

The Dutch MS Patient Voice Survey: impact of disease on daily life

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ePoster Session: P1057

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ePoster presentation at the 8th Joint ACTRIMS-ECTRIMS Meeting, MSVirtual 2020, September 11–13, 2020

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Disclosures

- C.C. Schouten, Dutch MS association - nothing to disclose
- E.M. de Wolf, Dutch MS association - nothing to disclose
- L. Avis, DVJ Insights - nothing to disclose
- L. Hoeijmakers, employee of Novartis Pharma The Netherlands
- A. Buurman, employee of Novartis Pharma The Netherlands
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The MS Patient Voice research collaboration group consists of:

- Dutch MS association
- National MS foundation
- DVJ insights
- Novartis pharma

Background and objective

- Shared decision-making is a key aspect in healthcare and patients are motivated to take ownership of their own lifestyle changes. Informing, coaching, and sharing knowledge with patients with multiple sclerosis (MS) are some of the key objectives of patient advocacy organizations. Therefore, gathering patient insights on disease burden and interests will help patient organizations and other stakeholders to support MS patients in the Netherlands. Moreover, they will be able to reach out to the MS community in an effective way

Objective

The Dutch Patient Voice Survey aims to research MS patients' opinions and perceptions about MS for each phenotype. This patient survey aimed at gathering insights on the symptom development, the impact of MS on activities of daily living (ADL) in relation to (co)mediation use and MS phenotype

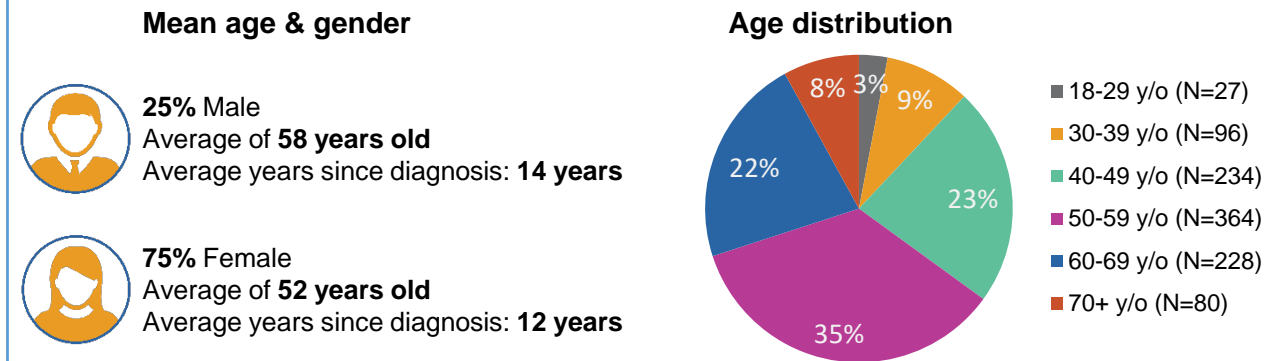
Methods: Patient voice: online patient survey

- From June until August 2019, 1029 MS patients participated in this (20 minute) online survey. Dutch patient advocacy organizations, MS association Netherlands and the National MS Foundation, invited participants to fill in the survey. The survey consist of three sections:
 1. Characteristics of disease phenotype and disease activity
 2. Impact of disease on daily life
 3. Patient needs and information gathering
- Data presented here is section two of the survey:

