

Supplementary Material

Sociodemographic and Clinical Characteristics of People Living with Dementia and Their Associations with Unmet Healthcare Needs: Insights from the Baseline Assessment of the InDePendent Study

Supplementary Table 1. Description of PlwD assessed at baseline and those who dropped out before baseline assessment.

	Included (n=417)	Drop-outs (n=54)
Sex (female), n (%)	233 (55.9%)	27 (50%)
Age , mean (SD)	80.6 (7.0)	81.8 (6.6)
Study group (Intervention group), n (%)	191 (45.8%)	11 (20.4%)
Physician network membership		
Network 1, n (%)	150 (36.0%)	30 (55.6%)
Network 2, n (%)	64 (15.4%)	1 (1.9%)
Network 3, n (%)	52 (12.5%)	15 (27.8%)
Network 4, n (%)	93 (22.3%)	1 (1.9%)
Network 5, n (%)	58 (13.9%)	7 (13.0%)

Supplementary Table 2. Correlation of PlwD assessed at baseline and those who dropped out before baseline assessment.

	OR (CI)	p
Sex (Ref. male)	0.24 (-0.39/0.87)	0.461
Age	-0.05 (-0.10/0.01)	0.064
Study group (Ref. waiting control)	1.18 (-0.39/0.87)	0.001
Physician network membership (Ref. Network 1)		
Network 2	2.73 (0.70/4.75)	0.008
Network 3	-0.54 (-1.28/0.21)	0.159
Network 4	2.92 (0.91/4.94)	0.005
Network 5	0.62 (-0.27/1.52)	0.174

n=471, Pseudo R²: 0.1624, p<0.001

OR, odds ratio; CI, confidence interval

Supplementary Table 3. Sociodemographic and clinical variables of PlwD, separated by randomization group.

	Total sample (n=417)		Waiting control group (n=226)		Intervention group (n=191)		p
Sex (female), n (%)	233	55.9%	128	56.6%	105	55.0%	0.767
Age, mean (SD)	80.6	6.9	81.2	6.8	80	7.0	0.0846
Participating relative (yes), n (%)	186	44.6%	112	49.6%	74	38.7%	0.030
Family Status	n=414		n=224		n=190		0.6498
Single, n (%)	13	3.1%	6	2.7%	7	3.7%	
Married, n (%)	217	52.0%	117	52.2%	100	52.6%	
Divorced, n (%)	17	4.1%	9	4.0%	8	4.2%	
Separated, n (%)	3	0.7%	2	0.9%	1	0.5%	
Widowed, n (%)	164	39.6%	90	40.2%	74	39.0%	
Living alone	n=416		n=225		n=191		0.577
yes, n (%)	167	40.1%	94	41.8%	73	38.2%	
Having children	n=416		n=225		n=191		0.099
yes, n (%)	365	87.7%	204	90.3%	161	84.7%	
Graduation	n=401		n=214		n=187		0.8407
None, n (%)	15	3.7%	10	4.7%	5	2.7%	
Up to 10 years, n (%)	319	79.6%	169	79.0%	150	80.2%	
Over 10 years, n (%)	61	15.2%	60	14.0%	31	16.6%	
Other, n (%)	6	1.5%	5	2.3%	1	0.5%	
Financial situation	n=402		n=219		n=183		0.059
Good, n (%)	324	80.6%	169	77.2%	155	84.7%	
Cognitive impairment (MMST)	n=359		n=199		n=160		0.7855
Score, mean (SD)	18.6	6.5	18.5	6.7	18.7	6.3	
None to mild, n (%)	180	50.1%	99	49.8%	81	50.6	
Moderate, n (%)	141	39.3%	77	38.7%	64	40.0	
Severe, n (%)	38	10.6%	23	11.6%	15	9.4	
Number of diagnosis	n=412		n=222		n=190		0.0223
Score, mean (SD)	10.8	9.3	11.7	10.1	9.6	8.2	
Number of medications, mean (SD)	6.7	3.6	6.6	3.5	6.8	3.8	0.5908
Medication							
Antidementia treatment, n (%)	129	31.3%	65	29.3%	64	33.7%	0.340
Antidepressant treatment, n (%)	80	19.4%	40	18.0%	40	21.1%	0.456
Antipsychotic treatment, n (%)	88	21.4%	44	19.8%	44	23.2%	0.470
Inadequate medication (yes), n (%)	50	12.1%	28	12.6%	22	11.5%	0.9421
Diagnosis							
Dementia (F01-F03), n (%)	274	80.3%	182	82.0%	149	78.4%	0.574
Diabetes (E10-E14), n (%)	129	31.3%	67	30.2%	62	32.6%	0.596
High blood pressure (I10-I15), n (%)	277	67.2%	157	70.7%	120	63.2%	0.115
Cerebrovascular diseases (I60-I69), n (%)	77	18.7%	42	18.9%	35	18.4%	1.000
Coronary heart diseases (I20-I25), n (%)	83	20.2%	46	20.7%	37	19.5%	0.806
Body Mass Index	n=397		n=211		n=186		0.7614
Mean (SD)	26	4,5	25,9	4,3	26,1	4,7	
Having a caregrade (yes)	n=399		n=214		n=185		0.016
n, (%)	276	69.0%	162	75.7%	114	61.6%	
Quality of life (EQ-5D-5L)	n=407		n=220		n=187		0.3922
Score, mean (SD)	0.74	0.23	0.73	0.24	0.75	0.21	
Functional impairment (B-ADL)	n=256		n=138		n=118		0.0097
Score, mean (SD)	5.4	2.3	5.0	2.3	5.8	2.3	
Mobility impairment (DEMMI)	n=350		n=182		n=168		0.2795
Score, mean (SD)	56.7	18.9	55.7	18.0	57.9	20.0	

