

Disease progression and longitudinal clinical outcomes of Lewy Body Dementia: a retrospective analysis of the NACC database

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Supplemental Tables and Figures

Table S1. Outcome assessments over time of the LBD cohort overall and stratified by CDR-SB at index

	Follow-up visit 1					Follow-up visit 3					Follow-up visit 5				
	Overall LBD	Mild LBD	Moderate LBD	Severe LBD		Overall LBD	Mild LBD	Moderate LBD	Severe LBD		Overall LBD	Mild LBD	Moderate LBD	Severe LBD	
	N = 2,052	N = 219	N = 988	N = 845		N = 1,126	N = 143	N = 596	N = 387		N = 510	N = 90	N = 273	N = 147	
Select comorbidities															
Hypertension	53.7%	60.7%	50.4%	55.7%		57.2%	64.3%	53.2%	60.7%		57.3%	68.9%	53.1%	57.8%	
Hypercholesterolemia	56.9%	61.2%	55.3%	57.8%		61.0%	64.3%	58.6%	63.6%		59.2%	65.6%	58.2%	57.1%	
Depression	48.7%	33.8%	49.4%	51.8%	*	51.3%	39.2%	51.3%	55.8%		43.3%	38.9%	44.3%	44.2%	
Traumatic brain injury	11.6%	10.0%	10.0%	14.0%		11.5%	12.6%	10.6%	12.7%		11.2%	13.3%	10.6%	10.9%	
Diabetes	11.7%	11.9%	10.5%	13.1%		13.6%	16.1%	12.2%	14.7%		13.9%	14.4%	14.7%	12.2%	
Atrial fibrillation	9.3%	11.4%	9.6%	8.4%		11.2%	16.1%	10.2%	10.9%		14.5%	22.2%	14.3%	10.2%	
Transient ischemic attack	5.4%	6.8%	4.9%	5.7%		6.5%	9.8%	5.2%	7.2%		8.2%	11.1%	6.2%	10.2%	
Stroke	6.3%	5.5%	6.0%	7.0%		7.5%	4.2%	7.9%	8.3%		8.8%	7.8%	7.3%	12.2%	
Sleep disorders	4.8%	7.8%	5.6%	3.1%		6.3%	7.7%	6.7%	5.2%		8.8%	2.2%	10.6%	9.5%	
Alcohol abuse	7.0%	4.1%	6.0%	8.9%		6.7%	3.5%	7.4%	7.0%		5.5%	4.4%	4.8%	7.5%	
AD medications															
Memantine	33.2%	8.7%	24.5%	49.8%	*	38.1%	16.1%	34.1%	52.5%	*	35.7%	18.9%	34.1%	49.0%	*
Cholinesterase inhibitors	62.3%	28.3%	56.1%	78.3%	*	64.4%	42.0%	64.1%	73.1%	*	56.7%	37.8%	61.2%	59.9%	*
Other medications															
Anti-Parkinson agents	20.1%	19.2%	23.3%	16.6%		24.4%	21.0%	28.0%	20.2%		21.4%	23.3%	25.3%	12.9%	
Antidepressants	45.7%	26.5%	45.2%	51.2%	*	48.1%	28.0%	49.0%	54.3%	*	44.7%	26.7%	51.3%	43.5%	*
Anti-psychotic agents	11.1%	0.9%	7.2%	18.3%	*	13.5%	4.2%	9.6%	23.0%	*	17.3%	7.8%	15.0%	27.2%	*
Anxiolytics, sedatives, or hypnotic agents	16.4%	11.9%	18.1%	15.6%		18.2%	14.0%	20.8%	15.8%		20.4%	12.2%	23.1%	20.4%	
Cognitive assessments [§]															
CDR-GS score	1.0 ± 0.7	0.4 ± 0.2	0.7 ± 0.4	1.5 ± 0.7	-	1.3 ± 0.9	0.6 ± 0.6	1.1 ± 0.7	2.0 ± 0.8	-	1.6 ± 1.0	0.8 ± 0.8	1.4 ± 0.9	2.4 ± 0.8	-
CDR-SB score	5.5 ± 4.1	1.2 ± 1.2	3.6 ± 2.5	8.7 ± 3.8	-	7.6 ± 5.4	2.7 ± 3.8	6.1 ± 4.4	11.7 ± 4.5	-	9.2 ± 6.2	4.1 ± 5.0	8.1 ± 5.5	14.3 ± 4.3	-
CDR domain scores															
Memory	1.1 ± 0.7	0.4 ± 0.3	0.8 ± 0.5	1.6 ± 0.7	-	1.4 ± 0.9	0.7 ± 0.6	1.2 ± 0.7	2.0 ± 0.8	-	1.6 ± 1.0	0.9 ± 0.8	1.5 ± 0.9	2.4 ± 0.8	-
Orientation	0.9 ± 0.8	0.1 ± 0.3	0.5 ± 0.5	1.4 ± 0.8	-	1.2 ± 1.0	0.4 ± 0.7	1.0 ± 0.8	1.9 ± 0.9	-	1.5 ± 1.1	0.7 ± 0.9	1.3 ± 1.0	2.3 ± 0.9	-
Judgement and problem solving	1.0 ± 0.7	0.3 ± 0.3	0.7 ± 0.5	1.5 ± 0.7	-	1.3 ± 0.9	0.5 ± 0.7	1.1 ± 0.8	1.9 ± 0.9	-	1.5 ± 1.1	0.7 ± 0.8	1.4 ± 1.0	2.4 ± 0.8	-
Community affairs	0.9 ± 0.8	0.2 ± 0.3	0.6 ± 0.5	1.5 ± 0.7	-	1.3 ± 0.9	0.5 ± 0.7	1.1 ± 0.8	1.9 ± 0.7	-	1.6 ± 1.0	0.7 ± 0.9	1.4 ± 1.0	2.4 ± 0.7	-

