

Supplementary Material

The Impact of Agitation in Dementia on Caregivers: A Real-World Survey

Supplementary Table 1. Type of regression analysis used for different outcomes

Type of regression analysis	Outcomes
Negative binomial regression	Non-professional caregiver time/week, hours
	Non-professional caregiver burden - overall
	Non-professional caregiver burden – personal strain
	Non-professional caregiver burden – role strain
	Non-professional caregiver burden – guilt
Linear regression	Non-professional caregiver EQ-5D-3L health utility index
	Non-professional caregiver EQ-5D-3L VAS score
	Non-professional caregiver absenteeism
	Non-professional caregiver presenteeism
	Non-professional caregiver overall work impairment
	Non-professional caregiver total activity impairment

Supplementary Table 2. Patient demographics and clinical characteristics

	Total (n=1,349)	Non- agitated (n=656)	Agitated (n=693)	p	Total (n=1,244)	No Care (n=305)	Remote Care (n=248)	Proximate Care (n=691)	p
Age, y									
n	1349	656	693		1,244	305	248	691	
Mean (SD)	75.5 (9.0)	75.0 (8.8)	76.0 (9.1)	0.0307	75.6 (9.1)	70.0 (8.6)	79.3 (8.6)	76.7 (8.4)	<0.0001
Range	50–90	50–90	50–90		50–90	50–90	52–90	50–90	
Sex, n (%)									
n	1346	655	691		1241	305	247	689	
Male	625 (46)	295 (45)	330 (48)	0.3254	566 (46)	169 (55)	90 (36)	307 (45)	<0.0001
Female	721 (54)	360 (55)	361 (52)		675 (54)	136 (45)	157 (64)	382 (55)	
Ethnicity, n (%)									
n	1347	654	693		1243	305	247	691	
White/Caucasian	976 (73)	500 (77)	476 (69)	0.0014	906 (73)	234 (77)	182 (74)	490 (71)	0.1248
African American	186 (14)	70 (11)	116 (17)		173 (14)	28 (9)	35 (14)	110 (16)	
Hispanic/Latino	99 (7)	51 (8)	48 (7)		89 (7)	24 (8)	13 (5)	52 (8)	
Other	86 (6)	33 (5)	53 (8)		75 (6)	19 (6)	17 (7)	39 (6)	
Employment status, n (%)									
n	1327	644	683		1223	300	244	679	
Working full-time	53 (4)	34 (5)	19 (3)		51 (4)	43 (14)	0 (0)	8 (1)	
Working part-time	46 (4)	34 (5)	12 (2)		42 (3)	30 (10)	1 (<1)	11 (2)	
Homemaker	129 (10)	61 (10)	68 (10)		116 (10)	21 (7)	21 (9)	74 (11)	
Student	4 (0.3)	3 (0.5)	1 (0.1)	0.0007	4 (<1)	2 (1)	1 (<1)	1 (<1)	<0.0001
Retired	1014 (76)	480 (75)	534 (78)		934 (76)	190 (63)	199 (82)	545 (80)	
Unemployed	81 (6)	32 (5)	49 (7)		76 (6)	14 (5)	22 (9)	40 (6)	
Current hospital status, n (%)									
n	1305	639	666		1207	298	234	675	
Outpatient	1226 (94)	615 (96)	611 (92)	0.0007	1133 (94)	286 (96)	195 (83)	652 (97)	<0.0001
Inpatient	79 (6)	24 (4)	55 (8)		74 (6)	12 (4)	39 (17)	23 (3)	
Home circumstances, n (%)									
n	1338	650	688		1236	302	247	687	
Lives with spouse/partner	770 (58)	410 (63)	360 (52)		713 (58)	210 (70)	37 (15)	466 (68)	
Lives with other family	284 (21)	115 (18)	169 (25)	<0.0001	254 (21)	25 (8)	23 (9)	206 (30)	<0.0001
Lives alone	102 (8)	70 (11)	32 (5)		96 (8)	59 (20)	36 (15)	1 (<1)	
Nursing home	121 (9)	30 (5)	91 (13)		117 (10)	0 (0)	116 (47)	1 (<1)	
Sheltered housing	31 (2)	10 (2)	21 (3)		28 (2)	5 (2)	18 (7)	5 (1)	
Lives with friends	9 (1)	3 (0.5)	6 (1)		8 (1)	2 (1)	2 (1)	4 (1)	

