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Title: Participants from the Swiss Multiple Sclerosis Registry (SMSR) who are not under regular medical care: Is there evidence for underuse?

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For Persons with Multiple Sclerosis (PwMS), regular medical care (RMC) by a general practitioner or neurologist is recommended [1]. Moreover, evidence shows that, for persons with relapsing remitting MS (RRMS), early initiation of disease modifying therapy (DMT) leads to a slower disease progression compared to a later one [2]. We aimed to determine the group size and characteristics of PwMS not under RMC for their MS in the last 12 months.

The nationwide, patient-centered SMSR recruits adult PwMS living in Switzerland. From June 2016 to December 2017, 1299 PwMS completed the baseline survey on which this analysis is based. Based on self-reported health care use, we identified those not under RMC. On this group, we performed a latent class analysis (LCA) to identify potential subgroups. Variables considered were disease duration, DMT usage, form of MS and number of symptoms. We then derived the group size of PwMS with potential underuse of care, defined as persons with RRMS who are not under RMC and never received DMT.

In total, 12% (n=159) were not under RMC. Among those, the LCA identified two subgroups: the first (n=114) consists predominantly of PwMS in the early stage (69% RRMS; 11% Clinically Isolated Syndrome), with a median disease duration of 11 years and a high Health-Related Quality of Life (HRQoL) (average of 83/100 compared to 70/100 among RMC users). The second subgroup (n=45) is characterized by higher percentages of progressive MS forms (35% primary and 31% secondary), a median disease duration of 24 years, and a lower HRQoL score (64/100). The PwMS with potential underuse of care were n=13 and n=7 per group.

In a health system with universal access to care and treatment, 12% of PwMS chose not to seek RMC, but only a small fraction (20/1299, 1.5%) might actually represent underuse. The majority of PwMS not under RMC have used DMT in the past and seem to either feel well or be in a progressive disease phase with still limited treatment options available.