

Supplementary tables and figures

Supplementary Table 1: Demographic characteristics of AMSLS participants with good vs poor sleep quality, as assessed by the Pittsburgh Sleep Quality Index

	Total study sample (N=1717)	Good sleep quality PSQI≤5 (n=551) 32%	Poor sleep quality (PSQI>5) (n=1166) 68%	P value
Age (years), mean (SD)	57.7 (11.3)	58.2 (11.6)	57.4 (11.2)	0.20
MS duration since symptom onset (years), mean (SD)	22.4 (11)	22 (11)	22.6 (10.9)	0.36
MS duration since diagnosis (years), mean (SD)	16.8 (9.5)	17.2 (9.1)	16.7 (9.7)	0.36
Sex, female, N (%)	1368 (80)	418 (76)	950 (81)	0.01
Marital status				0.80
Single, never married	112 (11)	34 (10)	78 (11)	
Currently married / living as married	741 (73)	240 (73)	501 (73)	
Currently separated, divorced, widowed	161 (16)	55 (17)	106 (15)	
Currently on disease modifying therapy, N (%)	1710 (64)	549 (62)	1161 (65)	0.21
Relapse, last 12 months, N (%)	202 (15)	45 (10)	157 (17)	<0.001
MS onset type, N (%)				0.83
Relapse-onset MS	1024 (76)	336 (76)	688 (76)	
Progressive-onset MS	177 (13)	59 (13)	118 (13)	
Body mass index (kg/m ²), N (%)				0.007
Healthy BMI (18.5 -24.9)	570 (41)	207 (46)	363 (38)	
Overweight (25.0-29.9)	463 (33)	149 (33)	314 (33)	
Obese (≥30.0)	370 (26)	98 (22)	272 (29)	
Patient determined disease steps (PPDS) (0-8), N (%)				<0.001
No disability (PDDS score = 0)	331 (23)	151 (32)	180 (19)	
Mild disability (PDDS score = 1-2)	322 (23)	105 (23)	217 (23)	
Moderate disability (PDDS score= 3-5)	503 (35)	120 (26)	383 (40)	
Severe disability (PDDS score ≥6)	263 (19)	90 (19)	173 (18)	
Education attainment, N (%)				0.011
Primary and secondary school	441 (27)	125 (24)	312 (28)	
Occupational certificate / diploma	543 (33)	160 (31)	383 (35)	
University bachelor's degree or postgraduate degrees	645 (40)	233 (45)	412 (37)	
Individual MS symptoms (0-10), mean (SD)	n=1423	n=467	n=955	
Fatigue severity	5.1 (2.8)	3.9 (2.7)	5.6 (2.6)	<0.001
Walking difficulties	4.5 (3.3)	3.8 (3.5)	4.9 (3.2)	<0.001
Difficulty with balance	4.7 (3.1)	4.0 (3.2)	5.0 (3.0)	<0.001
Cognitive symptoms	3.7 (2.7)	2.8 (2.5)	4.2 (2.7)	<0.001
Pain	3.4 (3.1)	2.1 (2.6)	4.0 (3.1)	<0.001
Vision symptoms	2.3 (2.6)	1.8 (2.3)	2.6 (2.6)	<0.001

Bladder symptoms	4.3 (3.3)	3.6 (3.3)	4.6 (3.3)	<0.001
Bowel symptoms	3.3 (3.1)	2.5 (2.9)	3.7 (3.2)	<0.001
Sexual symptoms	3.8 (3.5)	2.8 (3.4)	4.2 (3.5)	<0.001
Feelings of depression	3.0 (2.8)	1.8 (2.3)	3.6 (2.9)	<0.001
Feelings of anxiety	3.1 (2.8)	1.8 (2.2)	3.7 (2.8)	<0.001
Sensory symptoms	4.2 (2.9)	3.1 (2.6)	4.7 (2.9)	<0.001
Spasticity	3.7 (3.1)	2.9 (2.9)	4.1 (3.1)	<0.001