	Total (n=1,349)	Non- agitated (n=656)	Agitated (n=693)	p	Total (n=1,244)	No Care (n=305)	Remote Care (n=248)	Proximate Care (n=691)	p
Other	21 (2)	12 (2)	9 (1)		20 (2)	1 (<1)	15 (6)	4 (1)	
Reason for living in a nursing home, n (%)									
n	120	29	91		116	0	115	1	
Dementia	104 (87)	21 (72)	83 (91)	0.0232	100 (86)	0 (0)	100 (87)	0 (0)	0.1379
Other	16 (13)	8 (28)	8 (9)		16 (14)	0 (0)	15 (13)	1 (100)	
Current diagnosis, n (%)									
n	1,205	585	620		1,115	269	228	618	
MCI	237 (20)	154 (26)	83 (13)		220 (20)	135 (50)	18 (8)	67 (11)	
Amnestic MCI	13 (1)	12 (2)	1 (0.2)		12 (1)	9 (3)	1 (<1)	2 (<1)	
Pre-dementia AD	84 (7)	43 (7)	41 (7)		77 (7)	20 (7)	10 (4)	47 (8)	
Prodromal AD	49 (4)	28 (5)	21 (3)		43 (4)	14 (5)	8 (4)	21 (3)	
AD	649 (54)	271 (46)	37 (61)	<0.0001	597 (54)	51 (19)	150 (66)	396 (64)	<0.0001
Early onset AD	106 (9)	54 (9)	52 (8)		101 (9)	29 (11)	13 (6)	59 (10)	
Mixed vascular dementia / AD	61 (5)	19 (3)	42 (7)		59 (5)	9 (3)	25 (11)	25 (4)	
Other	6 (1)	4 (1)	2 (0.3)		6 (1)	2 (1)	3 (1)	1 (<1)	
Physician-perceived dementia stage, n (%)									
n	1,340	651	689		1,238	304	246	688	
MCI	250 (19)	177 (27)	73 (11)	<0.0001	236 (19)	172 (57)	13 (5)	51 (7)	<0.0001
Mild	473 (35)	270 (42)	203 (30)		433 (35)	115 (38)	68 (28)	250 (36)	
Moderate	482 (36)	183 (28)	299 (43)		439 (36)	16 (5)	103 (42)	320 (47)	
Severe	135 (10)	21 (3)	114 (17)		130 (11)	1 (<1)	62 (25)	67 (10)	
Most recent MMSE score									
n	1,116	542	574		1,031	253	188	590	
Mean (SD)	20.5 (5.7)	22.0 (5.4)	19.2 (5.7)	<0.0001	20.5 (5.8)	24.5 (4.4)	17.4 (5.9)	19.7 (5.4)	<0.0001
Range	0–30	0–30	0–30		0–30	0–30	0–30	0–30	
Agitation symptoms severity score									
n	1,349	656	693		1,244	305	248	691	
Mean (SD)	N/A	N/A	3.6 (3.1)	<0.0001	1.8 (2.9)	0.7 (1.3)	3.1 (4.0)	1.9 (2.7)	<0.0001
Range	N/A	N/A	1–21		0–21	0–6	0–21	0–20	

AD, Alzheimer's disease; IPA, International Psychogeriatric Association; MCI, Mild cognitive impairment; MMSE, Mini Mental State Examination; SD, standard deviation

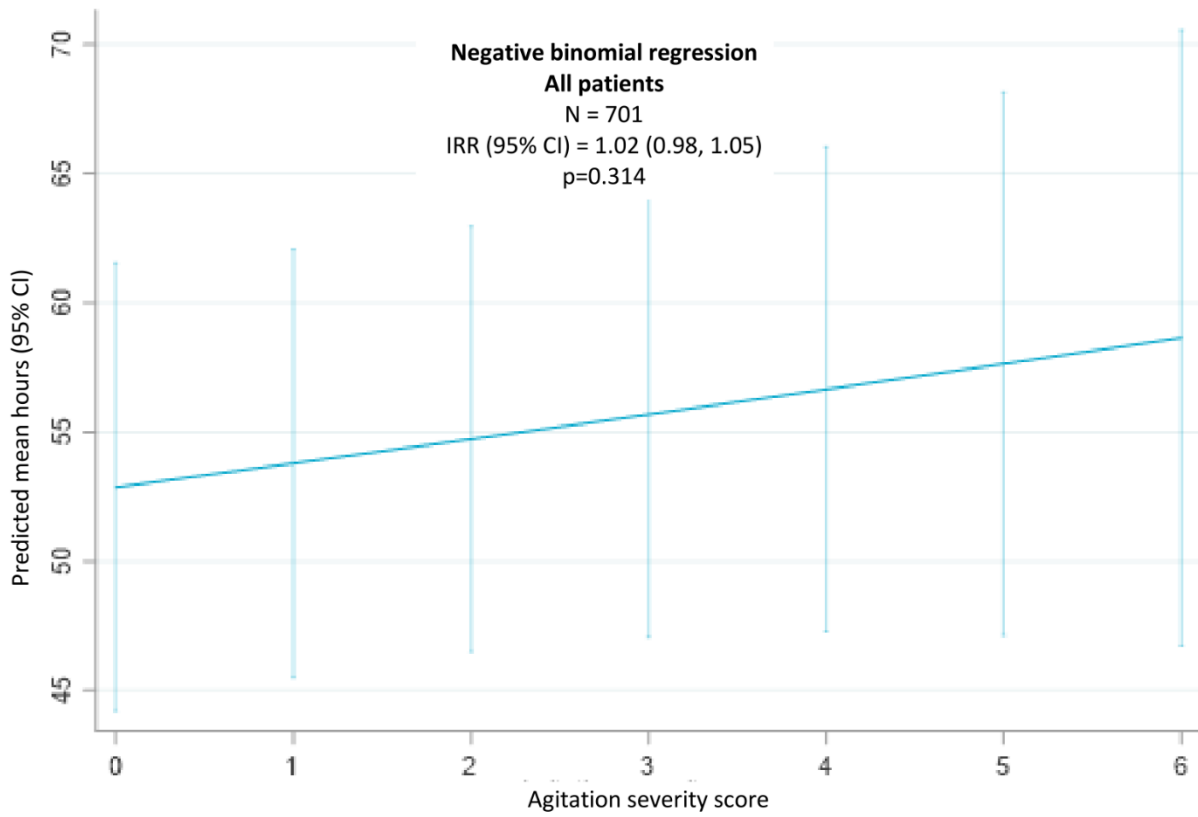
Supplementary Table 3. Summary of all findings