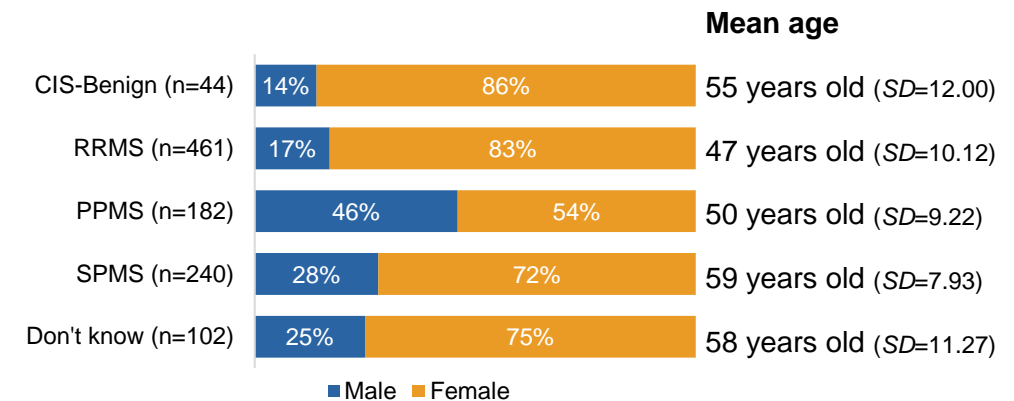
Study population profile

- This Patient survey is the largest MS patient survey ever conducted in the Netherlands
- More than half of the 1,029 participants were older than 50 years (65%) and a large proportion of participants were female (75%)
- The average years till diagnosis was 12 years for the female population and 14 years for the male population
- 10% of the participants could not report their MS phenotype
- The MS study population may have biased some of the results

Characteristics (age, gender & disease duration)



Characteristics (age & phenotype)



Results: (Co) Medication use by phenotype

- A majority of the PPMS (64%) and SPMS (68%) patients do not use disease-modifying therapies (DMTs)
- RRMS patients used a DMT in 74% of the cases which is significantly different from the SPMS and PPMS group
- Medication home delivery is used by 78% of the RRMS patients and 77% of the SPMS patients
- The use of medication other than DMTs was significantly lower for RRMS patients than for SPMS and PPMS patients, with the exception of depression and fatigue treatments for PPMS patients
- Almost half of the SPMS patients (48%) use medication (non-DMT) to treat their spasms. 36% of the PPMS patients are treated for urological problems

Current DMT therapy *

	RRMS (A)	SPMS (B)	PPMS (C)
Starting therapy	40% BC	13% AC	2% AB
Follow-up therapy (capsule or tablet)	11% BC	2% A	3% A
Infusion therapy	18% B	6% AC	20% B
Other DMTs	5% B	12% A	9%
No medication	26% BC	68% A	64% A

Base: Currently using MS medication. RRMS: N=339; SPMS: N=77; PPMS: N=65. CIS-Benign: N=5 and therefore not reported. A/B/C: significantly different from column with corresponding letter

Co-medication use

	CIS-Benign (A)	RRMS (B)	SPMS (C)	PPMS (D)
Use of co-medication (%Yes)	25% BCD	48% ACD	74% ABD	62% ABC
For: Walking	2% CD	11% CD	33% AB	27% AB
Pain	18% C	27% C	37% AB	29%
Spasms	5% BCD	18% ACD	48% ABD	34% ABC
Depression	9%	10% C	17% BD	9% C
Fatigue	7% C	12% C	20% ABD	11% C
Urological complaints	5% CD	14% CD	44% AB	36% AB

