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Characterizing People With Untreated Multiple Sclerosis in Real-World Evidence: Insights From Literature and the German NeuroTransData Registry (2018-2024)

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Stefan Braune,[1] Yanic Heer,[2] Martin Traber,[3] Ana Ferro,[4] Arnfin Bergmann,[1] Katya Glactionova,[3] NTD Study Group, Carmen G. Berardo[3*]

*Presenting author.

[1]NeuroTransData, Neuburg, Germany; [2]Rewoso AG, Zurich, Switzerland; [3]F. Hoffmann-La Roche Ltd, Basel, Switzerland; [4]Roche Products Ltd, United Kingdom

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OBJECTIVE

This retrospective cohort analysis of real-world evidence from people with MS (PwMS) captured in the German NeuroTransData (NTD) registry aimed to assess the epidemiological trends and reasons for staying untreated.

KEY TAKEAWAYS

- Despite a trending decrease in untreated PwMS, substantial treatment gaps persist
- Progressive course, lower disease activity, age above 55 years and PwMS preferences characterised the untreated population
- New therapeutic approaches are needed to address the remaining unmet need

BACKGROUND

- High-efficacy disease-modifying therapies (DMTs) have transformed MS care, yet >40% of diagnosed PwMS remain untreated[1-4]
- PwMS who are untreated are rarely the primary focus of clinical research, leading to significant gaps in the characterisation of root causes and clinical profiles of those who remain untreated post diagnosis[1,2]

METHODS

- A pragmatic literature review was conducted to map definitions of "untreated" PwMS
- This retrospective cohort study analysed data from the German NTD, a disease-specific MS outpatient registry, with a total of 119 neurologists in 59 offices and including >22,000 PwMS
- All data (clinical, demographical, treatment status or decision reasons) were collected by physicians and study nurses during regular office visits through a web-based platform and routine visits typically occurring 3-4 times per year
- Clinical and socioeconomic data were summarized with descriptive statistics

Predefined episodes based on:

- Start and stop/pause dates of DMT
- Duration of untreated period
- MS subtype

Groups

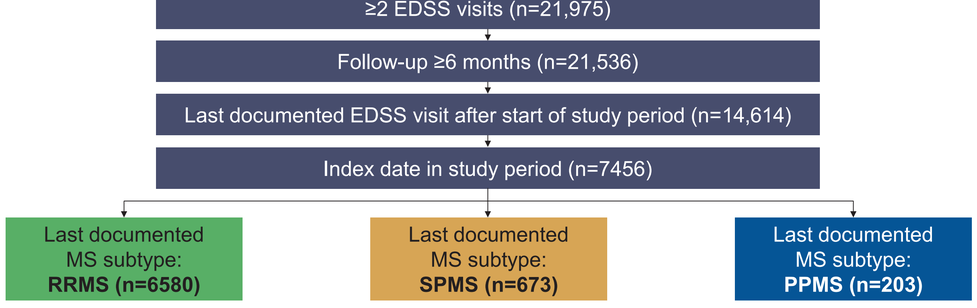
- Treated/untreated primary progressive MS (**PPMS**)
- Treated/untreated secondary progressive MS (**SPMS**)
- Treated/untreated relapsing-remitting MS (**RRMS**)
- **RRMS** ≥55 years old

RESULTS

Summary of Literature Review Findings

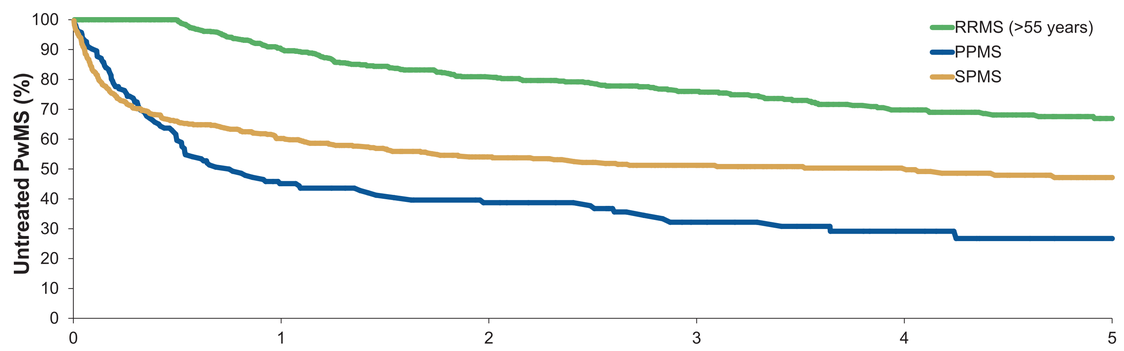
- There is a lack of detailed clinical and socioeconomic data for the untreated MS population, as this has not been a primary research focus
- There is no standardised definition for "untreated" or "undertreated" across the literature, leading to high variability in how these PwMS are classified and tracked
- Extended gaps in therapy, such as the absence of drug refills for 3-6 consecutive months, are generally recognised as treatment interruptions or periods of supportive care
- Older age (eg, >55 years) and progressive MS phenotypes (SPMS and PPMS) are consistently identified as primary factors for remaining untreated
- Decisions to forego treatment are frequently driven by PwMS preferences and barriers, including mild symptoms, fear of side effects, dislike of injections and economic burden

