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Multiple Sclerosis Multidisciplinary Care: a national survey and lessons for the global community

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Abstract

Background: Access to, standardization and reimbursement of multidisciplinary care for people with MS (PwMS) is lacking in many countries. Therefore, this study aims to describe the current multidisciplinary care for people with MS (PwMS) in Belgium and identify benefits, needs and future perspectives. **Methods:** A survey for PwMS questioned various aspects of MS and viewpoints on care. For MS nurses (MSN) and neurologists, employment, education, job-content, care organization and perspectives were inquired. Descriptive and univariate statistics were performed. **Results:** The PwMS survey comprised 916 respondents with a mean age of 46 ± 12.7 years and 75,4% of the respondents being female. The majority of the participants had relapsing remitting MS (60.8%) and the mean patient determined disease steps (PDDS) was 2.0 (IQR=3). 65.3% and 60.4% of the PwMS reported having access to a multidisciplinary team (MDT) or MSN. Access to an MSN was associated with more frequent disease modifying treatment ($p=.015$), spasticity ($p=.042$) and gait treatment ($p=.035$), but also more physiotherapy ($p=.004$), driver's license adjustment ($p<.001$) and a higher employment rate ($p=.004$). MDT access was associated with more frequent symptomatic bladder treatment ($p=.047$), higher physiotherapy rate ($p<.001$), higher work- ($p=.002$), insurance- ($p<.001$) and home support measures ($p=.019$). PwMS without an available MDT more often indicated that MS care needs improvement ($p<.001$). MSN's ($n=22$) were mainly funded through various budgets, including hospital and neurology practice budgets. Finally, 69% and 75% neurologists ($n=62$) working without an MSN or MDT stated a need of such support and 61% agreed that MDT's should be organized at hospital-network level. **Conclusion:** MDT and MSN availability may enhance medical and socio-economic support for PwMS. Guidelines, alignment and reimbursement are needed.

1 Introduction

Multiple sclerosis (MS) is the most common non-traumatic neurological disease causing physical disability in young adults¹ affecting 2.8 million people worldwide². It is thought that a complex interaction between environmental and genetic factors triggers inflammation and degeneration in the central nervous system of people with MS (PwMS)³. Recent therapeutic developments have had a beneficial impact on the neuro-inflammatory process, thereby reducing clinical and radiological disease activity. However, the impact on long term disability accrual remains suboptimal^{4,5}. Also, attention for hidden symptoms such as chronic fatigue, neuropathic pain, incontinence, anxiety and depression remains inadequate. An increase in disease burden including these neglected aspects has been correlated to reduced quality of life, higher healthcare costs, decreased income, and relational problems^{6,7}. The complexity and burden of MS, next to its increasing prevalence², can only be tackled by a multidisciplinary approach with a central role for neurologists and MS Nurses (MSN). Although not strictly defined minimum requirements for a multidisciplinary MS Care Unit, next to MSNs and neurologists, should comprise physiotherapists, occupational therapists, (neuro-)psychologists and a secretary in close collaboration with external part-time specialists, as proposed in the “The Multiple Sclerosis Care Unit” position paper⁸. Despite the emerging attention for collaborative and integrated health care and evidence of added value of multidisciplinary teams (MDT) in other neurological disorders (e.g. stroke and amyotrophic lateral sclerosis)^{9,10}, most healthcare systems, including Belgium’s, are still lacking a standardized and reimbursed multidisciplinary approach for PwMS. Although recent multi-stakeholder surveys identified MS care units as a major research priority, the domain remains understudied^{11,12}. This study aimed to gather information and opinions from various stakeholders regarding current care provision for MS, unmet needs and future perspectives through online surveys in Belgium.