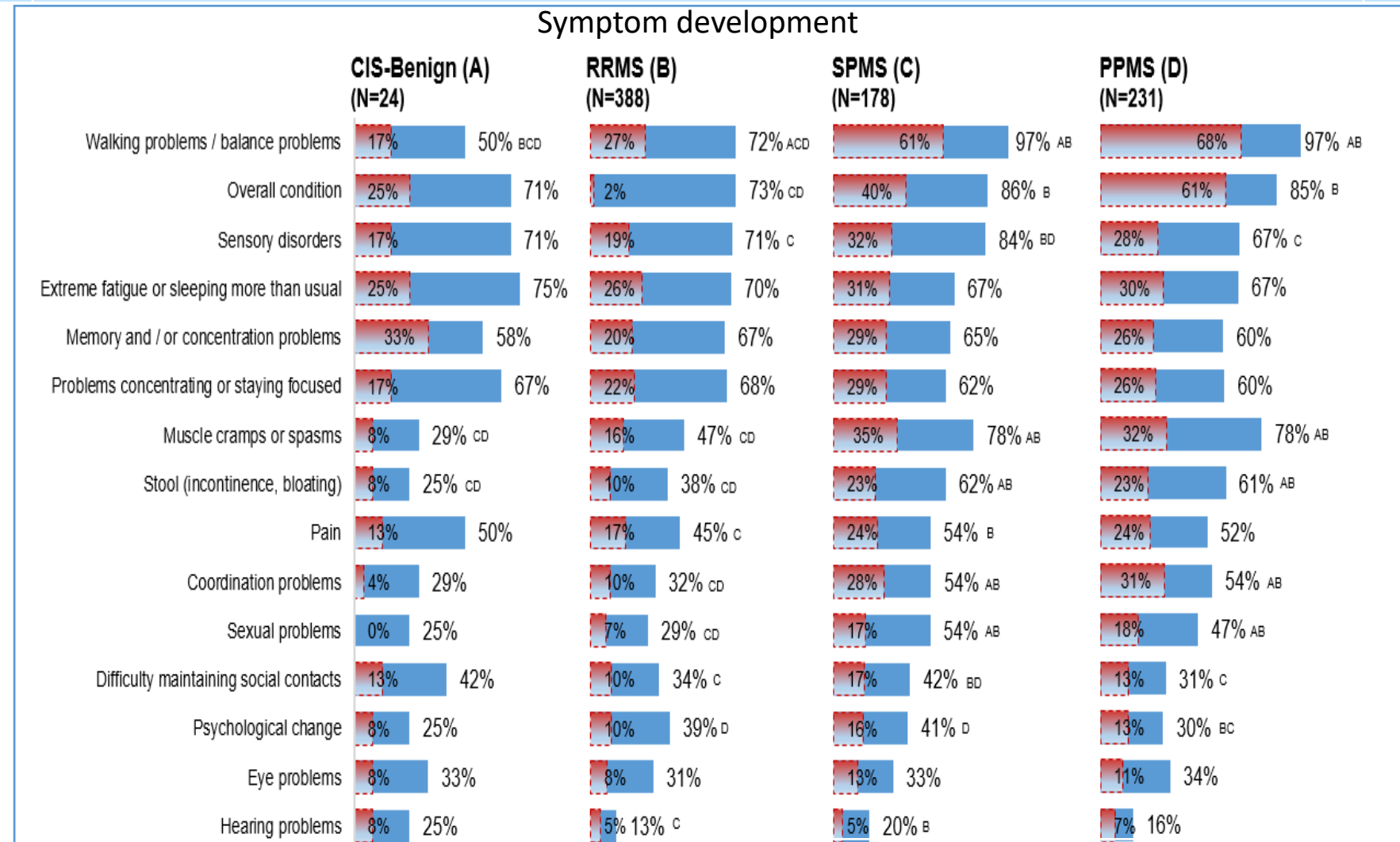
CIS-Benign: N=44; RRMS: N=461; SPMS: N=240; PPMS: N=182
A/B/C/D: significantly different from column with corresponding letter

* The therapies were clustered:

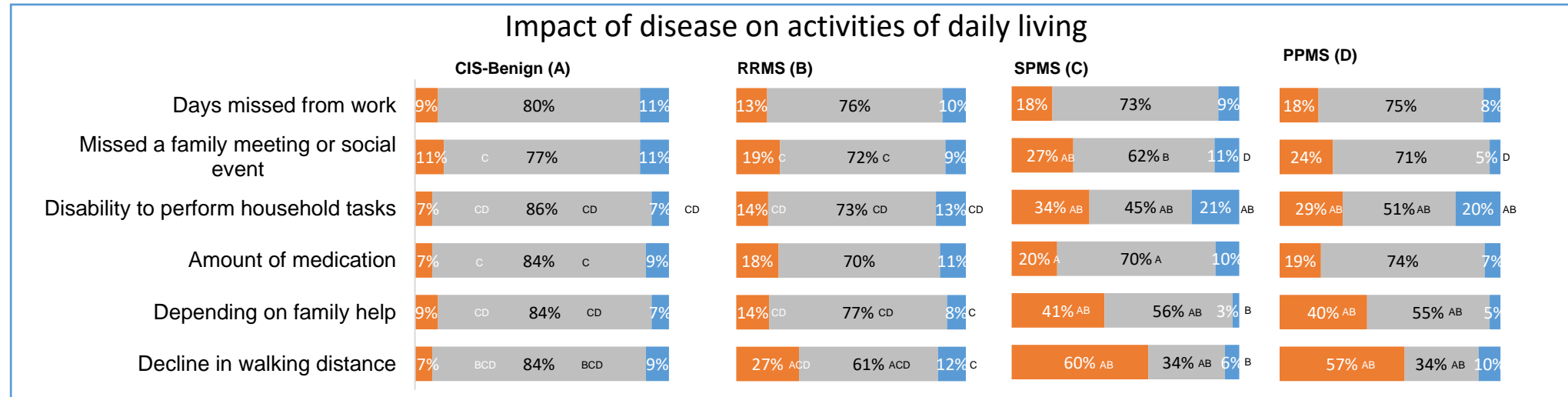
- Start therapy: interferon, glatirameeracetaat, dimethyl fumarataat, teriflunomide
- Follow-up therapy: fingolimod, cladribine
- Infusion therapy: alemtuzumab, ocrelizumab

