assistance in daily activities was an important unmet need (nearly half of the subjects required personal assistance), with the majority paying out-of-pocket. These results concur with other reports on people with severe MS [21, 31]. The predictors related to the satisfaction of the need for personal assistance were higher age and a longer disease duration, both variables common in more advanced MS, when the satisfaction of this need becomes imperative. As noted previously, in Italy, the assistance of people with severe MS is often delegated to the family or paid privately [27, 28].

The need to eliminate architectural barriers was reported by 40% of subjects, and in 80%, it remained an unmet need. Not only was this issue addressed during the UN Convention on the Rights of Persons with Disabilities as a necessity for assuring social integration, it is the subject of three separate legal provisions in Italy, specifically related to accessibility [32–35]. The fact that the elimination of architectural barriers continues to be an unmet need for people with disabilities is evidence that Italy continues to be "behind the times" concerning the rights of people with disabilities, particularly related to social integration.

Finally, employment needs, including career guidance and workplace adaptation, were largely unmet. As expected, career guidance was more likely met for those currently working. This is relevant not only in terms of cost-effectiveness, for example, aiding in reducing claims for disability benefits, upon which even those with early MS may become dependent, but also considering the social and psychological benefits of employment as well [36]. On the other hand, career guidance for individuals with MS who wish to enter or re-enter the workforce appears to be lacking.

One shortcoming of the study is that subjects were not asked to provide reasons for privately paying for services to meet health- and social-related needs. Not using the NHS for receiving some types of health and social care may simply be a personal choice and not due to the unavailability or inadequacy of services. In addition to deficiencies on the part of the NHS in terms of service provision, under-utilization of available resources may be another factor in reporting unmet needs. An earlier study in Italy reported that there is limited availability of information about services in some parts of the country [21]. Further, the MS Society recently reported that there is likely still a lack of understanding on the part of many people with MS regarding the value of some important services including psychological support and rehabilitation and that this may contribute to resource under-utilization [37]. While this might be a challenge to assess, it is worthy of consideration. A further limitation is that the cross-sectional design precludes any definitive conclusions about the causal relationships between variables. Also, it is important to note that the current sample included a higher percentage of subjects with moderate/severe disability, compared to a previous report [38]; consequently, some needs could be overestimated.

Finally, the total number of individuals invited to participate in the study by the MS Society volunteers is unknown. It is possible that individuals who did not wish to participate felt that their needs were satisfied.

## Conclusions

The current results provide insight into the range of interventions, care, and support people with MS report as important to them at different points in the disease trajectory. Thus, findings provide a starting point for planning advocacy activities to inform public resource allocation that will contribute to meeting the needs of people with MS. More emphasis should be put on the inequitable distribution of NHS services in different geographic areas of Italy as well as on particularly fragile subgroups of the MS population (older individuals, and those with higher levels of disability) because the care of these individuals continues to be primarily assumed by the family.

**Acknowledgements** We wish to thank the people with MS who participated in this study and the volunteers from the local branches of the Italian MS Society who made an important contribution to making this study possible.