2 Methods

2.1 Design and participants

Three online surveys were developed using REDCap®-11.1.29. The survey for PwMS, MSN and neurologists, hereafter respectively called BELSIMS, MS Nurse and NEUROMS, were critically reviewed by the board members of the Belgian Study Group for MS (BSGMS). The BSGMS was founded to (i) foster research on the causes and treatment of MS and (ii) to provide information on MS to medical professionals. Since the surveys were distributed in Dutch, French and English, they were all reviewed for comprehensiveness and correct use of language by a native French, Dutch and English-speaking person. The MS Nurse and the BELSIMS survey were also reviewed for terminology, adequacy and consistency by two MSN and one PwMS. PwMS older than 18 years could participate in the BELSIMS

survey. In all three surveys, demographic data were collected (e.g. age, sex, marital status, level of education,...). In the BELSIMS survey we focused on MS characteristics such as MS disease course, current treatment and patient determined disease steps (PDDS), which is a valid patient reported outcome (PRO) to determine level of disability¹³. Besides that, the availability of an MS nurse and multidisciplinary team, as described in the MS Care Unit, was questioned. Furthermore, questions on Health-related Quality of Life (HRQoL) using the EQ-5D-5L questionnaire, evaluation of driver's license adaption to disability, current health care provision and location, and suggestions for improvement in the current health care situation were asked (for the complete survey see supplementary file 3). In the MS Nurse and NEUROMS survey, questions on employment status, education, financial support, type of organization, current job content, view on future perspectives and perceived workload were incorporated (complete survey in Supplementary file 4 and 5). The BELSIMS survey was available online between May 2021 and February 2022. Posters and flyers were developed in Dutch and French and contained the RedCap link and a QR code for easy survey access. To reach as much PwMS as possible, the MS patient organization (MS Liga), neurologists and MSN from every province were contacted to disseminate the flyers and posters via waiting rooms in hospitals and practices or on their websites. The NEUROMS and MS Nurse questionnaires were made available between April and October 2021 respectively and closed in February 2022. Neurologists were recruited via the mailing list of the BSGMS. The link for the MSN survey was sent via the mailing list of the MS Nurse academy, which is a formal association uniting all MSN in Belgium. A newsletter with a recruitment update was sent twice to all members of the BSGMS.

2.2 Statistical analysis

Due to the nature of the study, descriptive statistics and mean comparison analysis are presented. Statistical analyses were performed using SPSS statistics 26 (IBM Corp. Armonk, New York). Descriptive statistics included mean and standard deviation, median and interquartile range (IQR). Independent t-tests for normal distributed variables and Mann-Whitney U tests for non-normal distributions were used. For unpaired comparison of two categorical variables, chi-square test was applied. P-values <0.05 are considered statistically significant. The graphs were created with Microsoft Excel and GraphPad Prism 9.2.0.

2.3 Protocol approvals, registrations and patient consents

The study was approved by the ethics committee of UZ Gent with Belgian registration numbers: B6702021000399 and B6702021000744. Online informed consent was obtained from all survey participants and the study was conducted in accordance with the declaration of Helsinki and Good Clinical Practice guidelines.

3 Results

The distribution of respondents for the three surveys in Belgium shows a majority of participants from the Flemish region (see figure 1). 93% of the 62 responding neurologists were members of the BSGMS.

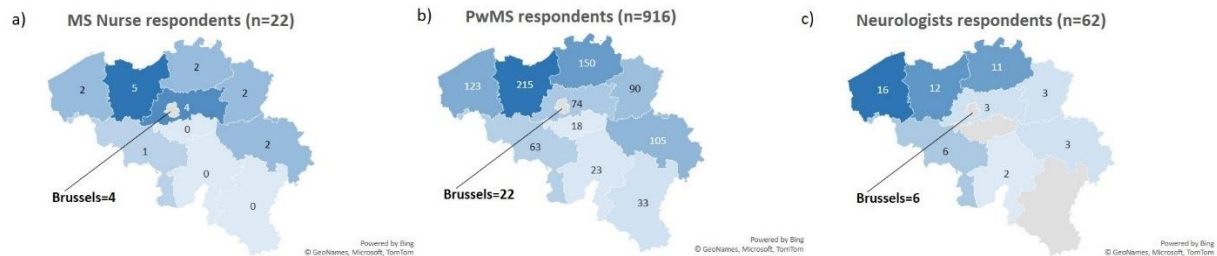


Figure 1 Participation rate in Belgium for the BELSIMS, MSN and NEUROMS survey, lowest to highest respondent rate is illustrated from light to dark grey