Outcome	Assessed by	Regression analysis of agitation severity score versus outcome		
All caregivers				
Hours/week	Physician-reported caregiver time	n=701;	IRR (95% CI) = 1.02 (0.98, 1.05); p=0.314	
Burden	Zarit Burden Interview	Guilt:	n=191;	Coef (95% CI) = 0.12 (0.01, 0.23); p=0.027
		Role strain:	n=191;	Coef (95% CI) = 0.73 (0.28, 1.19); p=0.002
		Personal strain:	n=191;	Coef (95% CI) = 1.04 (0.41, 1.66); p=0.001
		Total burden:	n=191;	Coef (95% CI) = 1.62 (0.67, 2.56); p=0.001
Health status	EuroQoL-5D-3L	Health utility index:	n=203	Coef (95% CI) = -0.003 (-0.009, 0.003); p=0.294
		VAS:	n=199	Coef (95% CI) = -0.036 (-1.09, 0.27); p=0.259
Productivity	Work Productivity and Activity Impairment questionnaire	Absenteeism:	n=60;	Coef (95% CI) = -0.88 (-2.80, 1.03); p=0.358
		Presenteeism:	n=61;	Coef (95% CI) = 2.52 (0.76, 4.29); p=0.006
		Overall work impairment:	n=57;	Coef (95% CI) = 2.05 (0.06, 4.04); p=0.043
		Total activity impairment:	n=194;	Coef (95% CI) = 3.14 (1.97, 4.30); p<0.001
Proximate caregivers				
Hours/week	Physician-reported caregiver time	n=523;	IRR (95% CI) = 1.05 (1.02, 1.08); p=0.001	
Burden	Zarit Burden Interview	Guilt:	n=152;	Coef (95% CI) = 0.057 (-0.028, 0.141); p=0.186
		Role strain:	n=152;	Coef (95% CI) = 0.87 (0.40, 1.33); p<0.001
		Personal strain:	n=152;	Coef (95% CI) = 1.15 (0.48, 1.83); p=0.001
		Total burden:	n=152;	Coef (95% CI) = 1.76 (0.73, 2.78); p=0.001
Health status	EuroQoL-5D-3L	Health utility index:	n=160	Coef (95% CI) = -0.004 (-0.012, 0.003); p=0.262
		VAS:	n=156	Coef (95% CI) = -0.550 (-1.354, 0.254); p=0.178
Productivity	Work Productivity and Activity Impairment questionnaire	Absenteeism:	n=33;	Coef (95% CI) = -0.58 (-2.84, 1.69); p=0.607
		Presenteeism:	n=33;	Coef (95% CI) = 2.77 (0.49, 5.04); p=0.019
		Overall work impairment:	n=31;	Coef (95% CI) = 2.38 (-0.18, 4.93); p=0.067
		Total activity impairment:	n=151;	Coef (95% CI) = 3.33 (2.00, 4.65); p<0.001
Remote caregivers				
Hours/week	Physician-reported caregiver time	n=178;	IRR (95% CI) = 1.03 (0.92, 1.16); p=0.609	

Outcome	Assessed by	Regression analysis of agitation severity score versus outcome		
Burden	Zarit Burden Interview	Guilt:	n=39;	Coef (95% CI) = 0.57 (0.31, 0.82); p=0.001
		Role strain:	n=39;	Coef (95% CI) = -0.03 (-1.50, 1.44); p=0.970
		Personal strain:	n=39;	Coef (95% CI) = 0.37 (-1.38, 2.12); p=0.671
		Total burden:	n=39;	Coef (95% CI) = 0.96 (-1.86, 3.78); p=0.493
Health status	EuroQoL-5D-3L	Health utility index:	n=43	Coef (95% CI) = -0.006 (-0.017, 0.004); p=0.232
		VAS:	n=43	Coef (95% CI) = 0.102 (-1.212, 1.416); p=0.876
Productivity	Work Productivity and Activity Impairment questionnaire	Absenteeism:	n=27;	Coef (95% CI) = -3.32 (-8.95, 2.32); p=0.235
		Presenteeism:	n=28;	Coef (95% CI) = 1.76 (-1.55, 5.07); p=0.284
		Overall work impairment:	n=26;	Coef (95% CI) = 1.10 (-3.00, 5.21); p=0.583
		Total activity impairment:	n=43;	Coef (95% CI) = 2.27 (-0.13, 4.66); p=0.063