## Compliance with ethical standards

**Conflict of interest** The authors declare that they have no conflict of interest.

**Publisher's note** Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

## References

1. Compston A, Coles A (2002) Multiple sclerosis. Lancet 359:1221–1231
2. Atlas of MS 2013. http://www.msif.org/wp-content/uploads/2014/09/Atlas-of-MS.pdf. Accessed 28 Nov 2018
3. Battaglia MA, Bezzini D (2017) Estimated prevalence of multiple sclerosis in Italy in 2015. Neurol Sci 38(3):473–479
4. Milo R, Kahana E (2010) Multiple sclerosis: geoepidemiology, genetics and the environment. Autoimmun Rev 9(5):A387–A394
5. Compston A, Coles A (2008) Multiple sclerosis. Lancet 372:1502–1517
6. Asche CV, Singer ME, Jhaveri M, Chung H, Miller A (2010) All-cause health care utilization and costs associated with newly diagnosed multiple sclerosis in the United States. J Manag Care Pharm 16(9):703–712
7. Kobelt G, Thompson A, Berg J, Gannedahl M, Eriksson J, MSCOI Study Group; European Multiple Sclerosis Platform (2017) New insights into the burden and costs of multiple sclerosis in Europe. Mult Scler 23(8):1123–1136
8. Ytterberg C, Johansson S, Gottberg K, Holmqvist LW, von Koch L (2008) Perceived needs and satisfaction with care in people with multiple sclerosis: a two-year prospective study. BMC Neurol 8:36
9. Forbes A, While A, Taylor M (2007) What people with multiple sclerosis perceive to be important to meeting their needs. J Adv Nurs 58:11–22
10. Patten SB, Williams JV, Lavorato DH, Terriff D, Metz LM, Berzins S, Bulloch AG (2012) Perceived met and unmet health-care needs in a community population with multiple sclerosis. Int J MS Care 14(1):2–8
11. Edmonds P, Vivat B, Burman R, Silber E, Higginson IJ (2007) 'Fighting for everything': service experiences of people severely affected by multiple sclerosis. Mult Scler 13(5):660–667
12. Freeman JA, Thompson AJ (2000) Community services in multiple sclerosis: still a matter of chance. J Neurol Neurosurg Psychiatry 69(6):728–732
13. Rieckmann P, Centonze D, Elovaara I, Giovannoni G, Havrdová E, Kesselring J, Kobelt G, Langdon D, Morrow SA, Oreja-Guevara C, Schippling S, Thalheim C, Thompson H, Vermersch P, Aston K, Bauer B, Demory C, Giambastiani MP, Hlavacova J, Nouvet-Gire J, Pepper G, Pontaga M, Rogan E, Rogalski C, van Galen P, Ben-Amor AF (2017) Members of the MS in the 21st Century Steering Group. Mult Scler Relat Disord 19:153–160
14. Polman CH, Reingold SC, Banwell B, Clanet M, Cohen JA, Filippi M, Fujihara K, Havrdova E, Hutchinson M, Kappos L, Lublin FD, Montalban X, O'Connor P, Sandberg-Wollheim M, Thompson AJ, Waubant E, Weinshenker B, Wolinsky JS (2011) Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. Ann Neurol 69(2):292–302
15. Ponzio M, Tacchino A, Zaratin P, Vaccaro C, Battaglia MA (2015) Unmet care needs of people with a neurological chronic disease: a cross-sectional study in Italy on multiple sclerosis. Eur J Pub Health 25(5):775–780
16. Collins CD, Ivry B, Bowen JD, Cheng EM, Dobson R, Goodin DS, Lechner-Scott J, Kappos L, Galea I (2016) A comparative analysis of patient-reported expanded disability status scale tools. Mult Scler 22(10):1349–1358
17. Kurtzke JF (1983) Rating neurologic impairment in multiple sclerosis: an expanded disability status scale (EDSS). Neurol 33:1444–1452
18. StataCorp (2017) Stata Statistical Software: Release 15. StataCorp LLC, College Station
19. Lonergan R, Kinsella K, Fitzpatrick P, Duggan M, Jordan S, Bradley D, Hutchinson M, Tubridy N (2015) Unmet needs of multiple sclerosis patients in the community. Mult Scler Relat Disord 4(2):144–150
20. Potemkowski A, Brola W, Ratajczak A, Ratajczak M, Kowalewski M, Lewita M, Kapica-Topczewska K, Tarasiuk J, Stępień A, Gocyła-Dudar K, Zaborski J, Bartosik-Psujek H (2017) The most important psychological and psychosocial needs of Polish multiple sclerosis patients and their significant others. Neuropsychiatr Dis Treat 13:1817–1824
21. Borreani C, Bianchi E, Pietrolongo E, Rossi I, Cilia S, Giuntoli M, Giordano A, Confalonieri P, Lugaresi A, Patti F, Grasso MG, de Carvalho LL, Palmisano L, Zaratin P, Battaglia MA, Solari A, PeNSAMI project (2014) Unmet needs of people with severe multiple sclerosis and their carers: qualitative findings for a home-based intervention. PLoS One 9(10):e109679
22. Freeman JA, Langdon DW, Hobart JC, Thompson AJ (1997) The impact of inpatient rehabilitation on progressive multiple sclerosis. Ann Neurol 42:236–244
23. Kraft GH (1999) Rehabilitation still the only way to improve function in multiple sclerosis. Lancet 354:2016–2017
24. Wiles CM, Newcombe RG, Fuller KJ, Shaw S, Furnival-Doran J, Pickersgill TP, Morgan A (2001) Controlled randomized cross over trial of the effects of physiotherapy on mobility in chronic multiple sclerosis. J Neurol Neurosurg Psychiatry 70:174–179
25. Galobardes B, Lynch J, Smith GD (2007) Measuring socioeconomic position in health research. Br Med Bull 81-82:21–37
26. European Multiple Sclerosis Platform (2012) Recommendation on rehabilitation services for persons with multiple sclerosis in Europe. Available at: https://www.eurims.org/News/recommendations-on-rehabilitation-services-for-persons-with-multiple-sclerosis-in-europe.html. Accessed 27 June 2018
27. Battaglia M, Kobelt G, Ponzio M, Berg J, Capsa D, Dalén J, European Multiple Sclerosis Platform (2017) New insights into the burden and costs of multiple sclerosis in Europe: results for Italy. Mult Scler 23(2_suppl):104–116
28. Ponzio M, Gerzeli S, Brichetto G, Bezzini D, Mancardi GL, Zaratin P, Battaglia MA (2015) Economic impact of multiple sclerosis in Italy: focus on rehabilitation costs. Neurol Sci 36(2):227–234
29. Dennison L, Moss-Morris R, Chalder T (2009) A review of psychological correlates of adjustment in patients with multiple sclerosis. Clin Psychol Rev 29(2):141–153
30. OECD. Targeted action needed to reduce the high level of variation in health care that persists across Italy. http://www.oecd.org/italy/Geographic-Variations-in-Health-Care_Italy.pdf. Accessed 28 Nov 2018
31. Galushko M, Golla H, Strupp J, Karbach U, Kaiser C, Ernstmann N, Pfaff H, Ostgathe C, Voltz R (2014) Unmet needs of patients feeling severely affected by multiple sclerosis in Germany: a qualitative study. J Palliat Med 17:274–281
32. United Nations (UN) (2006) Convention on the rights of persons with disabilities and optional protocol. New York: UN. http://www.