	Follow-up visit 1					Follow-up visit 3					Follow-up visit 5				
	Overall LBD	Mild LBD	Moderate LBD	Severe LBD		Overall LBD	Mild LBD	Moderate LBD	Severe LBD		Overall LBD	Mild LBD	Moderate LBD	Severe LBD	
	N = 2,052	N = 219	N = 988	N = 845		N = 1,126	N = 143	N = 596	N = 387		N = 510	N = 90	N = 273	N = 147	
Home and hobbies	1.0 ± 0.9	0.2 ± 0.3	0.6 ± 0.6	1.7 ± 0.8	-	1.4 ± 1.0	0.5 ± 0.7	1.1 ± 0.9	2.1 ± 0.8	-	1.6 ± 1.1	0.8 ± 0.9	1.5 ± 1.0	2.5 ± 0.7	-
Personal care	0.6 ± 0.8	0.0 ± 0.1	0.3 ± 0.6	1.1 ± 0.9	-	1.0 ± 1.1	0.2 ± 0.7	0.7 ± 0.9	1.8 ± 1.0	-	1.3 ± 1.2	0.5 ± 0.9	1.1 ± 1.1	2.3 ± 0.9	-
MoCA score, mean ± SD	17.1 ± 7.7	23.7 ± 3.9	20.0 ± 6.3	12.0 ± 6.9	-	15.9 ± 8.1	21.5 ± 5.7	17.3 ± 7.5	10.5 ± 7.0	-	16.6 ± 8.1	20.2 ± 7.0	16.8 ± 7.8	10.8 ± 7.2	-
Functional assessments															
FAQ score	16.6 ± 10.2	2.9 ± 5.7	12.6 ± 8.7	23.7 ± 6.0	*	20.4 ± 10.0	7.9 ± 10.0	19.0 ± 9.3	26.6 ± 4.9	*	22.3 ± 10.3	12.5 ± 11.9	21.1 ± 10.1	28.7 ± 2.9	*
FAQ score range, %					*					*					*
≥9 (impaired function)	45.3%	8.2%	35.4%	66.5%		54.9%	24.5%	49.5%	74.4%		60.2%	35.6%	56.0%	83.0%	
< 9 (normal function)	16.6%	57.1%	20.2%	1.9%		12.2%	46.2%	11.4%	0.8%		11.6%	27.8%	12.5%	0.0%	
Missing	38.1%	34.7%	44.3%	31.6%		32.9%	29.4%	39.1%	24.8%		28.2%	36.7%	31.5%	17.0%	
Level of independence [†]										*					
Able to live independently	25.6%	74.0%	31.9%	5.8%	-	16.8%	53.8%	17.6%	1.8%	-	18.0%	48.9%	17.6%	0.0%	-
Requires some assistance with complex activities	40.1%	20.5%	49.8%	33.7%	-	31.4%	30.8%	42.8%	14.2%	-	22.7%	27.8%	26.7%	12.2%	-
Requires some assistance with basic activities	27.0%	4.6%	15.6%	46.3%	-	33.3%	11.9%	28.7%	48.3%	-	28.8%	16.7%	34.8%	25.2%	-
Completely dependent	7.3%	0.9%	2.7%	14.2%	-	18.4%	3.5%	10.9%	35.4%	-	30.4%	6.7%	20.9%	62.6%	-
Any PD symptoms present	68.5%	57.1%	68.3%	71.7%	*	57.5%	55.2%	60.7%	53.5%		47.8%	57.8%	49.8%	38.1%	
Falls	24.6%	17.4%	23.8%	27.5%		35.4%	27.3%	36.2%	37.2%		43.5%	34.4%	42.9%	50.3%	
Tremors	36.5%	28.3%	39.1%	35.7%		45.0%	39.2%	46.5%	45.0%		50.2%	45.6%	53.1%	47.6%	
Slowness	52.0%	36.5%	52.5%	55.5%	*	63.2%	52.4%	61.4%	70.0%	*	68.6%	58.9%	68.1%	75.5%	
Neuropsychiatric assessments															
NPI-Q total score, mean ± SD	5.3 ± 5.1	2.2 ± 2.8	4.8 ± 4.7	6.8 ± 5.4	*	5.8 ± 5.2	2.9 ± 4.0	5.7 ± 5.0	7.1 ± 5.6	*	5.7 ± 5.8	3.4 ± 4.1	5.8 ± 5.7	7.0 ± 6.6	*
NPI-Q items															
Delusions	16.2%	4.1%	10.8%	25.6%	*	20.1%	6.3%	17.8%	28.7%	*	17.3%	3.3%	20.5%	19.7%	*
Hallucinations	15.0%	2.7%	11.8%	21.9%	*	19.2%	5.6%	17.4%	26.9%	*	17.1%	7.8%	16.1%	24.5%	
Agitation or aggression	33.5%	19.2%	31.0%	40.1%	*	35.8%	19.6%	36.2%	41.1%	*	35.1%	22.2%	34.8%	43.5%	
Depression or dysphoria	39.7%	31.1%	41.2%	40.2%		38.3%	28.7%	40.3%	38.8%		30.0%	30.0%	31.5%	27.2%	
Anxiety	41.2%	24.2%	37.8%	49.6%	*	41.3%	24.5%	42.3%	46.0%	*	38.4%	27.8%	42.9%	36.7%	
Elation or euphoria	6.0%	2.3%	4.8%	8.4%	*	4.6%	1.4%	4.5%	5.9%		3.9%	2.2%	4.8%	3.4%	
Apathy or indifference	43.4%	16.0%	38.3%	56.6%	*	48.2%	27.3%	48.2%	56.1%	*	44.1%	27.8%	44.3%	53.7%	*
Disinhibition	21.9%	6.4%	18.9%	29.5%	*	23.4%	9.8%	22.3%	30.0%	*	25.3%	11.1%	27.1%	30.6%	
Irritability or lability	40.2%	26.0%	40.5%	43.6%	*	37.3%	18.2%	40.3%	39.8%	*	35.9%	30.0%	38.1%	35.4%	