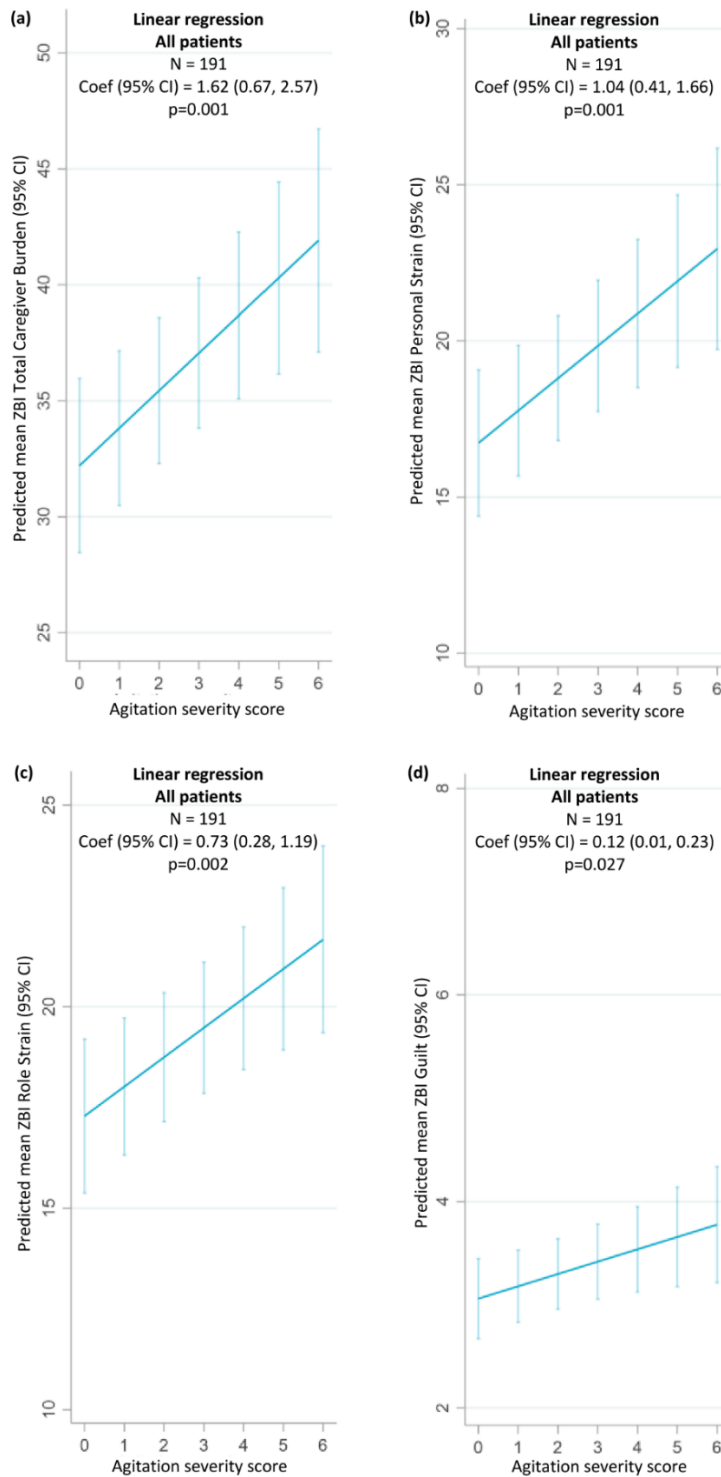
All regressions were controlled for patient demographics (age and sex) and clinical characteristics (time since diagnosis, current MMSE score). Coef, coefficient; CI, confidence interval; IRR, incidence rate ratio; MMSE, Mini-Mental State Examination; VAS, visual analog scale; ZBI, Zarit Burden Interview

Supplementary Figure 1. Hours/week non-professional caregiving by agitation severity score – all patients



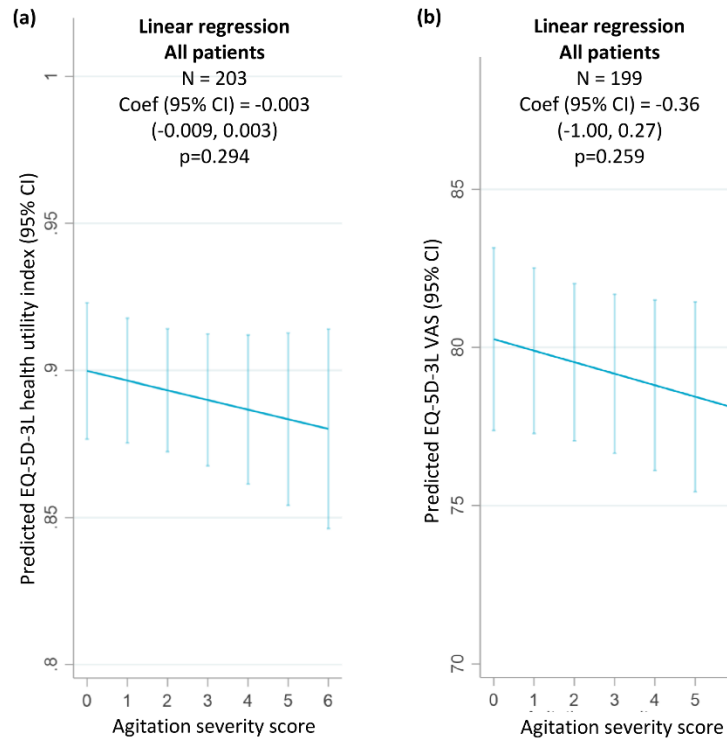
All regressions were controlled for patient demographics (age and sex) and clinical characteristics (time since diagnosis, current MMSE score). CI, confidence interval; IRR, incidence rate ratio; MMSE, Mini-Mental State Examination