Participant Disposition



DMT Reinitiation: Untreated PPMS, Untreated SPMS and Untreated RRMS (>55 years)

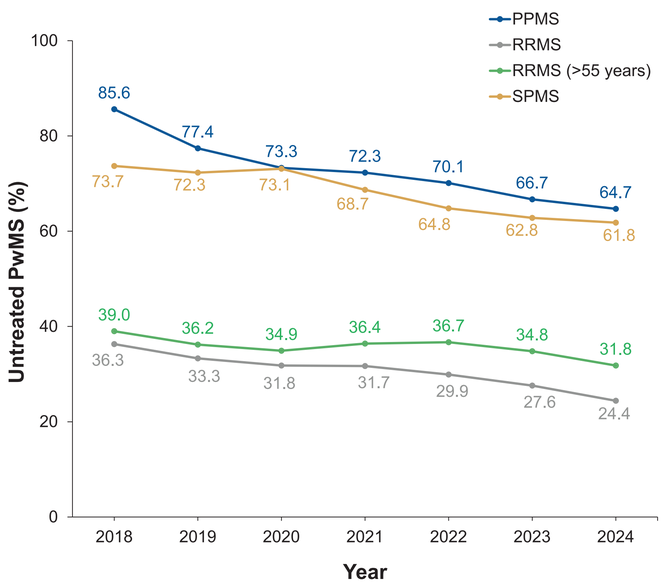
- At 5 years after diagnosis, only 25% of people with RRMS (>55 years) reinitiated treatment



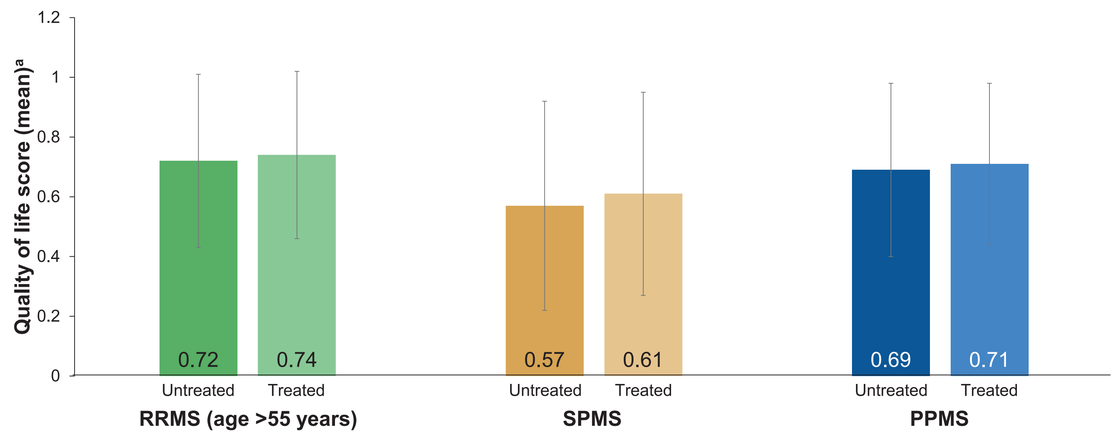
No. at risk (n)						
RRMS (>55 years)	910	616	403	275	183	97
PPMS	165	63	44	26	15	7
SPMS	579	267	193	135	89	48

Proportion of Untreated PwMS Per MS Subtype and in RRMS (>55 Years)

- The proportion of untreated PwMS declined between 2018 and 2024
- Treatment gaps persist in progressive MS and older people with RRMS (>55 years), whose proportion among the untreated increased