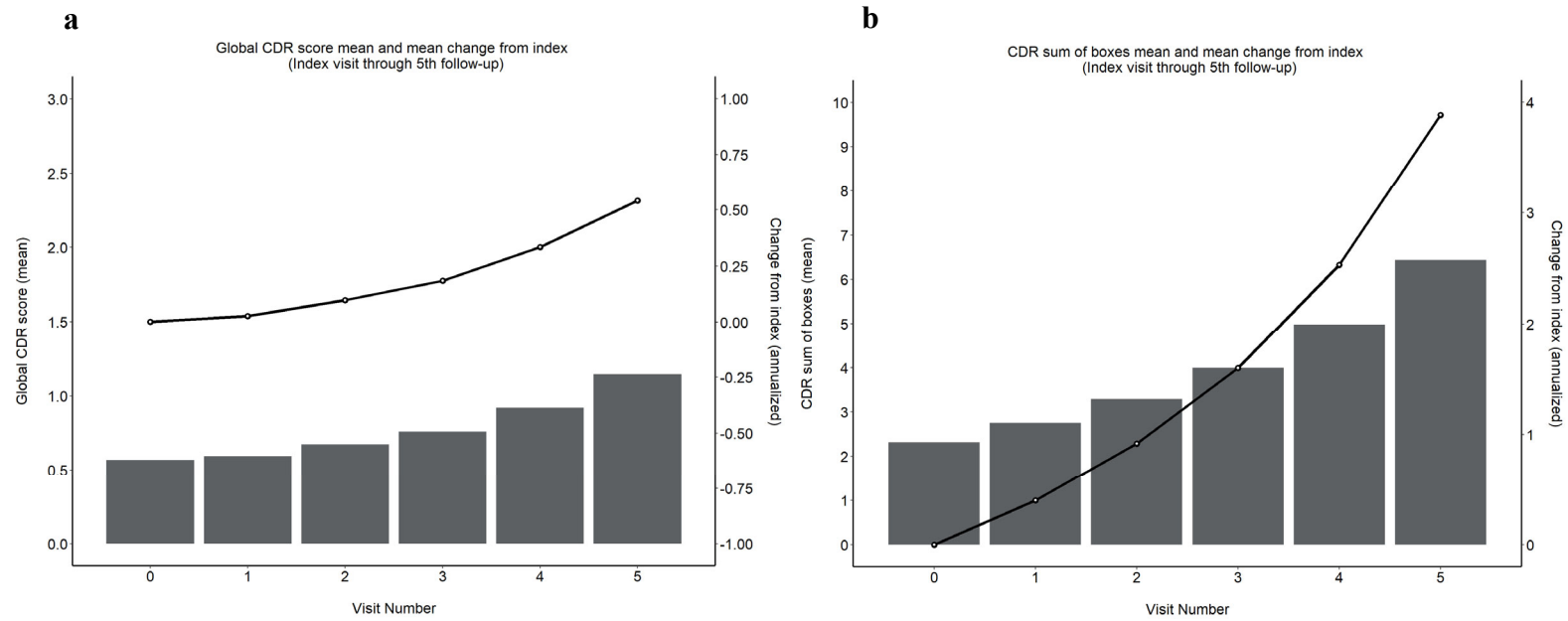
	Follow-up visit 1					Follow-up visit 3					Follow-up visit 5			
	Overall LBD	Mild LBD	Moderate LBD	Severe LBD		Overall LBD	Mild LBD	Moderate LBD	Severe LBD		Overall LBD	Mild LBD	Moderate LBD	Severe LBD
	N = 2,052	N = 219	N = 988	N = 845		N = 1,126	N = 143	N = 596	N = 387		N = 510	N = 90	N = 273	N = 147
Motor disturbance	21.4%	4.6%	15.8%	32.4%	*	26.1%	12.6%	22.8%	36.2%	*	26.3%	21.1%	23.4%	34.7%
Nighttime behaviors	37.8%	24.7%	38.1%	40.9%	*	39.0%	22.4%	40.6%	42.6%	*	32.7%	28.9%	32.6%	35.4%
Appetite and eating problems	28.4%	11.0%	28.5%	32.8%	*	27.7%	17.5%	28.0%	31.0%		23.7%	14.4%	24.5%	27.9%