The respondents from the BELSIMS survey (n=916) show a mean age of $46 \pm 12,7$ years and a majority of female respondents (75,4%) (Table 1). MSN's (n=22) are mainly employed in a university hospital (45.5%) whilst the majority of neurologists work in a general hospital (75.8%).

MS MDT's are largely organized within the hospital (local) with a team generally consisting of a neurologist, MSN, a (neuro)psychologist, social worker, physiotherapist and/or rehabilitation physician (Table 1).

Table 1 Demographics and organizational data of survey respondents BELSIMS: PwMS survey

	BELSIMS	MS NURSE	NEUROMS
Respondents (n)	916	22	62
Age (mean \pm SD, range)	46 \pm 12,7 (18-83)	44,3 \pm 9,3 (27-61)	45,3 \pm 9,8 (31-66)
Female (%)	691 (75,4)	18 (82)	33 (53)
QoL (mean \pm SD, range)	65.5 \pm 20.1 (6-100)	N/A	N/A
EQ-5D index (median (IQR))	0.754 (0.318)	N/A	N/A
Type organization (%)			
University hospital	42,7	45,5	25,8
General hospital	37,9	36,4	75,8
Rehabilitation center	14,6	27,3	8,1
Private clinic	2,7	0	9,7
University	N/A	N/A	4,8
Multidisciplinary team available (MDT) (%)	65,3	76,2	52,5
MDT Team members (%)			
Neurologist	89,8	87,5	96,8
MS Nurse	82,4	87,5	93,5
Psychologist	52,7	50,0	64,5

Social worker	50.3	81.3	93.5
Physiotherapist / rehabilitation physician	53.9	65.5	72.6
Urologist	36.9	25.0	29.0
Speech therapist	18.1	12.5	29
Occupational therapist	N/A	12.5	48.4
Other	15.3	31.3	16.1
MDT organization (%)			
Local MDT	N/A	62.2	83.9
External MDT	N/A	25.0	16.1
MS Nurse available (%)	60,4	N/A	53,2
In need of an MDT? (%)		100	75
In need of an MS nurse? (%)		N/A	69

SD = standard deviation, N/A = not applicable

The BELSIMS data was used to compare the characteristics of PwMS regarding the availability of an MSN/MDT or not (Table 2, supplementary). First of all, figure 2 shows a striking difference regarding the availability of MSN's and MDT's between the northern and southern parts of the country. In addition, PwMS who have access to an MSN or MDT are significantly younger than those who don't (43.5 ± 11.9 versus $48,8 \pm 13,2$ years, $t(746) = -2.9$, $p = .004$ and 45.0 ± 12.5 vs 47.12 ± 12.9 years, $t(808) = -2.3$, $p = .025$ respectively). The average PDDS does not differ between these groups. The proportion of RRMS is larger in both the MSN group (67.3% vs 55.1%) as in the MDT group (62.8% vs 58.7%). Centers that do not offer an MSN (11.5% vs 22.6%) nor MDT (12.7% vs 21.0%) have a larger population of PwMS who are unaware which MS disease course they have (MSN $X^2(3, 748) = 19.3$, $p < .001$; MDT $X^2(3, 810) = 10.9$, $p = .012$) (Table 3, supplementary).