Supplementary Figure 2. Caregiver burden by agitation score – all patients: (a) Total burden; (b) Personal strain; (c) Role strain; (d) Guilt



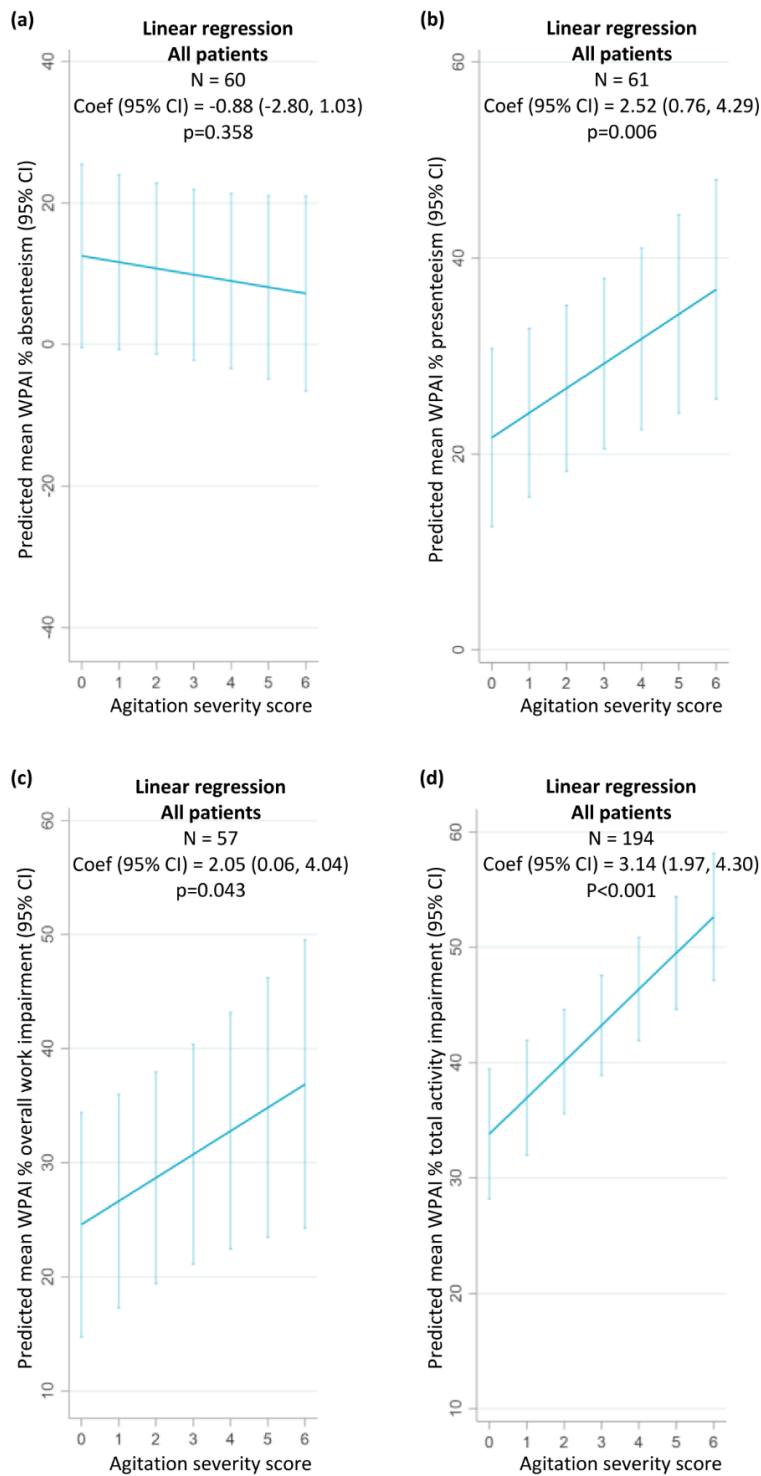
All regressions were controlled for patient demographics (age and sex) and clinical characteristics (time since diagnosis, current MMSE score). Coef, coefficient; CI, confidence interval; MMSE, Mini Mental State Examination; ZBI, Zarit Burden Interview

Supplementary Figure 3. EQ-5D-3L-assessed caregiver health status by agitation score – all patients: (a) Health utility index; (b) VAS score