Abbreviations: AD: Alzheimer's disease; ADC: Alzheimer's Disease Center; CDR: Clinical Dementia Rating; CDR-GS: Clinical Dementia Rating Global Score; CDR-SB: Clinical Dementia Rating Sum of Boxes; FAQ: Functional Activities Questionnaire; MoCA: Montreal Cognitive Assessment; NPI-Q: Neuropsychiatric Inventory–Questionnaire

Notes: Means and standard deviations are shown for continuous characteristics; percentages are shown for categorical characteristics, unless otherwise noted.

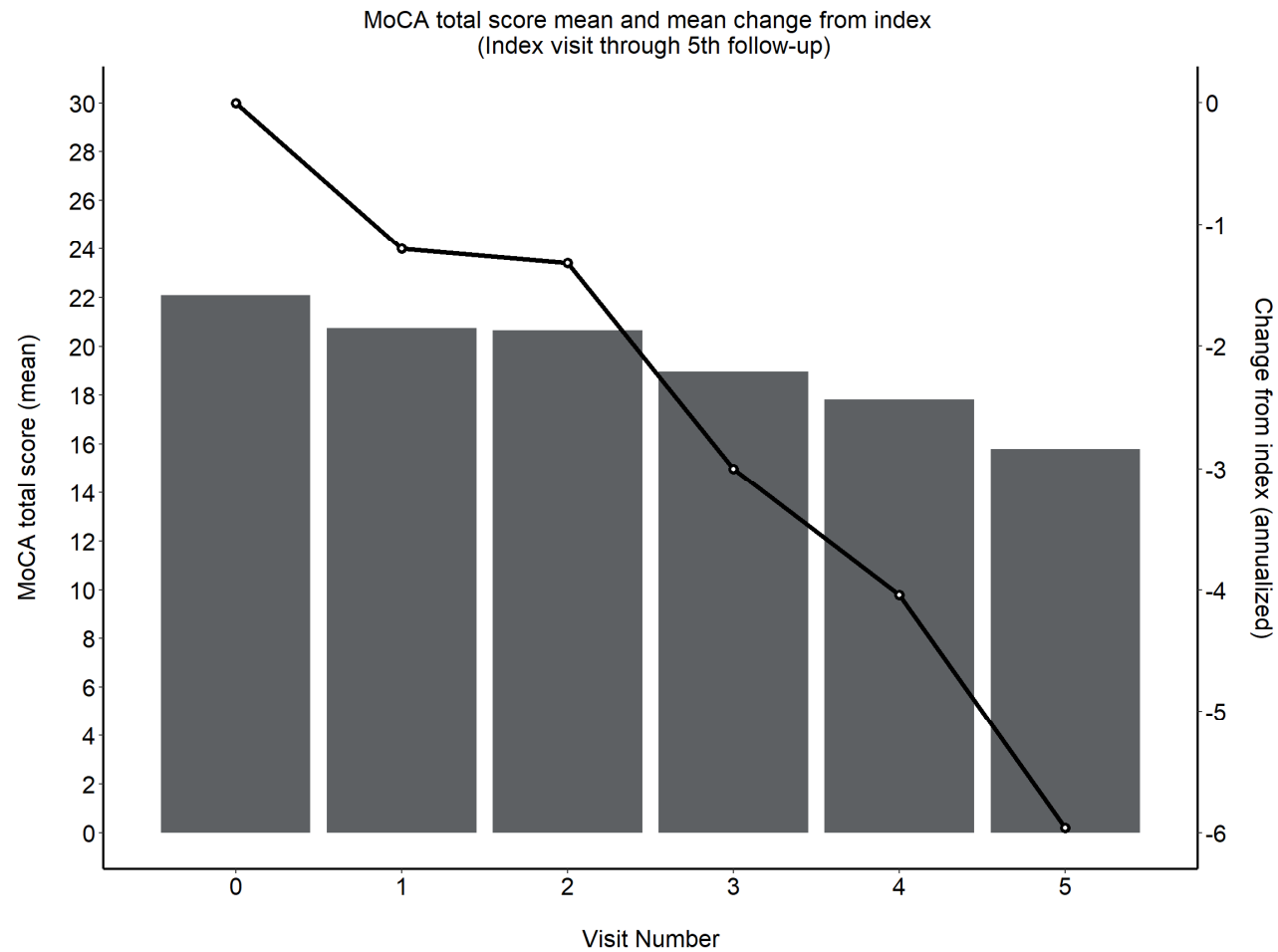