Results: Symptom progression during the last 6 months for each phenotype

- CIS-Benign and RRMS patients report similar symptoms, with the exception of walking/ balance problems
- SPMS and PPMS patients are more likely to suffer from walking/ balance problems, muscle cramps or spasms and sexual problems
- SPMS and PPMS patients also show a more frequent decline in overall condition, walking/ balance problems and muscle cramps
- Cognitive impairment occurs at all stages, including CIS and deterioration on the level of memory, concentration and focus is most pronounced in SPMS



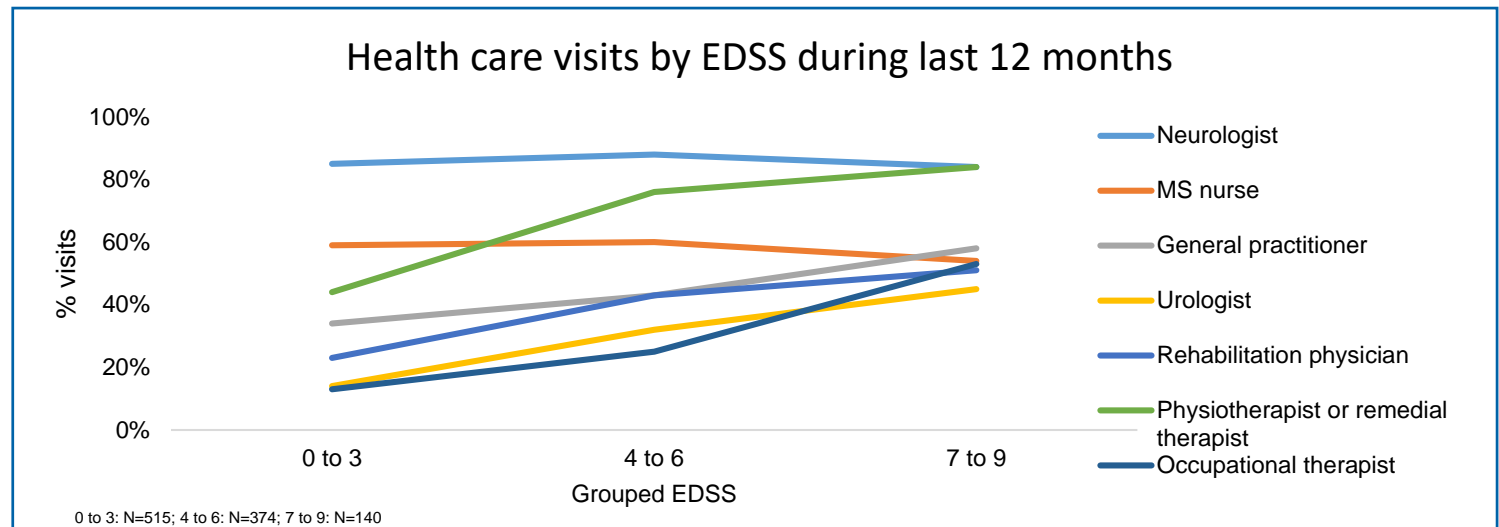
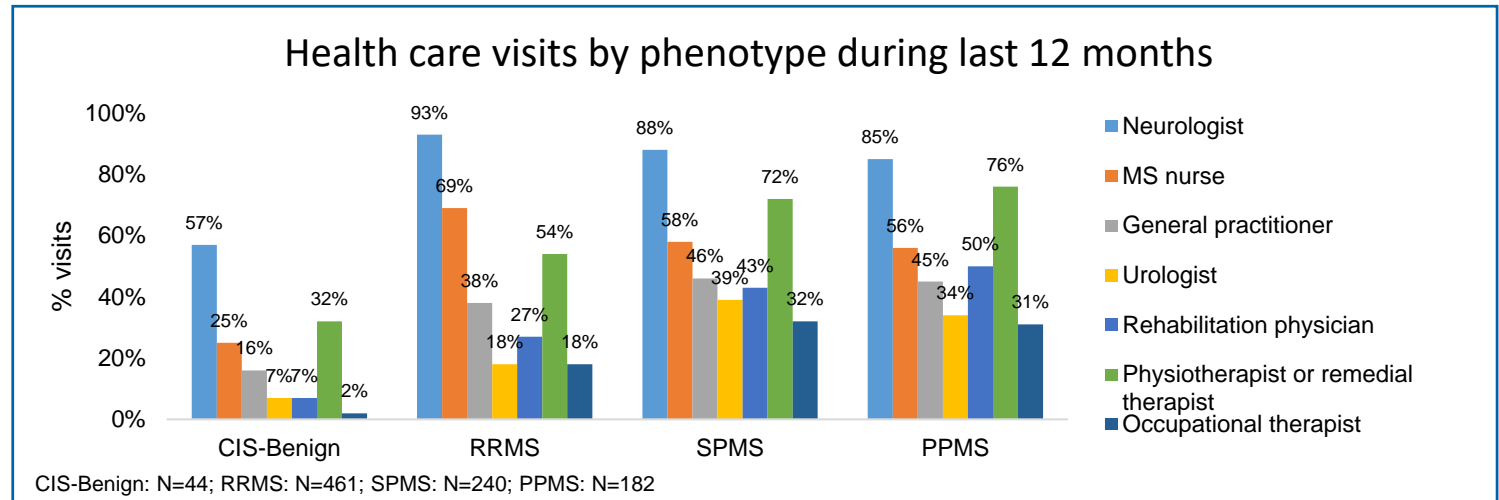
Results: Impact of disease on daily life activities