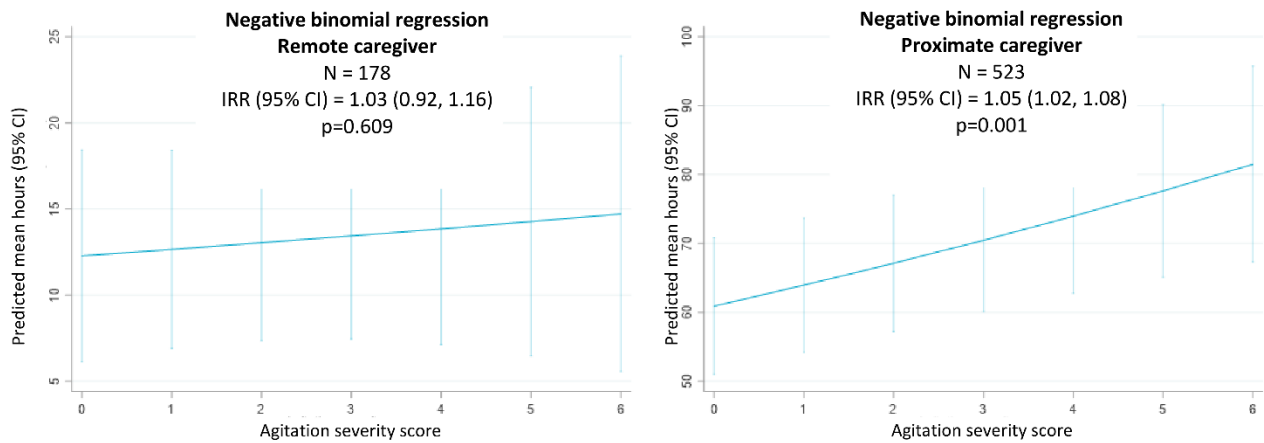
All regressions were controlled for patient demographics (age and sex) and clinical characteristics (time since diagnosis, current MMSE score). CI, confidence interval; EQ-5D-3L, EuroQoL-5D-3L; MMSE, Mini Mental State Examination; VAS, visual analog scale

Supplementary Figure 4. WPAI-assessed productivity and activity by agitation score – all patients: (a) Absenteeism; (b) Presenteeism; (c) Overall work impairment; (d) Total activity impairment



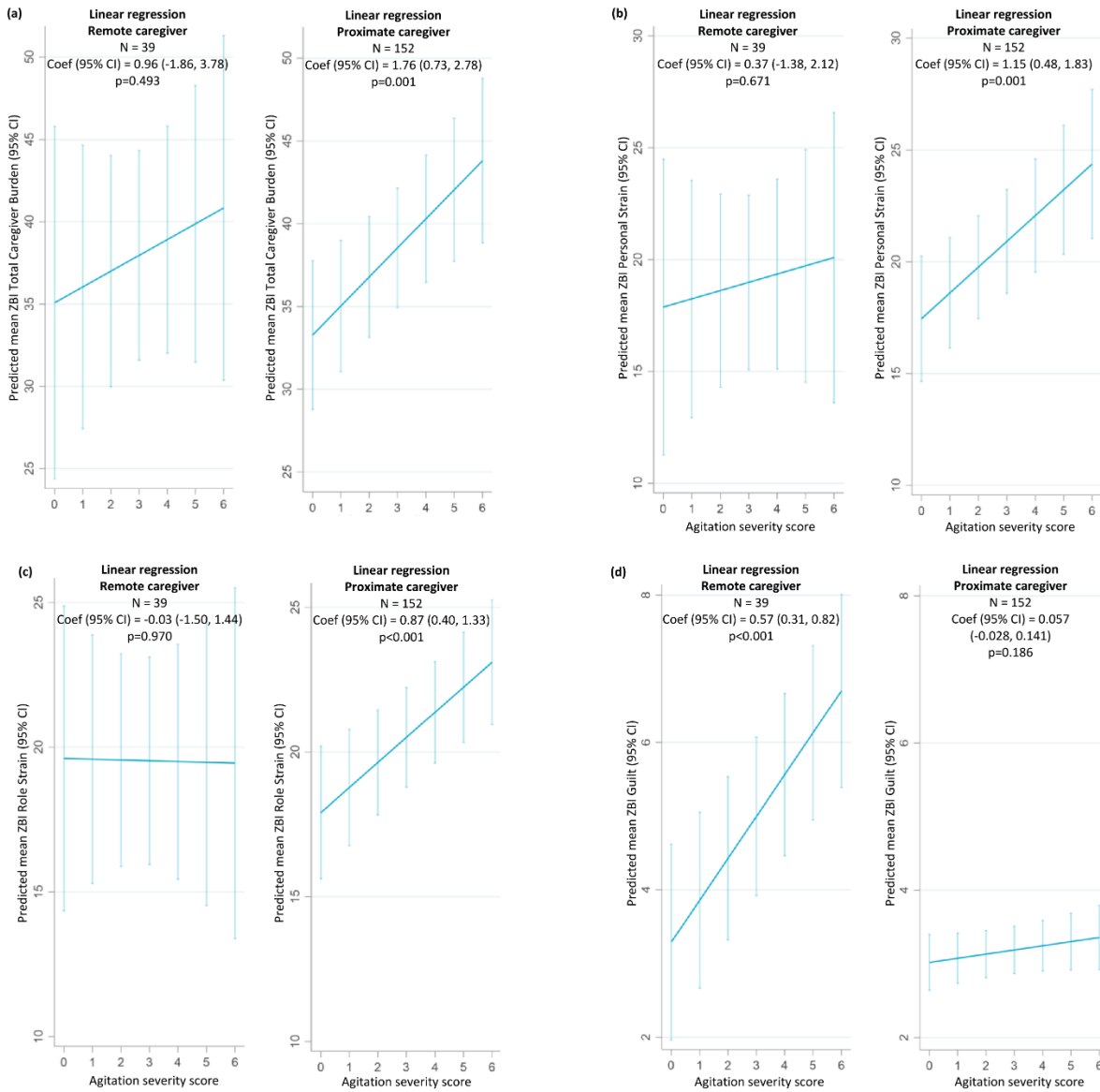
All regressions were controlled for patient demographics (age and sex) and clinical characteristics (time since diagnosis, current MMSE score). CI, confidence interval; MMSE, Mini Mental State Examination; WPAI, Work Productivity and Activity Index