*denotes $p < 0.001$ based on Wilcoxon rank-sum tests for continuous characteristics and chi-square tests for categorical characteristics among three groups. [§] P-values were not assessed for cognitive assessments because by design the stratification by severity level was based on the cognitive status on the index date. [†] P-values were not assessed for characteristics where at least one of the cells had a count of 0.

Fig. S1 Change in CDR-GS and CDR-SB scores in the restricted LBD cohort (n=287). A) CDR-GS B) CDR-SB



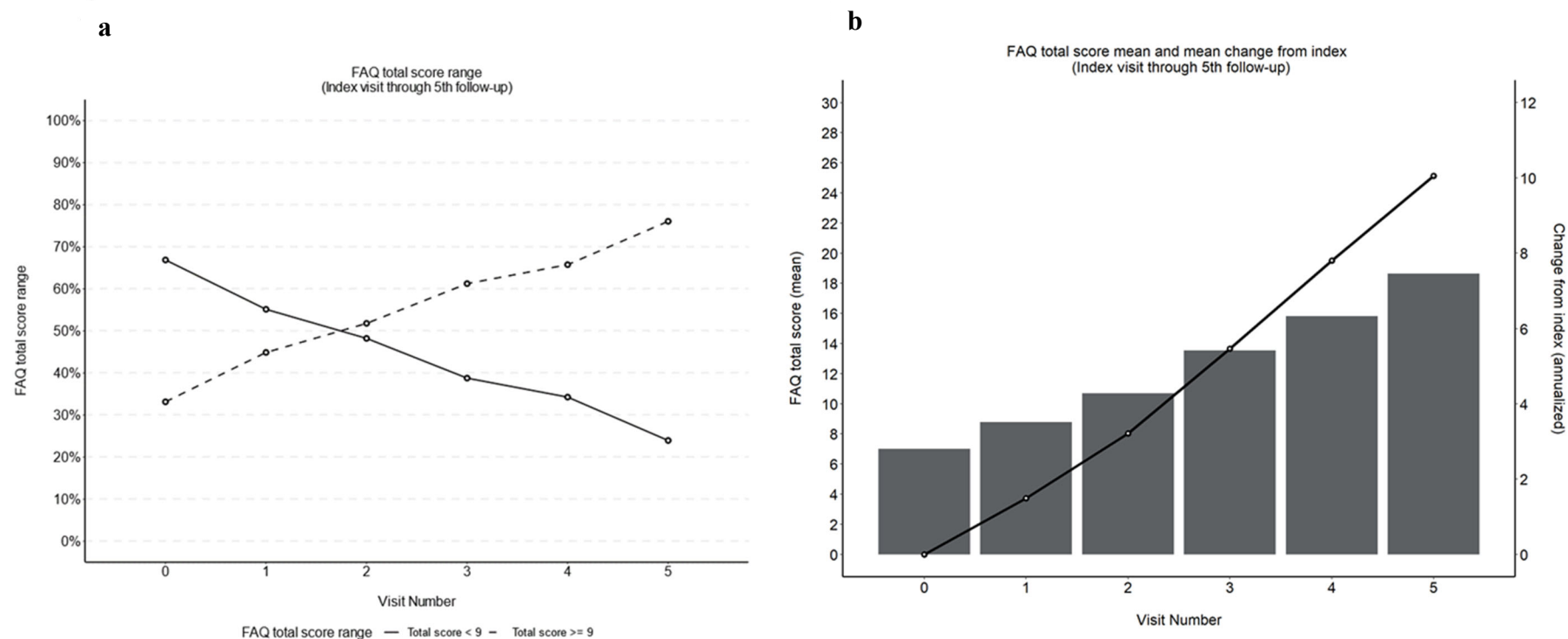
Abbreviations: CDR: Clinical Dementia Rating; CDR-GS: CDR Global Score; CDR-SB: CDR Sum of Boxes; LBD: Lewy body dementia