PwMS with availability of an MSN have a higher frequency of being treated with an MS disease modifying treatment (DMT) (82.9% vs 75.7%, $X^2(1, 598)$, 5.9, $p = .015$), higher frequency of specific symptomatic treatments against spasticity (24.6% vs 18.2%) ($X^2(1, 165)$, 4.1, $p = .042$) or treatments to improve mobility (24.6% vs 18.2%) ($X^2(1, 83) = 4.4$, $p = .035$). Management by a physiotherapist is more encouraged in centers with an MSN (52.9% vs 42.2%) $p = .004$ and MDT (53.0% vs 40.2%) ($X^2(1, 376) = 11.2$, $p < .001$). Driving ability advice to adjust ones driver's license received more attention in centers with an MSN (51.1% vs 32.4%, $X^2(1, 327)$, 25.4, $p < .001$) and MDT (50.2% vs 30.3%, $X^2(1, 327)$, 27.6, $p < .001$). PwMS are more frequently employed in the MSN group (63.3% vs 52.7%, ($X^2(1, 442) = 8.3$, $p = .004$). Support for work adaptation measures is more frequent in the MSN group (23.0% vs 15.9%) ($X^2(1, 151) = 5.6$, $p = .018$) and in the MDT group (21.7% vs 12.8%) ($X^2(1, 151) = 9.6$, $p = .002$). Regarding HRQoL no differences were found for the five subscales (mobility, selfcare, daily life, pain and discomfort, and depression or anxiety; all $p > .05$) (table 4, supplementary). The HRQoL in

employed PwMS, on the other hand, is higher than in unemployed PwMS (70.7% vs 58.7%, $t(851)=8.99$, $p<.001$), even when measured for PDDS ≤ 3 (73.3% vs 66.2%, $t(607)=4.69$, $p<.001$) (Table 5, supplementary). Finally, PwMS without an available MDT more often indicate that MS care needs improvement (23.4% vs 36.2%, $X^2(1, 209)$, 13.8, $p < .001$) (Table 3, supplementary).

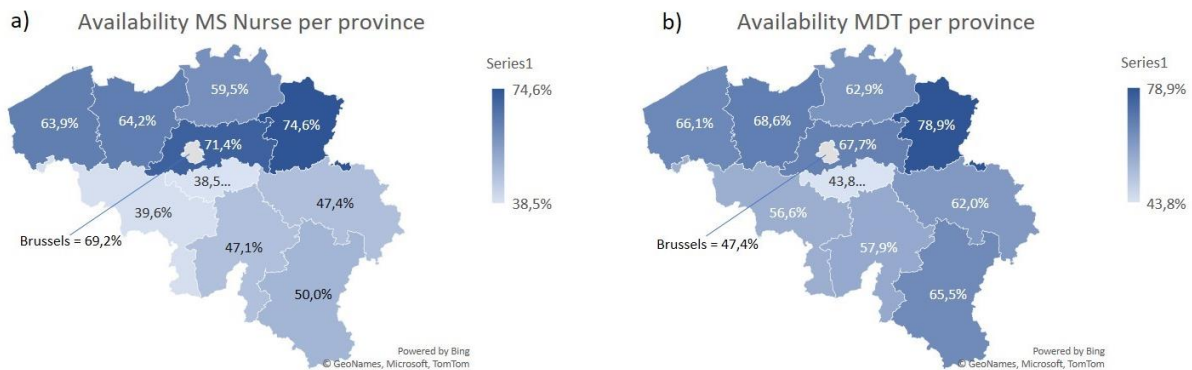


Figure 2 Proportion (%) of a) available MS nurses and b) MDT's per province for PwMS