Supplementary Figure 5. Hours/week non-professional caregiving by agitation severity score and type of care



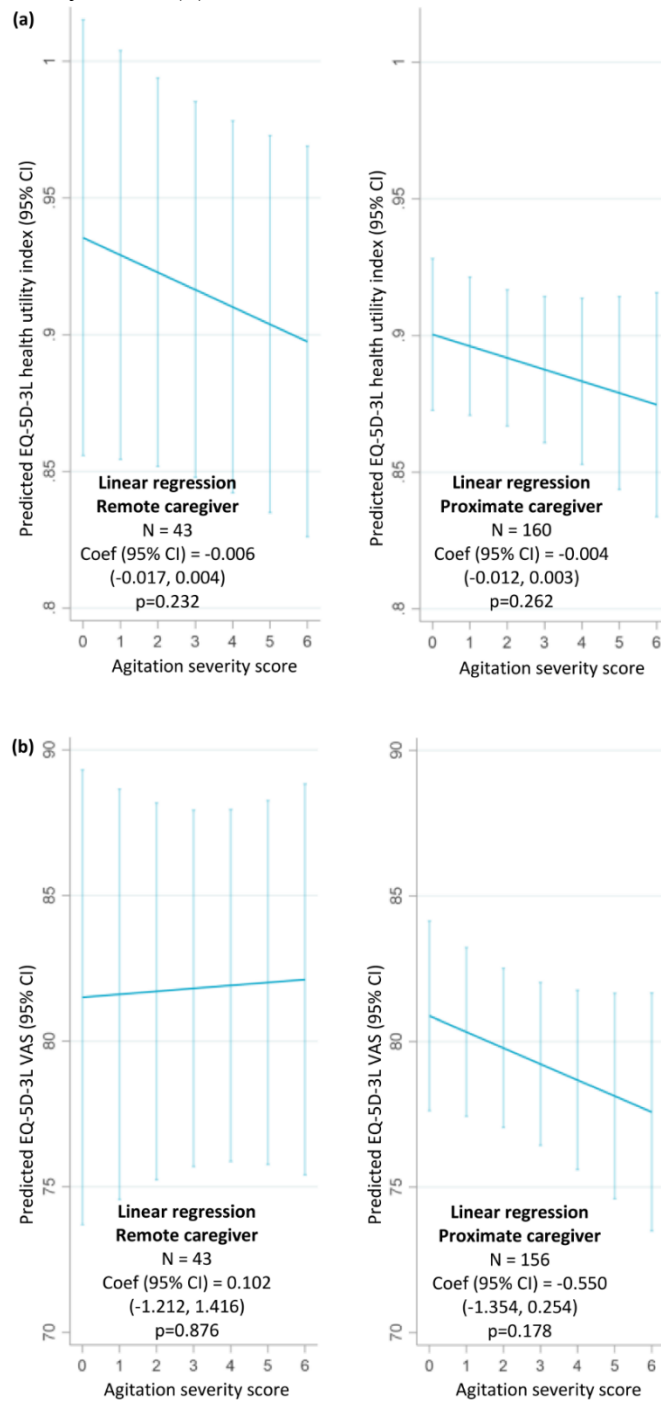
Remote Care, caregiver not living with patient; Proximate Care, caregiver living with patient
All regressions were controlled for patient demographics (age and sex) and clinical characteristics (time since diagnosis, current MMSE score). CI, confidence interval; IRR, incidence rate ratio; MMSE, Mini-Mental State Examination

Supplementary Figure 6. Caregiver burden by agitation score and type of care: (a) Total burden; (b) Personal strain; (c) Role strain; (d) Guilt