Fig. S2 Change in MoCA score over time in the restricted LBD cohort (n=287)



Abbreviations: LBD: Lewy body dementia; MoCA: Montreal Cognitive Assessment

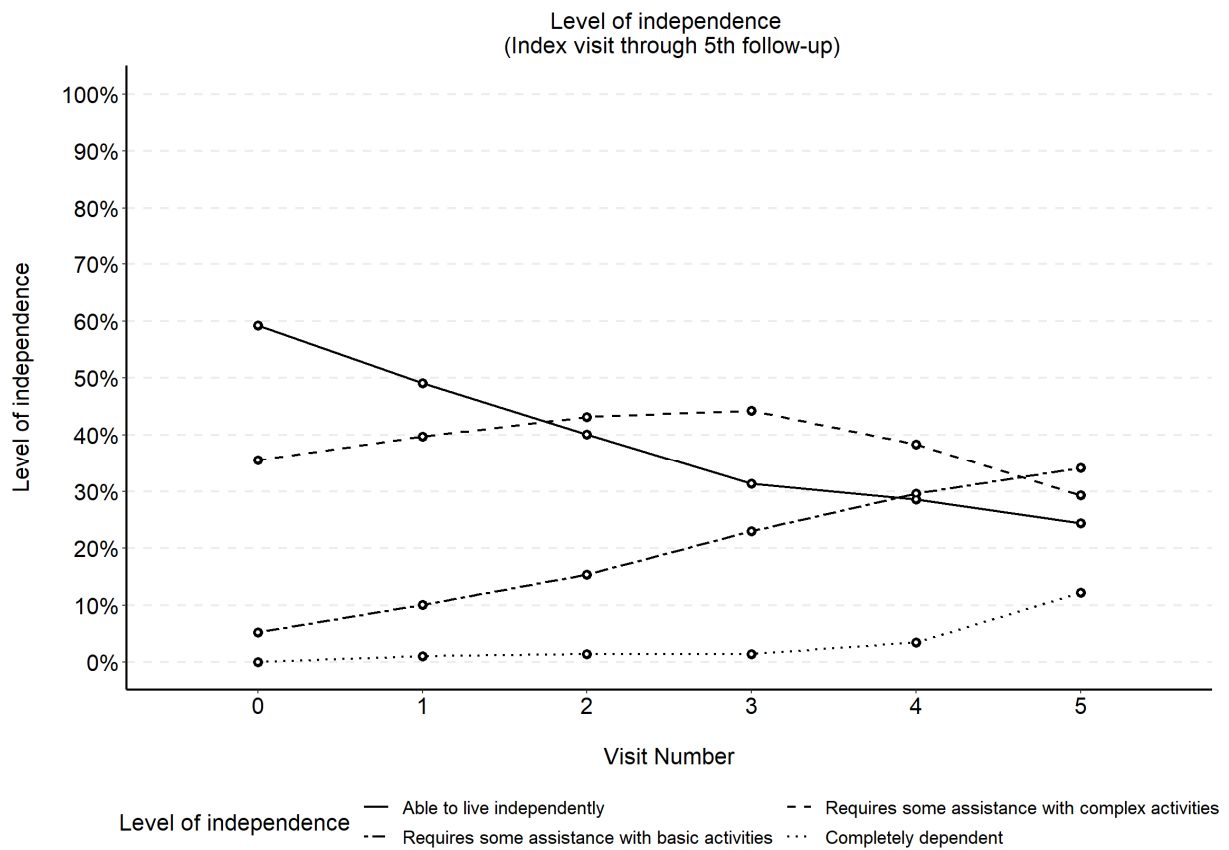
Fig. S3 Change in FAQ score over time in the restricted LBD cohort (n=287). A) FAQ score ≥ 9 ; B) Total FAQ score