3.1 MS Nurse survey

The majority of MSN who completed the survey have a bachelor degree in nursing (59.1%) (Figure 3a). The international MS Nurse Pro course is the most widely used MS training tool, alongside (inter)national conferences (68.2%) and a semi-annual MSN Academy organized in Belgium (68.2%) (figure 3b). Most of the MSN participating in the survey are employed in a university hospital (45.5%) followed by a general hospital (36.4%) (Figure 3c). Seventy percent of the MSN state they have over one hundred PwMS in follow-up, 45% of them follow more than 300 PwMS on a regular basis (Figure 3d). The three main MSN tasks include (i) availability by phone and email (34.5%), (ii) psychosocial support (30.5%) and (iii) performing test batteries (e.g. MSFC, BICAMS) (23.6%). Tasks ranked as important by neurologists follow the same trend, even though, academic research support is a little more prominent. Finally, only 9.1% of the MSN are funded by the national health care insurance system. The majority of MSN are funded by local non-governmental budgets, within a budget made available by neurologists (39.4%) or by available hospital budgets (36.4%). 21% of the MSN's are funded by revenues from clinical trials.

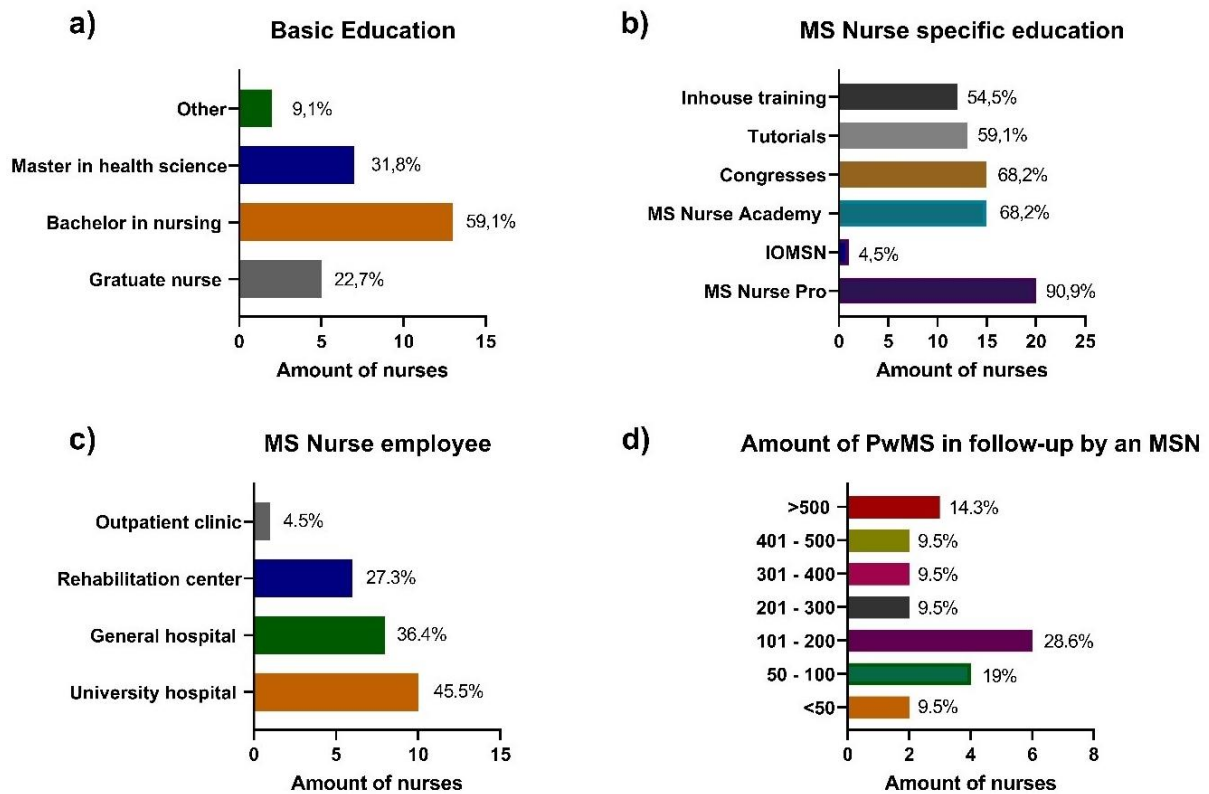


Figure 3 a) Basic and b) specific MSN education, c) employment of MSN and d) Amount of PwMS in follow-up by an MSN

