Differences in Symptoms, Functioning and Quality of Life between People with Relapsing Versus Progressive Forms of Multiple Sclerosis

Robert N. McBurney, PhD[1], Meilan Chen, MS[2], Hollie Schmidt, MS[1], Sara Loud, MSEE, MBA[1], and Laura Kolaczkowski, BA[3].

[1]Accelerated Cure Project for MS, Waltham, MA; [2]University of Massachusetts, Amherst, MA; [3]iConquerMS™ PPRN, Waltham, MA

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Background

iConquerMS™ is a multiple sclerosis (MS) people-powered research network established in 2014 with funding by the Patient-Centered Outcomes Research Institute. It is dedicated to engaging all MS stakeholders to enable research on topics that matter most to people affected by MS. To date, more than 4,000 people affected by MS have joined iConquerMS™ and consented to contribute their ideas and data for research purposes.

At the time they join the network (baseline) and at 6-monthly intervals, participants complete a number of surveys, including Demographics, MS Characteristics, the PROMIS® Global Health Survey (GHS), and the Neuro-QoL Adult Short Forms (ASF).

In June 2017, a dataset comprising the baseline data provided by more than 2,000 iConquerMS™ participants was downloaded in order to determine the characteristics of the network members.

Here, we present the ***Symptoms, Functioning and Quality of Life*** data for network participants self-reporting their ***MS Subtypes***.

Objectives

- **To create graphical comparisons of the characteristics of respondents self-reporting relapsing (RRMS) vs progressive forms of MS (secondary, SPMS; progressive, PPMS).**
- **To undertake statistical comparisons of the characteristics of respondents reporting RRMS vs SPMS vs PPMS.**
- **To reveal differences amongst RRMS vs SPMS vs PPMS in the ranking of symptoms, functioning and quality of life.**

Methods

From the Demographics and MS Characteristics data, we created pie charts to show female vs male characteristics and bar charts to show age distributions of respondents reporting RRMS vs SPMS vs PPMS (see Figures 1 and 2).

Data for the 13 domains of the Neuro-QoL ASF (see, for example, Table 2) were used to compare the symptoms, functioning and quality of life of respondents reporting RRMS vs SPMS vs PPMS.

Respondents' answers to each Neuro-QoL domain question were converted to integer value raw scores, then averaged across all domain questions for each respondent. Average raw scores for RRMS, SPMS and PPMS cohorts for each domain were rank ordered (see Tables 2-4). Comparisons of domain scores for RRMS, SPMS or PPMS were performed using Chi-squared statistics or Fisher's Exact Test (see Table 1 for summary of comparisons). Cohen's d was calculated for differences between the average scores for each Neuro-QoL domain for RRMS vs SPMS vs PPMS.

Neuro-QoL Comparisons for MS Subtypes

Table 1: Results of Statistical Pairwise Comparisons of Neuro-QoL Domain Scores for MS Subtypes

Comparison	Number of Domains p<0.05	Largest Difference	2nd Largest Difference
RRMS vs SPMS	8 of 13	Lower Extremity	Social Satisfaction
RRMS vs PPMS	9 of 13	Lower Extremity	Social Satisfaction
SPMS vs PPMS	1 of 13	Cognitive Function	-

RRMS, SPMS & PPMS Cohorts

Figure 1: Female vs Male Characteristics of the Cohorts

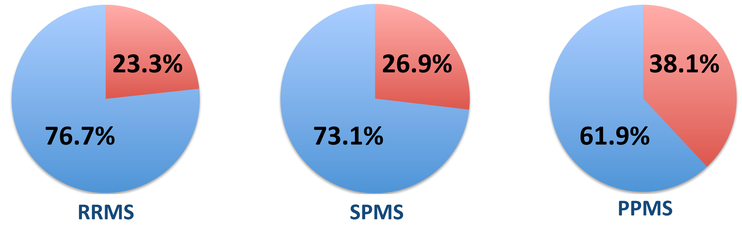
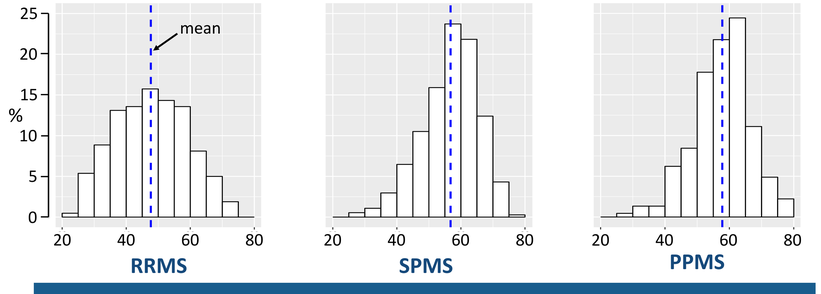