Supplementary Table 2: Characterisation of sleep difficulties in the total study sample (n=1717)

	n (%)
Measure of sleep quality	
<i>Pittsburgh Sleep Quality Index total score (0-21)</i>	
Good sleep quality (≤ 5)	551 (32)
Poor sleep quality (> 5)	1166 (68)
<i>Epworth Sleepiness Scale total score (0-24)</i>	
Normal sleepiness (< 11)	1329 (77)
Abnormal sleepiness (≥ 11)	369 (21)
Potential causes of poor sleep	
<i>Restless Legs rating scale (0-40)</i>	
None (0)	614 (36)
Mild (1-10)	326 (19)
Moderate (11-20)	480 (28)
Severe / very severe (21-40)	288 (17)
<i>Difficulty falling asleep 3 or more times per week for any of the following reasons</i>	
Restless legs	258 (16)
Pain	293 (18)
Sensitivity to temperature	460 (28)
Needing to go to the toilet	576 (34)
Anxiety / stress or low mood	243 (15)
<i>Difficulty staying asleep 3 or more times per week for any of the following reasons</i>	
Restless legs	193 (12)
Pain	276 (17)
Sensitivity to temperature	416 (25)
Needing to go to the toilet	826 (49)
Anxiety / stress or low mood	196 (12)
<i>Unable to get back to sleep 3 or more times per week for any of the following reasons</i>	
Restless legs	129 (8)
Pain	218 (13)
Sensitivity to temperature	288 (17)
Needing to go to the toilet	488 (29)
Anxiety / stress or low mood	172 (10)
Potential results of poor sleep	
<i>How often do sleep problems interfere with activities of daily living?</i>	
Not during the past month	940 (55)
<once per week	289 (17)
Once per week or more	477 (16)
<i>How often do your sleep problems interfere with social functioning?</i>	
Not during the past month	946 (55)
<once per week	344 (20)
Once per week or more	254 (25)

Supplementary Table 3: Factors associated with the PSQI global score (0-21)

	β coefficient (95% CI)	β coefficient (95% CI) n=1095
	Univariate associations	Multivariate model
<u>Demographic and disease factors</u>		
Age (per year)	-0.004 (-0.01 to 0.003)	-0.03 (-0.05 to -0.004)
Sex		-
Female	Reference	
Male	-0.96 (-1.44 to -0.48)	
Relationship status		-
Married or living as married	Reference	
Separated, divorced or widowed	0.12 (-0.59 to 0.83)	
Single	0.06 (-0.77 to 0.89)	
Body mass index		
Healthy BMI (18.5 -24.9)	Reference	Reference
Overweight (≤ 25 -29.9)	0.65 (0.15 to 1.15)	0.59 (0.08 to 1.10)
Obese (≤ 30)	1.37 (0.83 to 1.92)	1.18 (0.61 to 1.74)
Education level		
Primary and secondary school	Reference	Reference
Occupational certificate / diploma	-0.11 (-0.64 to 0.43)	-0.06 (-0.63 to 0.51)
University degree (bachelor, postgraduate)	-0.88 (-1.38 to -0.38)	-0.97 (-1.51 to -0.43)
Disease course		-
Relapse onset MS	Reference	
Progressive onset MS	-0.36 (-1.02 to 0.31)	
PDDS		
No disability (0)	Reference	Reference
Mild disability (1-2)	1.30 (0.70 to 1.90)	0.94 (0.30 to 1.58)
Moderate disability (3-5)	2.15 (1.6 to 2.71)	1.93 (1.32 to 2.54)
Severe disability (≥ 6)	1.17 (0.54 to 1.8)	1.17 (0.42 to 1.92)
Currently using a disease modifying therapy	0.27 (-0.15 to 0.68)	-
MS relapse, past 12 months, doctor diagnosed	1.85 (1.22 to 2.47)	1.03 (0.39 to 1.66)
<u>7 Symptoms / Symptom clusters</u>		
	n=1401	n=1401
Fatigue and cognitive symptoms	0.65 (0.56 to 0.73)	0.21 (0.10 to 0.33)
Feeling of anxiety and depression	0.63 (0.55 to 0.7)	0.35 (0.26 to 0.45)
Pain and sensory symptoms	0.60 (0.52 to 0.68)	0.28 (0.19 to 0.38)
Vision symptoms	0.37 (0.29 to 0.45)	-
Difficulties with walking, balance and spasticity	0.32 (0.25 to 0.40)	§
Bladder and bowel problems	0.30 (0.23 to 0.37)	-
Sexual symptoms	0.24 (0.18 to 0.30)	-

Analysed using linear regression.

