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Unmet care needs of people with a neurological chronic disease: a cross-sectional study in Italy on Multiple Sclerosis

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Background: Community-based studies are required to accurately describe the supportive services needed by people with multiple sclerosis (MS). **Methods:** A total of 1205 people with MS participated in a cross-sectional study evaluating their unmet health and social care needs through a questionnaire collecting information used in the study. It was specifically developed by a multi-disciplinary team. **Results:** Overall, 79% of the responders declared at least one health or social care needs. The most prevalent health care need was the psychological support (27.5%), whereas the transport was the social care need more frequent (over 41%) in our sample. The multivariate analysis highlighted that unmet health care needs depended mainly on clinical factors such as disease stage, influenced by disease duration, and disability degree, whereas the social care needs were related to both clinical and socio-demographic factors. **Conclusion:** These findings suggest that MS needs significantly change over time during the disease development and to find the best way to personalize PwMS management is crucial. Moreover, more public funding directed at improving the health-related quality of life of people with MS is needed. For this reason, we think that these results will provide important information and baseline data on how to build the national service strategies thereby making healthcare planning more efficient.

Background

Multiple sclerosis (MS), the most common non-traumatic disease of the central nervous system, is cause of permanent disability. MS course is both highly variable and equally unpredictable in terms of symptoms, signs and the resulting disability degree. Currently, MS affects around 2.3 million people, with as many as 600 000 in Europe¹ and approximately 72 000 in Italy.² MS effects are wide-ranging, having an impact on physical, psychological and social well-being.³ Furthermore, it is known that psychological, psychiatric and social issues play a major role in health-related quality of life (QoL).⁴ Thus, it must be recognized that people with MS (PwMS) are a non-homogeneous population with many difficulties that varies also according to the lived individual experiences of the disease, personal symptoms and disease stages.

In this frame, PwMS show a large number of needs that should be satisfied, even if, due especially to economic, environmental and organizational causes, they remain frequently unmet. Therefore, to date, although the concept of ‘unmet need’ is crucial, it is still ambiguous, particularly in managing neurodegenerative pathologies such as MS. Drennan *et al.*⁵ described an unmet need as a complex concept with different interpretations depending on the considered perspective. For example, clinicians, relying on epidemiological knowledge during their enquiries on patient’s needs, may find a mismatch between unmet needs identified by themselves and those actually perceived by the patients.^{6–8} Therefore, it is important that the investigations are not restricted only to the clinician point of view but that PwMS are given the opportunity both to better define

what they perceive as difficulties and needs and, especially, to express their priorities along with their preferences regarding different forms of health and social care.⁹ Thus, several studies focused their attention in determining the healthcare preferences reported by PwMS. For example, Somerset *et al.*, in a cross-sectional survey in the United Kingdom, sent a postal questionnaire comprising socio-demographic, QoL and depression measures and healthcare original items. PwMS displayed a wide variation in their preferences for services and unmet needs, ranging from clearer information about management to relevant tailored advices and accesses to appropriately skilled professionals.¹⁰ More recent studies in the United Kingdom on severe forms expanded these results identifying a lack of information about services, aids and adaptations, and a lack of continuity and co-ordination of care¹¹ and suggesting to spend more attention to the emotional support.¹² Another study in Germany accounted for the need to improve professional–patient relationships to provide needs-tailored supports.¹³

In addition, other studies on MS needs reported a poor diagnosis management, variations in availability, accessibility and quality of care, high levels of preventable complications.^{10,14–16} All the results highlighted the key role of involving PwMS in identifying their preferences to better encounter their desires and to adequately tailor the services in accordance with each individual’s necessity.

Few studies were conducted about MS needs in Italy. The most recent was mainly focused on psychological support and evaluated the different perceptions of PwMS and caregivers about the disease management to gather information to ameliorate patients care. In particular, it was shown that the majority of participants of both

groups were satisfied with medical staff but expressed a desire that the staff was more forthcoming with information about MS. Moreover, most patients reported that a multidisciplinary approach was very useful, more than caregivers did. Both groups required psychological support for patients; however, for the patients, this was a need greater especially at the time of diagnosis, whereas for caregivers in post-diagnosis.¹⁷ Results confirmed previous findings¹⁸ that identified the most important needs for patients and caregivers, particularly underlining a high demand for more information about MS and psychosocial support (i.e. good relationships with physicians, MS healthcare team, family and friends).