Figure 2: Age Distributions of the Cohorts



Conclusions

This characterization of the iConquerMS™ people-powered research network highlights the symptoms, functioning and quality of life domains that affect people with different forms of MS and provides an excellent resource for future research.

For More Information see www.iConquerMS.org
General Information: Sara Loud, sloud@acceleratedcure.org, 781-487-0032
Research Opportunities: Hollie Schmidt, hollie@acceleratedcure.org, 781-487-0099

Neuro-QoL Domain Ranking Results

Table 2: Ranked Neuro-QoL Domains for RRMS Cohort

Rank Order	Neuro-QoL Domain (5-point Likert scale questions) Scored: 1[worst], 2, 3, 4 , 5[best]	Ave. Score ± SD (N = 987-1019)
1	Fatigue	2.92 ± 1.06
2	Satisfaction with Social Roles and Activities	3.31 ± 1.14
3	Sleep Disturbance	3.56 ± 0.81
4	Cognitive Function	3.62 ± 1.04
5	Positive Affect and Well Being	3.65 ± 0.91
6	Anxiety	3.69 ± 0.87
7	Ability to Participate in Social Roles and Activities	3.75 ± 0.95
8	Emotional and Behavioral Dyscontrol	3.90 ± 0.82
9	Depression	4.12 ± 0.92
10	Stigma	4.29 ± 0.77
* 11	Lower Extremity Functional Mobility	4.34 ± 0.76
12	Communication	4.41 ± 0.68
13	Upper Extremity Function Fine Motor ADL	4.72 ± 0.47

Table 3: Ranked Neuro-QoL Domains for SPMS Cohort

Rank Order	Neuro-QoL Domain (5-point Likert scale questions) Scored: 1[worst], 2, 3, 4 , 5[best]	Ave. Score ± SD (N = 342-355)
1	Satisfaction with Social Roles and Activities	2.60 ± 0.98
2	Fatigue	2.67 ± 0.90
* 3	Lower Extremity Functional Mobility	3.19 ± 1.00
4	Ability to Participate in Social Roles and Activities	3.22 ± 0.87
5	Positive Affect and Well Being	3.47 ± 0.91
6	Sleep Disturbance	3.61 ± 0.73
7	Cognitive Function	3.70 ± 1.00
8	Anxiety	3.82 ± 0.81
9	Stigma	3.91 ± 0.73
10	Emotional and Behavioral Dyscontrol	3.96 ± 0.72
11	Depression	4.10 ± 0.88
12	Upper Extremity Function Fine Motor ADL	4.27 ± 0.72
13	Communication	4.33 ± 0.65

* Cohen's *d* = 1.3

Table 4: Ranked Neuro-QoL Domains for PPMS Cohort

Rank Order	Neuro-QoL Domain (5-point Likert scale questions) Scored: 1[worst], 2, 3, 4 , 5[best]	Ave. Score ± SD (N = 203-212)
1	Satisfaction with Social Roles and Activities	2.68 ± 1.10
2	Fatigue	2.79 ± 1.01
3	Lower Extremity Functional Mobility	3.14 ± 1.13
4	Ability to Participate in Social Roles and Activities	3.22 ± 0.99
5	Positive Affect and Well Being	3.48 ± 0.97
6	Sleep Disturbance	3.62 ± 0.76
7	Anxiety	3.89 ± 0.79
8	Cognitive Function	3.93 ± 1.02
9	Stigma	3.97 ± 0.85
10	Emotional and Behavioral Dyscontrol	4.05 ± 0.76
11	Depression	4.06 ± 0.93
12	Upper Extremity Function Fine Motor ADL	4.19 ± 0.96
13	Communication	4.38 ± 0.73