3.2 NEUROMS: survey for neurologists

In centers where an MSN is available, neurologists generally spend more time on specific MS care (52.8 ± 24.8 vs 13.9 ± 13.9 minutes, $t(60) = -3.1$, $p < .001$) and have more MS patients in follow-up (253.6 ± 278.2 vs 92.8 ± 102.8) ($t(60) = -2.45$, $p = .014$) (Table 6, supplementary). Also, neurologists in centers with an MSN or MDT provide significantly more time (more than 30 minutes) during the consultation in which the MS diagnosis is announced and explained (56.9% vs 43.1%) ($\chi^2(1, 58), 4.9$, $p = .043$) or (56.4% vs 43.6%) ($\chi^2(1, 58), 4.8$, $p = .029$). The majority of neurologists who do not have an MSN or MDT available indicate needing such support (Figure 4). Furthermore, there are no differences regarding the frequency of follow-up of PwMS between the groups ($\chi^2(62, 4) 1.82$, $p = .854$) nor are there differences in preferable MDT organization ($\chi^2(4, 59) 7.382$, $p = .088$). Finally, a majority of neurologists prefers governmental organization of MS multidisciplinary care at a hospital network level ($61,0\%$) (Table 7, supplementary).

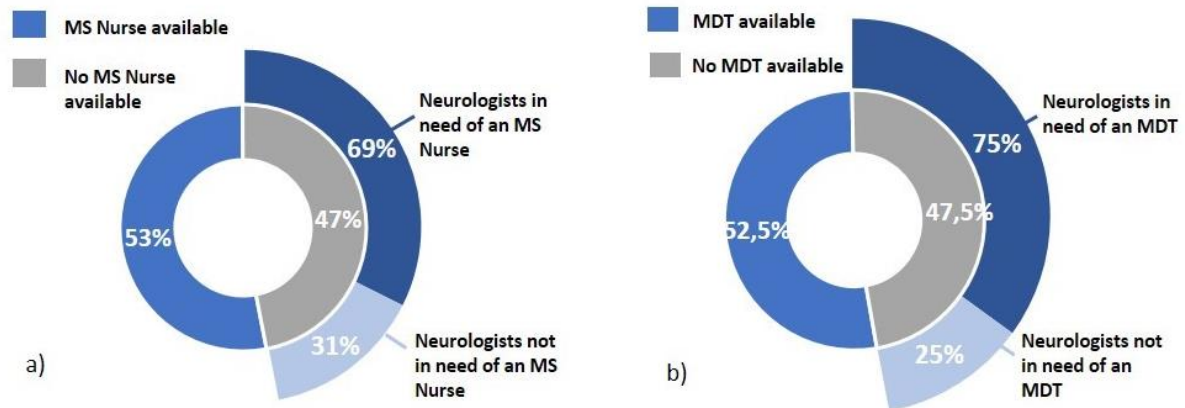


Figure 4 Prevalence of a) available MSN and b) MDT and required need in centers without

4 Discussion

MS Care Units have been proposed as a quintessential standard of care⁸. This study describes the multidisciplinary treatment landscape as well as unmet needs and perspectives from PwMS, MSN and neurologists in Belgium.