The main study aim was to identify the most perceived needs following the PwMS point of view, specifically focusing our attention on Italian MS patients. Secondly, with respect to previous studies, we took into account a larger and more representative sample of PwMS allowing a better evaluation of the factors associated with the unmet needs. Finally, because MS produces an escalation of physical impairments, socio-economic changes and psychological effects, this study tried to cover multiple aspects affecting PwMS, identifying and assessing a wider range of needs representative of health and social care requests. In this way, we wanted not only to provide more information with respect to the recent analysis conducted by Lorefice *et al.*¹⁷ but also to propose a large and necessary updating of the Italian context.¹⁹ However, it is fundamental to underline that our study did not want to assess whether PwMS actually fail to receive specific services by investigating possible causes such as limited resources or organizational incapacities, but it was limited to only understand what PwMS perceived as their own needs.

Methods

Sample

A cross-sectional study on PwMS was carried out in Italy during 2012. PwMS were identified through MS Clinical Centres, rehabilitation units or among members with MS of Italian MS Society (AISM). They were invited and recruited from MS Clinical Centres and rehabilitation units during clinical visit (consecutive recruitment strategy) or from the list of AISM's members if they previously consented to be contacted by AISM (random recruitment strategy). As each source of patients was mainly constituted by a specific target of MS disease stage, multiple sources of enrolment were necessary. The only inclusion criteria was a definite diagnosis of MS.²⁰

Data were collected using a self-administered paper questionnaires or, if required, through a telephone interview during which

ad-hoc trained personnel conducted the same questionnaire. The study was in accordance with the Declaration of Helsinki²¹ and the patient's informed consent was obtained.

Questionnaire

The questionnaire was developed specifically for the study by a multidisciplinary team of neurologists, psychologists and public health experts. Moreover, in designing the questionnaire, the team was aided by AISM representatives (included PwMS) to take into account especially the patients point of view about the disease management. The questionnaire was designed to collect socio-demographic status (gender, age, education, employment), clinical status (form, disease duration, disease disability level) and unmet needs. The disease disability level was assessed by a self-Expanded Disability Status Scale (EDSS) using the items of the original EDSS, as suggested in previous epidemiological studies.²² Participants were asked to identify their needs during the last year in a list of 12 yes/no unmet needs items (table 1).

Data analysis

The frequencies of unmet health and social care needs as well as demographic and clinical characteristics of the sample were reported using descriptive statistics. The unmet needs number reported by participants did not follow a normal distribution and, thus, the analysis was conducted using non-parametric test. Factors associated to the unmet needs were identified using a logistic regression model. The variables introduced into the multivariate model were selected considering the clinical context. Participants with missing data for a model variable were excluded from the analysis involving that variable. However, items without response were generally minimal (range: 0–2.9%; median: 0.58%). The results are presented with odds ratios (ORs) and 95% confidence intervals. Analyses were performed using Stata (version 11.0).

Results

Sample characteristics

In total, 1235 Italian PwMS returned the questionnaire or responded to the telephone interview; however, only 1205 was finally included: 30 (2.4%) were excluded due to not sufficiently completed data; 92.6% of the patients responded directly, while a caregiver on behalf of them responded in 7.4%. The average age was 44.9 (± 12.2) years (range: 10–85 years); considering 2 missing data, 825 (68.6%) patients were females and 378 (31.4%) males (sex ratio: 2.2); 89.6% had had at least one stable job, whereas 51.7%

Table 1 Definitions of 12 unmet needs

Health care needs	
Psychological support	Lack of psychological support when requested by the subject or by a physician
Temporary admission to rehabilitation	Lack of rehabilitation facilities to temporary admission
Access to aids	Difficulties to access to aids prescribed by the physician (i.e. wheelchairs, canes)
Access to drugs	Difficulties to access to drug therapies prescribed by the physician
Nursing home	Lack of nursing home (residential or day care centre)
Social care needs	
Assistance in transporting	Need for personal transport (i.e. accompaniment to the workplace or medical visits); difficulties to access to public transport (train, plane, bus)
Financial support	Lack of financial support
Architectural barriers	Difficulties to overcome architectural barriers both in public place and in home
Personal assistance	Lack of personal assistance in daily activities (i.e. personal care, domestic help, accompanying children to school)
Managing bureaucracy	Difficulties in managing bureaucracy (i.e. request of social security benefits)
Career guidance	Lack of vocational guidance or of support as legally protected status
Adaptation workplace	Lack of adaptation workplace (excluding architectural barriers)

The list of 12 unmet needs was selected by both previously published data and suggestions of the multidisciplinary team involved in the study. The questions evaluated two types of needs: five health and seven social care needs.