- In 6 months, the impact of MS on ADL increased more in SPMS and PPMS patients compared to patients with CIS-Benign MS and RRMS. Furthermore, patients reported an increase in disability to perform household tasks
- The walking distance declined the most in SPMS (60%) and PPMS (57%) patients over the last six months. Of the RRMS patients, 27% reported a decline during the last six months
- There is a significant correlation between the number of missed family meeting and the following symptoms: overall condition, extreme fatigue, cognitive problems and pain (see previous slide). Besides, the degree of family dependence strongly correlates with overall condition, coordination problems, walking problems and psychological change

Results: Health Care Professional visits by phenotype & EDSS

- MS patients visits a wide variety of Health Care Professionals (HCPs)
- Health care visits increase as the disease progresses. The neurologist is yearly visited on average 1.9 times. The MS nurse on average 2.3 times
- Neurologists and MS nurses are most frequently seen by patients with EDSS 0-6. The number of visits remain stable with increasing EDSS for these health care professional
- When EDSS score increases, other HCPs are visited more often. The largest increase is seen for the occupational therapist



Conclusions

- **Medication use:**
 - The majority of the PPMS and SPMS patients do not use DMTs. These groups report a decline in functionality and an increase in symptomatic treatment, which highlights the burden of disease and a potential medical need for these patients
 - The majority of the RRMS and SPMS patients have their medication delivered at home, which may be related to their impaired mobility and higher ECSS score
- **Disease impact on ADL:**
 - The burden of disease and progression of specific symptoms differ strongly for each phenotype. PPMS and SPMS patients report a higher burden of disease and impact on ADL than RRMS patients
 - There is a significant correlation between the number of missed family meeting and the following symptoms: overall condition, extreme fatigue, cognitive problems and pain. Besides, the degree of family dependence strongly correlates with overall condition, coordination problems, walking problems and psychological change
- **Health Care Professional support:**
 - Visits to the neurologists (1.9 visits per year) and MS nurses (2.3 visits per year) stay similar over the years of disease progression. The role of occupational therapists, rehabilitation physicians and urologists increase over time