

Tables

Table 1: Description of the MSA sample at inclusion and over time (N=536).

Characteristic	N (%)	mean \pm sd
<i>At inclusion</i>		
Sex		
Male	268 (50.0)	
Female	268 (50.0)	
Centre		
Bordeaux	308 (57.5)	
Toulouse	228 (42.5)	
Age at first symptom onset		60.6 \pm 8.1
Age at cohort entry		65.1 \pm 8.0
Years since first symptom onset		4.5 \pm 2.4
Diagnosis		
MSA-C, with predominant cerebellar impairment	173 (32.3)	
MSA-P, with predominant parkinsonism	363 (67.7)	
Diagnosis certainty		
Possible	136 (25.4)	
Probable	400 (74.6)	
Orthostatic hypotension		
Presence	361 (67.4)	
Absence	175 (32.6)	
Urinary disorder		
Presence	365 (68.1)	
Absence	171 (31.9)	
Treatments		
L-dopa	366 (68.3)	
antihypotensive treatment	161 (30.0)	
antidepressants	111 (20.7)	
Original MSA-QoL scale		
Sum score for motor dimension /56 (n=330)		27.0 \pm 12.2
Sum score for nonmotor dimension /48 (n=344)		20.1 \pm 8.9
Sum score for emotional/social dimension /56 (n=326)		25.6 \pm 13.0
Modified MSA-QoL scale		
Sum score for motor dimension /44 (n=333)		25.1 \pm 9.8
Sum score for oropharyngeal dimension /16 (n=387)		4.3 \pm 3.8
Sum score for nonmotor dimension /40 (n=350)		16.6 \pm 7.8
Sum score for emotional/social dimension /56 (n=326)		25.6 \pm 13.0
Disability degree (n=520)		
Completely independent (stage I)	111 (20.7)	
Not completely independent (stage II)	239 (44.6)	
More dependent (stage III)	105 (19.6)	
Very dependent (stage IV)	63 (11.8)	
Totally dependent (stage V)	2 (3.0)	
<i>During follow-up</i>		
Visits	1501	
Visits per patient		2.8 \pm 1.9
Years of follow-up		2.5 \pm 2.4
Early drop-out ^a	87 (16.2)	
Death	338 (63.1)	

^aearly dropout corresponds to alive patients with last visit prior to July 1st, 2020 (i.e., more than 1.5 years before administrative censoring).

Table 2: Original and modified versions of the MSA-QoL questionnaire. The central part of the table lists the 40 items evaluating the health-related quality of life in MSA. The left part of the table presents the allocation of items according to the original scale with three subdimensions: motor (14 items), nonmotor (12 items), and emotional/social (14 items). The right part of the table presents the allocation of items according to the modified scale using PROMIS method with four subdimensions identified (and item 25 deleted): motor (11 items), oropharyngeal (4 items), nonmotor (10 items), and emotional/social (14 items).

ORIGINAL MSA-QOL QUESTIONNAIRE	MOTOR	1. Had difficulty moving?	MOTOR	PROMIS MODIFIED MSA-QOL QUESTIONNAIRE	
		2. Had difficulty walking?			
		3. Had problems with your balance?			
		4. Had difficulty standing up without support?			
		5. Had difficulty speaking?			OROPHARYNGEAL
		6. Had difficulty swallowing food?			
		7. Had too much saliva or drooling?			MOTOR
		8. Had difficulty with handwriting?			OROPHARYNGEAL
		9. Had difficulty feeding yourself?			
		10. Had difficulty drinking fluids?			MOTOR
		11. Had difficulty dressing yourself?			
		12. Needed help to go to the toilet?			
		13. Had to stop doing things that you liked to do, e.g. your hobbies?			
		14. Had difficulty doing things around the house, e.g. housework?			
	NONMOTOR	15. Experienced bladder problems?	NONMOTOR		
		16. Experienced problems with constipation?			
		17. Experienced dizziness when standing up?			
		18. Suffered from cold hands or feet?			
		19. Experienced pain in your neck or shoulders?			
		20. Experienced pain elsewhere, e.g. in your legs or your back?			
		21. Had difficulty getting comfortable during the night?			
		22. Had difficulty breathing during the night?			
		23. Been feeling tired very quickly (without exerting yourself)?			
		24. Experienced lack of energy?			
		25. Experienced slowness of thinking?			X
	26. Had difficulty with your concentration, e.g. reading or watching TV?	NONMOTOR			
	EMOTIONAL / SOCIAL	27. Felt frustrated?	EMOTIONAL / SOCIAL		
		28. Felt depressed?			
		29. Experienced a loss of motivation?			
		30. Been feeling incapable?			
		31. Worried about the future?			
		32. Worried about your family?			
		33. Felt on your own or isolated?			
		34. Experienced loss of confidence when interacting with others?			
		35. Felt that your role in your family or among friends has changed?			
		36. Experienced difficulty seeing your friends?			
		37. Had to give up social activities, e.g. going out for a meal, participating in events?			
		38. Had difficulty talking to friends about your illness?			
		39. Been embarrassed to talk to people?			
		40. Felt that life has become boring?			