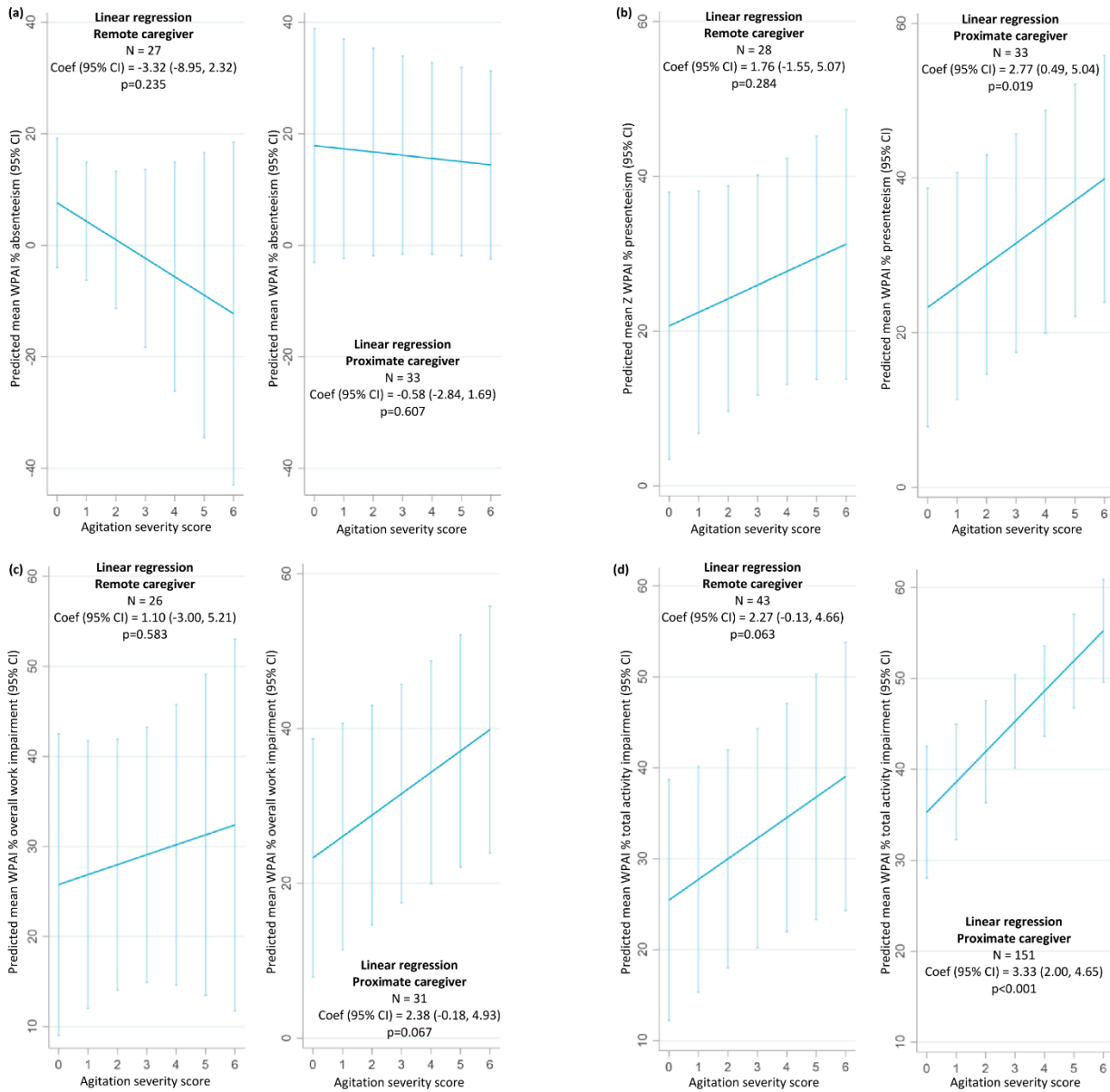
Remote Care, caregiver not living with patient; Proximate Care, caregiver living with patient
 All regressions were controlled for patient demographics (age and sex) and clinical characteristics (time since diagnosis, current MMSE score). Coef, coefficient; CI, confidence interval; MMSE, Mini Mental State Examination; ZBI, Zarit Burden Interview

Supplementary Figure 7. EQ-5D-3L-assessed caregiver health status by agitation score and type of care (a) Health utility index (b) VAS score



Remote Care = caregiver not living with patient; Proximate Care = caregiver living with patient
 All regressions were controlled for patient demographics (age and sex) and clinical characteristics (time since diagnosis, current MMSE score)
 CI, confidence interval; EQ-5D-3L, EuroQoL-5D-3L; MMSE, Mini Mental State Examination; VAS, visual analog scale

Supplementary Figure 8. WPAI-assessed productivity and activity by agitation score and type of care: (a) Absenteeism; (b) Presenteeism; (c) Overall work impairment; (d) Total activity impairment



Remote Care, caregiver not living with patient; Proximate Care, caregiver living with patient

All regressions were controlled for patient demographics (age and sex) and clinical characteristics (time since diagnosis, current MMSE score).

CI, confidence interval; MMSE, Mini-Mental State Examination; WPAI, Work Productivity and Activity Index