Timed-up-and-go	n=348	n=187	n=161	0.5628
Score, mean (SD)	27.1 31	28.0 33.2	26.1 28.5	
Unrestricted mobility, n (%)	56 16.1%	26 13.9%	30 18.6%	
Mobility impairment without relevance to everyday life, n (%)	124 35.6%	65 34.8%	59 36.7%	
Restricted mobility with relevance to everyday life, n (%)	65 18.7%	32 17.1%	33 20.5%	
Pronounced mobility impairment, n (%)	103 29.6%	64 34.2%	39 24.2%	
Depression (GDS)	n=341	n=179	n=162	0.4649
Score, mean (SD)	3.6 3	3.7 3.2	3.5 2.8	
No depressive symptoms, n (%)	281 82.4%	143 79.9%	138 85.2%	
Mild depression, n (%)	43 12.6%	27 15.1%	16 9.9%	
Severe depression, n (%)	17 5.0%	9 5.0%	8 4.9%	
Utilization (FIMA)				
Medical (last 3 months)	n=400	n=218	n=182	0.159
General Practitioner, n (%)	365 91.3%	203 93.1%	162 89.0%	
Neurologist/ Psychiatrist, n (%)	n=399 127 31.8%	n=218 60 27.5%	n=181 67 37.0%	0.052
Ambulatory care, n (%)	n=402 28 7.0%	n=219 19 8.7%	n=183 9 4.9%	0.170
Therapeutic	n=401	n=217	n=184	1.000
Physiotherapy, n (%)	90 22.4%	49 22.6%	41 22.3%	
Occupational therapy, n (%)	n=402 44 11.0%	n=218 22 10.1%	n=184 22 12.0%	0.631
Speech therapy, n (%)	9 2.2%	5 2.3%	4 2.2%	1.000
Ambulant nursing service, n (%)	152 37.8%	95 43.6%	57 31.0%	0.010
Relatives, n (%)	n=389 243 62.5%	n=210 125 59.5%	n=179 118 65.9%	0.208
Semi-stationary care facility, n (%) (last 12 months)	n=401 50 12.5%	n=217 27 12.4%	n=184 23 12.5%	1.000
Day clinic, n (%)	n=404 14 3.5%	n=220 10 4.6%	n=184 4 2.2%	0.276
Stationary treatment, n (%)	n=406 80 19.7%	n=221 45 20.4%	n=185 35 18.9%	0.802
Resource Utilization (RUD) - relatives' perspective	n=138	n=83	n=55	0.0991
ADL, mean (SD)	60.4 69.8	68.3 71.1	48.5 66.8	
IADL, mean (SD)	n=165 73.8 66.4	n=100 80.7 71.3	n=65 63.1 57	0.0815
Supervision, mean (SD)	n=100 82.9 152.5	n=58 97.9 171.4	n=42 62.1 120.6	0.2223
Social support (F-SozU)	n=358	n=185	n=173	0.5785
Mean (SD)	3.9 0.5	3.9 0.6	3.8 0.5	
Unmet needs PlwD (CANE) – PlwD perspective	n=242	n=121	n=121	0.3469
Mean (SD)	2.3 2.6	2.1 2.5	2.4 2.6	
Unmet needs PlwD (CANE) – relatives' perspective	n=184	n=109	n=75	0.7712
Mean (SD)	2.5 2.8	2.4 2.9	2.6 2.6	
Unmet needs (CANE) – both perspectives	n=414	n=223	n=191	0.3490
Mean (SD)	2.4 2.7	2.3 2.8	2.5 2.6	
Total unmet needs	985	505	480	
Unmet needs PlwD (IMS) – PlwD perspective	n=417	n=226	n=191	0.0339
Mean (SD)	13.9 5.0	14.4 5.2	13.4 4.7	

Caregiver sex (female) n, (%)	n=184 122 66.3%	n=111 72 64.9%	n=73 50 68.5%	0.531
Caregiver age Mean (SD)	n=177 67.9 12.4	n=107 68.8 12.5	n=70 66.5 12.2	0.4080
Caregiver burden (ZARIT) Mean (SD)	n=179 24.0 13.8	n=109 23.0 14.0	n=70 25.6 13.6	0.2138

MMST, Mini-Mental-Status-Test, range 0-30, higher score indicates better cognitive functioning; B-ADL, Bayer Activities of Daily Living Scale, range 0-10, lower score indicates better performance; GDS, Geriatric Depression Scale, sum score 0-15, score ≥ 5 indicates depression; F-SozU: range 0-5; higher score indicates better social support; ZARIT; range 0-88; higher scores indicates greater caregiver burden, EQ-5D-5L; range 0-1; higher score indicates better health-related quality of life. RUD: examines 3 domains: ADL: activities of daily living (such as personal hygiene, eating, dressing), 2) instrumental ADL (such as shopping, meal preparation, housekeeping) and 3) supervision (such as preventing dangerous events), data in hours per month.

No statistically significant differences were found between the intervention and the waiting control group on any variable (at a significance level of $p < 0.001$).