In centers with an MSN or MDT, patients were generally younger with a larger proportion of RRMS, whilst the disability level was comparable between centers with or without MSN or MDT. It is remarkable that PwMS without access to MSN or MDT were half as likely to have knowledge on their disease course of MS. There are three potential explanations for these findings. First of all, one study previously showed that MSN may increase information provision¹⁴. Secondly, our results indicate that neurologists working with an MSN or MDT have more patients in follow-up and spend significantly more time on MS care, notably on explaining the diagnosis, than neurologists without this support. And three, the degree of education¹⁵ or cognitive functioning might differ between groups, yet this was not included in the survey. The current algorithm for disease modifying and symptomatic treatments in MS has become increasingly complex and multidisciplinary support is recommended to guide PwMS through the treatment landscape⁸. According to the 2020 MS barometer report, Belgium has a disease modifying drug access rate of approximately 80%, which is the third highest rank of access to DMTs among 35 European countries^{16,17}. Yet, despite the high accessibility rate, disparities remain visible as our results showed that centers with a neurologist and MSN working together prescribe more DMTs than neurologists working without. The same pattern for symptomatic treatments was noted. For example, treatments to decrease spasticity and gait problems are more frequently prescribed in centers with a MSN and the same was noticed regarding treatment for bladder problems in centers with an MDT. Although cautiously, these findings may reinforce the theory that multidisciplinary care offers more individualized and appropriate treatments. When looking at non-pharmacological therapies, PwMS were more likely to be treated by a physiotherapist and have contact with social

workers when they are provided with an MDT or MSN. Although no causality can be claimed by this study, the ability of a specialized MSN to liaise between patients and different health care providers or medical systems has already been described¹⁸.

The socio-economic consequences following a diagnosis of MS should not be underestimated. Besides disability, older age and lower education, invisible symptoms such as fatigue and cognitive problems can cause early disruption in work-life balance¹⁹. Our data demonstrates a higher employment status in centers with an MSN, which could be explained by the younger and particularly RRMS population (although the PDDS was equal) in the group with an MSN. A previous study examined the psychological health in adults with MS and reported a higher QoL in employed patients in comparison with unemployed patients²⁰. Similar results were obtained in our study when looking at the QoL in PwMS with a PDDS of ≤ 3 who were still employed compared to those who were not. Support and guidance for specific work accommodations such as flexible hours, consciousness increase and early referral for physical and cognitive rehabilitation may extend the period during which the PwMS are employed²¹. Especially in the MDT group, significantly more PwMS seem to have support regarding invalidity and sickness benefits and health insurance measures, pointing out the advantage of an MDT for these socio-economic aspects.

An aspect easily overlooked in MS health care is advice regarding driving ability and adaptation of the driver's license. In Belgium, an adjustment is legally required when diagnosed with a neurological disease potentially influencing driving ability. However, it is difficult for a clinician to estimate the driving skills of their MS patients, especially when they are transitioning into a more progressive phase. Previous work showed that poor scores on the MS Functional Composite (MSFC) are associated with early signs of compromised driving²². Another qualitative study concluded that PwMS are in need of more support, information and guidance when their ability to drive is being questioned²³. Our study emphasizes the need for multidisciplinary support as we see that driver's license adjustment is fulfilled in half of the PwMS who have an MSN or MDT available whereas it is fulfilled in only a quarter of the PwMS in centers without.

As for Health-Related Quality of life (HRQoL) we found no major dissimilarities between the two groups. HRQoL is a complex parameter and it is difficult to identify the main aspect that defines a person's QoL. Yet, periodical measurement of QoL could provide more insights regarding treatment effectiveness²⁴ and covers a more holistic approach instead of merely using clinical or para-clinical parameters.

Ideally, multidisciplinary support should be available for every PwMS. Yet, our data show that only 2/3 of the questioned PwMS have access to an MSN or MDT. Especially older PwMS with a primary

progressive diagnosis do not seem to be offered a multidisciplinary approach. This might be influenced by their disease duration and the limited treatment options for progressive MS, possibly leading to less frequent follow-up. Also, when looking at the geographical distribution of BSGMS members we see a different ratio of available MS-neurologists per province, especially in the Walloon region, which might cause PwMS having to cover longer distances to get optimal care and illustrating regional health disparities (Figure 2).