Table 2 Factors associated with unmet health care needs for psychological support, temporary admission to rehabilitation, access to aids and to drugs and nursing home

Variables	Psychological support, OR (95% CI)	Temporary admission to rehabilitation, OR (95% CI)	Access to aids, OR (95% CI)	Access to drugs, OR (95% CI)	Nursing home, OR (95% CI)
Frequency in the sample, <i>n</i> (%)	331 (27.5%)	118 (9.8%)	81 (6.7%)	65 (5.4%)	38 (3.2%)
Gender					
Male	1	1	1	1	1
Female	1.24 (0.92–1.68)	0.87 (0.57–1.33)	1.03 (0.61–1.73)	1.22 (0.68–2.17)	0.66 (0.33–1.35)
Age	0.99 (0.97–1.00)	1.00 (0.98–1.02)	0.99 (0.96–1.01)	1.01 (0.98–1.04)	1.01 (0.98–1.05)
Education					
Primary school	1	1	1	1	1
High school	1.10 (0.75–1.61)	1.18 (0.67–2.06)	0.57 (0.31–1.04)	0.62 (0.33–1.20)	1.94 (0.71–5.31)
University degree	1.09 (0.71–1.68)	1.65 (0.86–3.09)	0.61 (0.28–1.32)	0.64 (0.29–1.38)	2.59 (0.87–7.77)
Employment					
Unemployed, other	1	1	1	1	1
Currently employed	0.93 (0.70–1.24)	0.82 (0.51–1.30)	0.71 (0.38–1.32)	0.70 (0.38–1.29)	0.63 (0.26–1.53)
MS form					
RR	1	1	1	1	1
RP	0.71 (0.39–1.29)	1.40 (0.66–2.97)	1.06 (0.37–3.00)	1.16 (0.42–3.18)	4.63* (1.35–15.9)
SP	1.23 (0.80–1.89)	1.33 (0.73–2.43)	3.54* (1.68–7.44)	1.89 (0.90–3.98)	2.49 (0.83–7.47)
PP	0.88 (0.55–1.42)	1.26 (0.66–2.44)	2.67* (1.21–5.93)	1.30 (0.54–3.10)	2.45 (0.76–7.95)
Disease duration (years)					
Over 10 years	1	1	1	1	1
2–10 years	1.07 (0.78–1.46)	0.84 (0.53–1.34)	1.45 (0.81–2.58)	0.54* (0.29–0.99)	0.41 (0.16–1.03)
2 years	3.51* (1.83–6.73)	0.30 (0.04–2.29)	1.12 (0.13–9.41)	—	1.19 (0.14–10.1)
Disease disability level (EDSS)					
Mild (0–3)	1	1	1	1	1
Moderate (4–6.5)	1.63* (1.18–2.27)	2.03* (1.15–3.59)	9.40* (2.74–32.24)	1.57 (0.80–3.08)	1.15 (0.39–3.35)
Severe (≥7)	2.01* (1.23–3.28)	3.98* (1.96–8.11)	23.62* (6.29–88.74)	0.80 (0.32–2.01)	2.00 (0.62–6.46)

OR, adjusted odds ratio; CI, confidence interval; RR, relapsing–remitting; PR, progressive–relapsing; SP, secondary progressive; PP, primary progressive.

* $P < 0.05$.

were currently employed. The educational level was medium–high: 17.8% primary school, 55.3% high school and 27.9% university degree.

The main disease course was relapsing–remitting (64.5%), whereas 7.2% was progressive relapsing, 16.2% secondary progressive and 12.1% primary progressive. The average time since diagnosis was 11.5 (± 8.9) years. In particular, 4.5% were newly diagnosed (2011–12), 53.9% were diagnosed between 2001 and 2010 and 41.6% before 2001. The distribution of self-EDSS was as follows: 43.5% showed mild disability (EDSS: 0–3), 39.4% moderate (EDSS: 4–6.5) and 17.1% severe (EDSS: ≥ 7).

Unmet needs

Overall, 79% of responders declared at least one health or social care need; specifically, 39% ($n = 467$) reported at least one health care need, whereas 75% ($n = 907$) at least one social care needs. Psychological support was the most prevalent health care need with 27.5%, followed by 9.8% of temporary admission to rehabilitation, 6.7% of access to technical aids, 5.4% of access to drugs and, finally, 3.2% of nursing home.