Abbreviations: FAQ: Functional Activities Questionnaire; LBD: Lewy body dementia

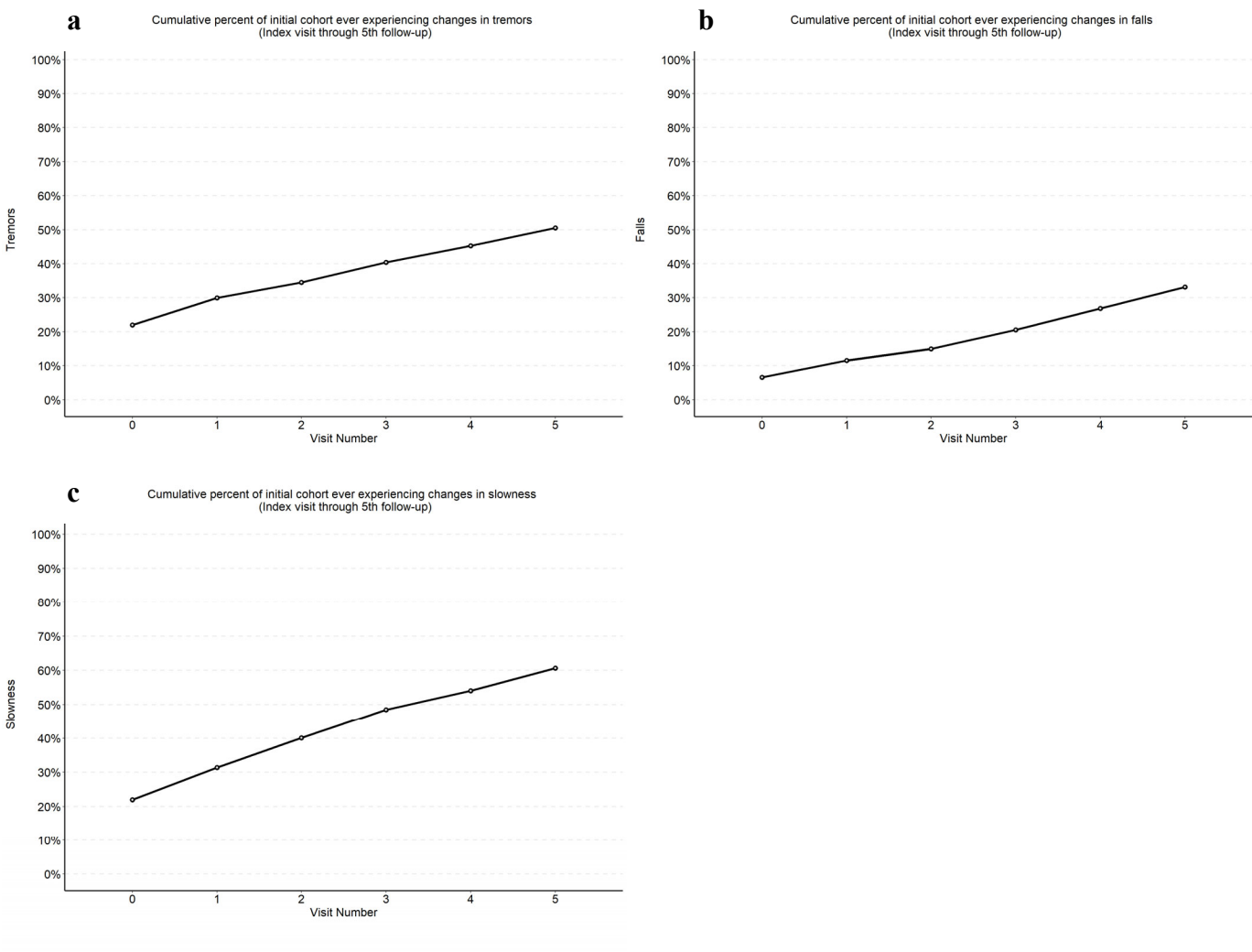
Note: FAQ score of ≥ 9 (dependent in three or more activities) was used to indicate impaired function [38] .