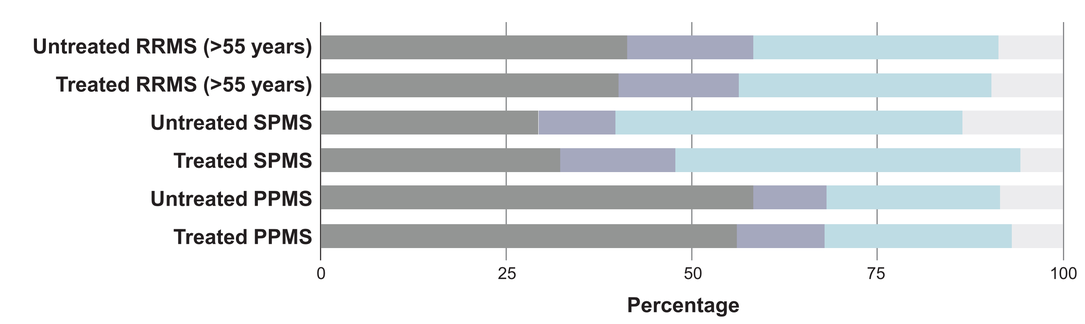


Quality of Life per MS Subtype and in RRMS (>55 Years)



[a]Quality of life uses EuroQol 5-Dimension (EQ-5D) questionnaire values with the published German value set and was not adjusted for key confounders, including age.[5]

Employment Status per MS Subtype and in RRMS (>55 Years)

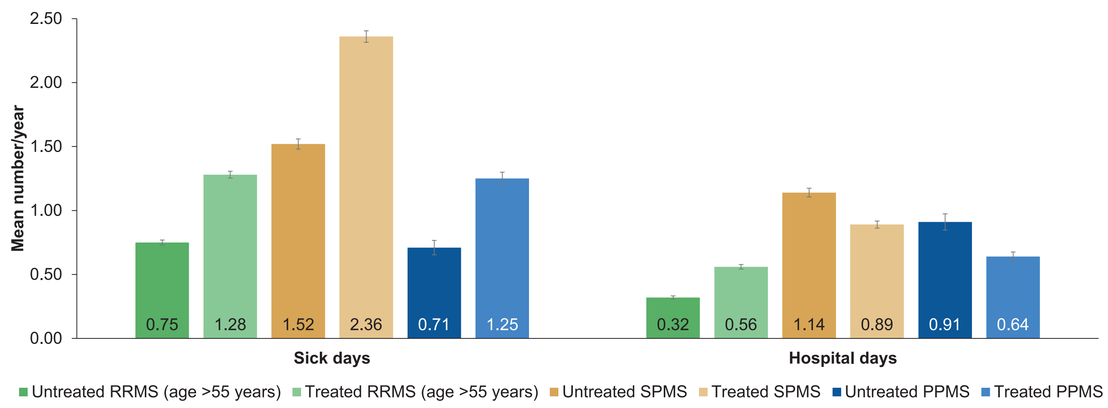


Baseline Characteristics

	Untreated RRMS (>55 years), n=910	Treated RRMS (>55 years), n=858	Untreated SPMS, n=579	Treated SPMS, n=590	Untreated PPMS, n=165	Treated PPMS, n=196
No. of unique PwMS[a]	888	695	507	432	144	164
Age, mean (SD), years	58.18 (4.90)	59.79 (4.21)	55.86 (9.70)	53.37 (8.39)	52.06 (11.07)	51.07 (10.50)
Female, n (%)	688 (75.6)	636 (74.1)	389 (67.2)	396 (67.1)	101 (61.2)	108 (55.1)
EDSS, mean (SD)	3.13 (2.11)	3.18 (1.76)	4.99 (1.71)	4.85 (1.61)	4.05 (1.97)	4.17 (1.84)
Missing, n (%)	301 (33.1)	183 (21.3)	96 (16.6)	101 (17.1)	60 (36.4)	51 (26.0)
No. of years since diagnosis, mean (SD)	15.86 (9.60)	14.76 (10.04)	18.49 (9.81)	17.43 (8.77)	4.50 (6.41)	5.82 (6.39)
Annualised relapse rate in previous year, mean (SD)	0.10 (0.40)	0.33 (0.60)	0.19 (0.50)	0.29 (0.63)	0.10 (0.34)	0.16 (0.41)
Untreated due to doctor decision, %	51.80		53.40		69.40	
Observation time, mean (SD), years	2.20 (1.82)	2.03 (1.86)	1.65 (1.89)	1.94 (1.76)	1.34 (1.58)	2.56 (1.97)

[a]Some pwMS show multiple times in the cohorts if they have multiple episodes of treated or untreated.

Sick Days and Hospital Days per MS Subtype and in RRMS (>55 Years)



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ABBREVIATIONS

DMT, disease-modifying therapy; **EDSS**, Expanded Disability Status Scale; **EQ-5D**, EuroQol 5-Dimension; **MS**, multiple sclerosis; **NTD**, NeuroTransData; **PPMS**, primary progressive multiple sclerosis; **PwMS**, people with multiple sclerosis; **RRMS**, relapsing-remitting multiple sclerosis; **SPMS**, secondary progressive multiple sclerosis.

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DISCLOSURES

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