Among social care needs, assistance in transporting was declared by about 41% of responders, whereas financial support, architecture barriers and personal assistance for over 30%, managing bureaucracy for over 20% and, finally, career guidance and adaptation workplace for over 10%.

Factors associated with unmet health and social care needs

As listed in table 2, health care unmet needs were dependent only on clinical factors, whereas socio-demographic aspect did not influence the reported needs. A progressive MS form was associated with access to aids and nursing home (about 3- or 4-fold increase). Disease duration was associated to psychological support (>3 -fold increase for newly diagnosed) and access to drugs (about half decrease in 2–10-year disease duration). Finally, disease disability level was related to psychological support, temporary admission to rehabilitation and access to aids needs, with a significantly increased

risk of requiring these needs for subjects with higher disability level. As expected, the average number of health care needs increased significantly with higher disability levels ($P = 0.0001$).

The multivariate analysis showed that almost all the factors, both socio-demographic and clinical, were related to unmet social care needs (table 3). For socio-demographic factors, we observed that female showed a higher risk to require needs as transport (OR = 1.44) and personal assistance (OR = 2.97); age was related to managing bureaucracy and career guidance (risk decreased with increasing age); educational level was related only to financial support and, in particular, a lower risk was associated only with university degree (OR = 0.48); currently employed subjects showed a lower risk to require assistance in transporting (OR = 0.74), financial support (OR = 0.57), managing bureaucracy (OR = 0.67) and career guidance (OR = 0.34) but a higher risk (>6 -fold) to require adaptation workplace. Considering clinical factors, progressive MS forms were associated to higher risk (approximately 2-fold increase) for assistance in transporting, architectural barriers and personal assistance; newly diagnosed patients (disease duration ≤ 2 years) showed an increased risk for financial support (OR = 2.10), managing bureaucracy (OR = 2.22), career guidance (OR = 2.29), whereas a decrease in architectural barriers was reported by both newly diagnosed and patients with 2–10-year disease duration (OR = 0.67 and OR = 0.13, respectively). Finally, higher disease disability levels were risk factors for all social care needs; we noticed that with increasing disability level an increase in the mean number of needs occurred ($P = 0.0001$).

Discussion

Following previous works adopting a series of in-depth interviews, this study explored health and social care unmet needs in the MS population. To provide a representative view of Italian needs, such as in other epidemiological studies,^{10,15,16,23} a large sample of patients with different MS severity levels was enrolled across Italian regions from several sources. We were in line with a disability social model that, respect to the medical model, embeds clinical care within the social care pathways avoiding to neglect impaired people by healthcare system.⁹

Table 3 Factors associated with unmet social care needs for assistance in transporting, financial support, architectural barriers, personal assistance, managing bureaucracy, career guidance and adaptation workplace