Fig. S4 Change in dependence in daily activities over time in the restricted LBD cohort (n=287)



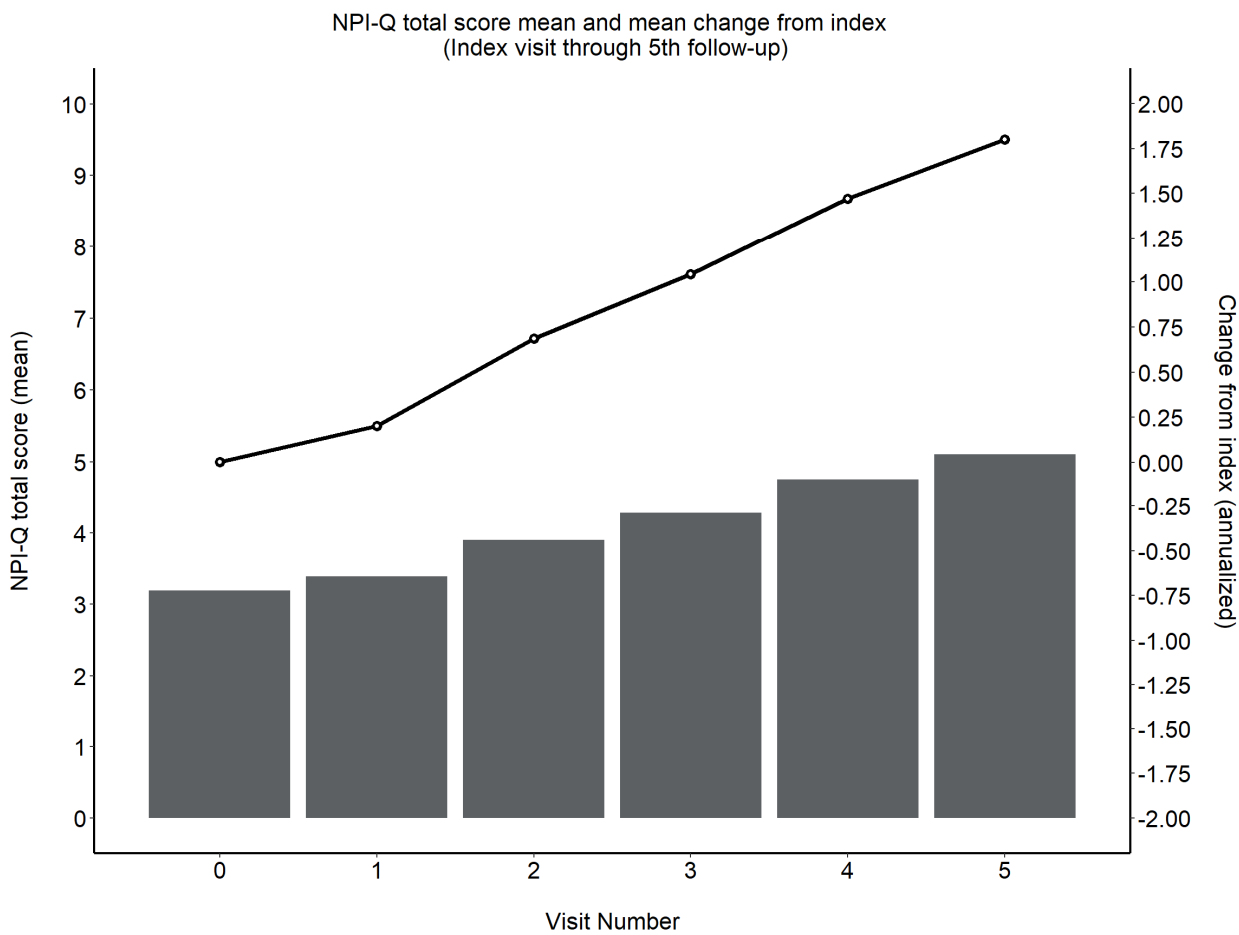
Abbreviation: LBD: Lewy body dementia

Fig. S5 Changes in tremors, falls, and slowness over time in the restricted LBD cohort (n=287)



Abbreviation: LBD: Lewy body dementia

Fig. S6 Change in NPI-Q score over time in the restricted LBD cohort (n=287)



Abbreviations: LBD: Lewy body dementia; NPI-Q: Neuropsychiatric Inventory-Questionnaire