un.org/disabilities/documents/convention/convoptprot-e.pdf. Accessed 28 Nov 2018
33. Italian law 13/89 (1989) "Disposal to facilitate the overcoming and elimination of architectural barriers in private buildings". http://www.certificazioni.it/uploads/tx_news/Testo_aggiornato_della_legge_9_gennaio_1989_e_circolare_esplicativa_01.pdf. Accessed 28 Nov 2018
34. Italian Ministerial Decree 236/89 (1989) http://www.gazzettaufficiale.it/eli/gu/1989/06/23/145/so/47/sg/pdf. Accessed 28 Nov 2018
35. Italian Decree of the President of the Republic 503/96 (1996) http://www.gazzettaufficiale.it/eli/gu/1996/09/27/227/so/160/sg/pdf. Accessed 28 Nov 2018
36. Pfleger CCH, Flachs EM, Koch-Henricksen N (2010) Social consequences of multiple sclerosis (1): early pension and temporary unemployment- a historical prospective cohort study. Mult Scler 16:121–126
37. Barometer of MS (2018) https://www.aism.it/download/AISM_Barometro 2018_16may.pdf. Accessed 28 Nov 2018
38. Pugliatti M, Rosati G, Carton H, Riise T, Drulovic J, Vécsei L, Milanov I (2006) The epidemiology of multiple sclerosis in Europe. Eur J Neurol 13(7):700–722 Review