Variables	Assistance in transporting, 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)	Adaptation workplace, OR (95% CI)
Frequency in the sample, <i>n</i> (%)	498 (41.3%)	445 (36.9%)	424 (35.2%)	388 (32.2%)	262 (21.7%)	158 (13.1%)	122 (10.1%)
Gender							
Male	1	1	1	1	1	1	1
Female	1.44* (1.07–1.94)	1.12 (0.85–1.47)	0.94 (0.69–1.28)	2.94* (2.11–4.08)	0.78 (0.57–1.06)	1.02 (0.66–1.56)	1.15 (0.74–1.80)
Age	1.00 (0.99–1.02)	0.99 (0.98–1.00)	1.01 (0.99–1.02)	1.01 (1.00–1.03)	0.98* (0.97–1.00)	0.95* (0.93–0.97)	0.99 (0.97–1.01)
Education							
Primary school	1	1	1	1	1	1	1
High school	0.78 (0.54–1.13)	0.80 (0.57–1.12)	1.05 (0.71–1.55)	0.69 (0.48–1.01)	0.80 (0.54–1.19)	1.34 (0.77–2.34)	0.84 (0.47–1.51)
University degree	0.85 (0.55–1.30)	0.48* (0.32–0.71)	1.07 (0.68–1.68)	0.66 (0.43–1.02)	0.83 (0.53–1.31)	0.87 (0.45–1.67)	0.62 (0.32–1.22)
Employment							
Unemployed, other	1	1	1	1	1	1	1
Currently employed	0.74* (0.55–0.98)	0.57* (0.44–0.75)	0.86 (0.63–1.19)	0.95 (0.70–1.30)	0.67* (0.48–0.90)	0.34* (0.23–0.50)	6.61* (3.79–11.5)
MS form							
RR	1	1	1	1	1	1	1
RP	1.98* (1.15–3.41)	0.97 (0.58–1.63)	1.61 (0.94–2.77)	2.21* (1.30–3.77)	0.57 (0.28–1.16)	0.33 (0.10–1.12)	0.59 (0.22–1.64)
SP	2.83* (1.84–4.34)	1.09 (0.73–1.64)	2.92* (1.89–4.51)	2.60* (1.70–3.98)	1.23 (0.76–1.96)	1.18 (0.62–2.23)	0.99 (0.49–1.99)
PP	1.82* (1.17–2.85)	1.12 (0.73–1.73)	1.80* (1.14–2.85)	1.99* (1.26–3.15)	1.46 (0.90–2.37)	0.61 (0.27–1.38)	1.30 (0.66–2.55)
Disease duration (years)							
Over 10 years	1	1	1	1	1	1	1
2–10 years	0.75 (0.55–1.01)	0.93 (0.70–1.25)	0.67* (0.49–0.92)	0.79 (0.57–1.08)	1.26 (0.89–1.78)	1.33 (0.83–2.12)	1.21 (0.76–1.93)
2 years	1.15 (0.56–2.35)	2.10* (1.10–4.03)	0.13* (0.03–0.56)	1.14 (0.54–2.42)	2.22* (1.10–4.48)	2.29* (1.01–5.18)	1.56 (0.58–4.21)
Disease disability level (EDSS)							
Mild (0–3)	1	1	1	1	1	1	1
Moderate (4–6.5)	3.53* (2.56–4.87)	1.50* (1.11–2.02)	5.52* (3.81–8.00)	2.20* (1.56–3.09)	1.57* (1.10–2.23)	1.60* (1.04–2.48)	1.88* (1.18–2.99)
Severe (≥7)	6.40* (3.92–10.4)	1.35 (0.86–2.11)	10.2* (6.10–17.1)	4.03* (2.49–6.54)	1.25 (0.73–2.14)	0.68 (0.30–1.55)	2.54* (1.13–5.67)

OR, adjusted odds ratio; CI, confidence interval; RR, relapsing–remitting; RP, progressive relapsing; SP, secondary progressive; PP, primary progressive.

* $P < 0.05$.

PwMS, here interviewed, reported several difficulties to access to multiple health and social care aspects. In fact, about four-fifths of respondents had at least one unmet need: nearly two-fifths reported at least one health care need, whereas 75% reported at least one social care need. Overall, unmet needs expressed by our sample validated other studies indicating a broad PwMS need variety, whose the most relevant were assistance during activities of daily living, psychosocial support, rehabilitation and non-professional care.^{16,18,24–26}

Here, the multivariate analysis highlighted that unmet health care needs depended mainly on clinical factors, whereas social care needs were related to both clinical and socio-demographic variables.

Among health care needs, psychological support was the most prevalent in our sample and was mainly expressed by patients recently diagnosed and/or with a high disease disability level. In fact, a new diagnosis and disease progression acceptance are two very demanding challenges for PwMS. This result indirectly shows that living with MS means both awareness to accept illness and its increasing difficulties and necessity to be continuously supported in reaching this aim. Therefore, healthcare providers should always take into account this need to prepare patients to accept MS progression and its management.²⁷ However, the most delicate aspect that healthcare providers have to face is whether PwMS are ready to receive information regarding their diagnosis or their disease progression. Therefore, in delivering it, psychologists should consider their intervention similarly to a drug treatment with the related side effects. In this light, they are suggested to stipulate and to apply specific guidelines like for evidence-based patient information²⁸ and complex interventions.²⁹

As expected, temporary admission to rehabilitation and access to aids were principally expressed with progressive disease, as shown by the correlations with disability level and MS form. Even if this correlation could seem obvious, instead it underlines that, also in the advanced disease stages, PwMS need to be independent, by looking for maximizing residual functional performances and minimizing disability and handicap as long as possible through physical therapy and use of aids.

Although the analysis on health care needs was actually important to shed new light on what is necessary to be considered in managing MS especially at advanced stages, social care needs seemed to show a

more impacting role on patients daily life activities, both being reported by a major number of interviewed subjects and being depended on all the clinical and socio-demographic factors.