Bold font indicates statistically significant results ($p \leq 0.05$)

§The walking / balance / spasticity cluster has been removed from the multivariate model due to collinearity

Supplementary Table 4: Comparison of PSQI global scores between participants of the MAILES sleep study (2010-2012) and male participants in the Australian MS Longitudinal Study (AMSLS)

Age group	MAILES 2010-2012		AMSLS 2020		Difference	p
	n	mean \pm SD	n	mean \pm SD		
35-54 years	293	5.97 \pm 3.38	103	6.95 \pm 3.69	0.98	0.008
55-64 years	265	5.82 \pm 3.39	111	7.40 \pm 3.86	1.58	<0.001
65-74 years	182	5.81 \pm 3.69	95	7.46 \pm 3.72	1.65	<0.001
75+ years	86	7.38 \pm 4.21	36	6.47 \pm 3.89	-0.91	0.170
Total	826	6.03 \pm 3.57	345	7.19 \pm 3.77	1.16	<0.001

Source: Personal communication, Dr Tiffany Gill, 2021.

Supplementary Table 5: Comparison of PSQI global scores between participants in the Leipzig Center for Civilization Diseases (LIFE) study¹⁰ and the Australian MS Longitudinal Study (AMSLS)

Age group	Males							Females						
	LIFE 2017		AMSLS 2020		Diff- erence	Cohen's d	p	LIFE 2017		LIFE 2020		Diff- erence	Cohen's d	p
n	mean ± SD	n	mean ± SD	n				mean ± SD	n	mean ± SD	n			
<39 yrs	255	3.86 ± 2.69	12	5.83 ± 3.13	1.97	-0.68	0.051	254	4.21 ± 2.76	93	8.24 ± 4.27	4.03	-1.12	<0.001
40-49 yrs	1180	4.40 ± 2.85	47	6.70 ± 3.82	2.30	-0.68	<0.001	1410	4.93 ± 3.39	273	8.15 ± 4.01	3.22	-0.87	<0.001
50-59 yrs	990	4.51 ± 3.04	104	7.39 ± 4.12	2.88	-0.80	<0.001	1184	5.91 ± 3.71	419	8.31 ± 4.15	2.40	-0.61	<0.001
60-69 yrs	1114	4.33 ± 3.11	111	7.67 ± 3.41	3.34	-1.02	<0.001	1237	5.67 ± 3.56	393	8.33 ± 4.42	2.66	-0.66	<0.001
>70 yrs	881	4.42 ± 3.08	75	6.73 ± 3.81	2.31	-0.67	<0.001	779	6.31 ± 3.70	190	7.82 ± 4.20	1.51	-0.38	<0.001
All ages	4420	4.38 ± 3.00	349	7.19 ± 3.78	2.81	-0.82	<0.001	4864	5.54 ± 3.58	1368	8.21 ± 4.21	2.67	-0.68	<0.001

Total sample

Age group	LIFE 2017		AMSLS 2020		Diff- erence	Cohen's d	p
	n	mean ± SD	n	mean ± SD			
<39 yrs	509	4.04 ± 2.73	105	7.96 ± 4.21	3.92	-1.10	<0.001
40-49 yrs	2590	4.69 ± 3.17	320	7.94 ± 4.01	3.25	-0.90	<0.001
50-59 yrs	2174	5.28 ± 3.49	523	8.12 ± 4.15	2.84	-0.74	<0.001
60-69 yrs	2351	5.03 ± 3.42	504	8.18 ± 4.22	3.15	-0.82	<0.001
>70 yrs	1660	5.31 ± 3.51	265	7.51 ± 4.11	2.20	-0.58	<0.001
All ages	9284	5.00 ± 3.37	1717	8.00 ± 4.15	3.00	-0.79	<0.001

Bold font indicates statistically significant results ($p \leq 0.05$)

Effect sizes (Cohen's d) are medium >0.5 , large >0.8 and very large >1.2 ¹⁸