The majority of neurologists stated the need for MDT support, even if they indicate that their workload and time management isn't influenced by its availability or not. Besides that, they mainly prefer MDT care to be organized at a hospital network level, which means more collaboration between several hospitals and concentration of expertise regarding complex diseases. Currently, MDT meetings for chronic diseases are usually organized locally, yet a mixed-method observational study from 2014 consented that MDT should have locally and national determined goals in order to decrease variability in care²⁵.

As the prevalence of chronic diseases is increasing, nurse practitioners will most likely play a greater role in maintaining and coordinating qualitative care. One randomized trial already showed that add-on nurse-led care was able to improve depression in PwMS²⁶. Besides that, a case study concluded that their input is largest in patient's self-management, decision making support and promoting proactive clinical care²⁷. A mixed-methods study in Germany also confirmed the supportive role of an MSN in the decision making process for first-line immunotreatments and the effectiveness of nurse counseling²⁸. Next to that, a meta-analysis confirmed the need for multi-professional guidance because it focuses on managing impairments and limitations from a PwMS's own perspective by using symptom and fatigue screening tools instead of merely focusing on the clinical examination (e.g. EDSS)²⁹. In 2019, a first Belgian framework for 'Advanced Practice Nursing' (APN) was outlined, but its interpretation raised a lot of questions³⁰ and the lack of clarity makes it difficult to fulfill a specific APN role. It is also noteworthy to mention that Belgium is lagging behind regarding job profiling of APNs (e.g. nurse counseling, medical counseling). A legal framework has been available since 2018³¹, but it has not been implemented and pilot studies have yet to be initiated³². This fundamental deficit might be one of the reasons that the tasks MSNs perform or are questioned about in this survey, do not represent and perhaps underrepresent the true value of an MSN. In addition, an international mixed-method study concluded that a high proportion of MSNs reported knowledge and skills gaps to guide individual patient goals into specific recommendations, advocating focused training and education in MS³³. When looking at our data, the majority of MSN have a bachelor in nursing and an MSN Pro certificate, which was encouraged by the national MSN Academy. Our results also show global similarity between the tasks performed by MSN and the preferred tasks by neurologists (Figure 2). Taken together, our data

show a high degree in variability of MSN education and performed tasks, stating the need for clear (inter)national quality standards and guidelines in MSN and MDT care. The current financing of MSN and MDT is mainly provided from local hospital budget or budget provided by the neurologists themselves, a situation that is not sustainable in the long term.

5 Strengths and limitations

Due to the cross-sectional character of this project, caution is advised when interpreting the results regarding causality. Moreover, the study cannot exclude a factor of reversed causation: by example higher DMT prescription rates in MSN-supported patients may be impacted by better education¹⁵, but equally by cognitive state or factors such as local availability of an MS center. Unfortunately, research on the topic remains scarce and randomized controlled trials are difficult to design. Another limitation that needs to be considered is a possible selection-bias associated with the recruitment method. This might have caused a relatively higher participation rate in centers with an MSN or MDT, and therefore, the access to such services could be lower than estimated in this study. Besides that, the study might have missed out on people who are not familiar with online surveys or PwMS with a higher disability grade due to practical implications. Also, there is no insight to what extent PwMS received care from an MSN and MDT and how many care contacts took place. And above that, the results from the MS nurse survey showed that there is no clear task profile, which makes it impossible to fully interpret its impact on HRQoL or disability.

6 Conclusion

Multidisciplinary care including an MSN or MDT may increase MS care quality. Further research is needed to identify and implement this multidisciplinary support, but also to track and prevent disparities regarding health care for PwMS. Clearly, there is a need for consensus quality criteria for MS care at an (inter)national level. Our findings may act as a basis for elaborating the policy procedure to obtain a national reimbursement for MSN and MDT, which might ultimately improve the medical and socio-economic outcomes for PwMS and their families.

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8 Disclosures

The authors have nothing to disclose.

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