Multivariate analysis on social care needs identified that financial support, managing bureaucracy and career guidance were more probably reported by people with lower age, without employment, with a recent diagnosis and with moderate disability level: in these cases the aspects correlated to job and to economic problems are crucial; in particular, they suggest the necessity to overcome the difficulty in orienting among social benefits and services, often available but unknown, to better fit into society. These considerations juxtapose and complement previous findings in which PwMS showed a significant risk to become unemployed within 5–10 years from the diagnosis, dramatically decreasing productivity and raising MS social costs.^{30,31} In a recent Italian study, it was reported that approximately 30% of the total MS cost was due to productivity losses.³² According to the literature, we observed also a lower significant risk factor for financial support when a higher educational level was present.³¹

As expected, also adaptation workplace need was strongly related to employment status. In particular, the strong relationship with a situation of current employment suggests that these services, although previously discussed and so made known,³³ remain still greatly inadequate for PwMS that want to maintain their job. Thus, assistance by counselling services and case managers should be encouraged by socio-political institutions to cope with MS and empower individuals in identifying solutions.³⁴

Moreover, assistance in transporting, architectural barriers, personal assistance and adaptation workplace resulted more probable especially for patient's progressive and with high disability level. Therefore, it would indicate that, although in Italy many social measures are present to help PwMS, there is still a lack of adequate services and general assistance especially when a worsening occurs. In fact, in Italy, like in other European countries, the management of everyday daily activities of PwMS at the most advanced disease stages is mainly a private question of the family that to an informal care often has to add an external paid assistance, usually totally in their charge.^{32,35} In addition, it is important to stress that unmet social care needs expressed by the most affected patients, as assistance in transporting and architectural

barriers, seem indirectly describing the request of better social integration, in line with previous findings showing that MS not only influences QoL physical aspects but also personal control and social activities.^{26,36} These considerations do not show only that social measures and services frequently fail to meet PwMS needs but also that more attention should be attributed also to the carers needs. Therefore, an important necessity arises to teach carers how to cope with their own physical and psychological burden and how to better handle any cognitive or behavioural problems that may occur.

The dissatisfaction revealed through our questionnaire suggests that PwMS perception is mandatory to be taken into account by MS stakeholders, such as clinicians, healthcare professionals and health authorities, to make more effective the coordination between the available services that may contribute to improve PwMS management, to optimize resources allocation and to reduce economic burden, especially considering the current European economic and social crises.

Strengths and limitations

This study, besides an integration, an updating and a more wide-range overview of health and social care PwMS Italian unmet needs, could open new perspective in approaching the MS management.

However, it is also important to recognize some limitations of our study. First, the data are derived from a cross-sectional study, so causality cannot be definitively determined. Second, all the measures were self-reported and may be subject to several biases. Third, a bias could derive from questionnaires filled out by caregivers. Nevertheless, it is not always possible to directly consult people with high disability; however, previous reports showed reasonable validity of informal carers' contributions.³⁷⁻³⁹ Finally, the choose of unmet care needs considered in the questionnaire could not cover all the PwMS needs.

Conclusion

PwMS needs significantly change over time during the disease development, to find the best way to personalize PwMS management becomes a priority.⁴⁰ Focusing on individual patient needs is a prerequisite for a patient-centred approach, which also means engaging patients in healthcare decision making as much as possible.⁴¹ However, an increased involvement involves great challenges to both PwMS (due to a required major self-responsibility) and similarly healthcare providers.⁴²

Finally, more public funding directed at improving the health-related QoL of PwMS is needed. For this reason, we think that these results will provide important information and baseline data on how to build the national service strategies, thereby making healthcare planning more efficient.

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Conflicts of interest: None declared.

Key points

- Multiple sclerosis (MS) is a complex condition, which requires a careful treatment management and profoundly influences life of people who are affected.

- There is an increasing attention for research advocacy programs aimed to infuse the patient perspective into research, making scientific and medical advices more timely and effective.
- This cross-sectional study reports the point of view of a large sample of people with MS about what they perceive should be the most helpful in meeting their needs.
- The results show that the 79% of the people with MS in Italy declares at least one unmet health or social care needs, stressing that these significantly change over time during the development of the disease.
- These results will provide important information and baseline data on how to ameliorate or redefine the national service strategies making healthcare planning more efficient.

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