Supplementary Material

Healthcare Needs Patterns and Pattern-Predicting Factors in Dementia: Results of the Comprehensive, Computerized Unmet Needs Assessment from the Randomized, Controlled Interventional Trial InDePendent

Supplementary Table 1. List of unmet needs and predefined trigger conditions

Area	Unmet Need	Predefined Trigger Conditions
MEDICAL CARE NEEDS		
Dementia diagnostic	Clarification of dementia diagnosis Clarification of differential diagnosis for dementia Unmet need memory	**MMSE** < 27 and no dementia diagnosis or no differential diagnosis or F03 diagnosis (positive DemTect Screening with DemTect score ≤ 8 only); **BADL** > 5 and no dementia diagnosis; **CANE** Section Memory =2 (serious problems)
Visual and audio diagnostic support	Unmet needs vision and hearing Problems with hearing Problems with vision	**CANE** Section Eyesight/hearing/communication with serious problems; **self-developed assessment instrument**: if difficulties with conversations, watching TV, listening to the radio, reading newspaper and recognizing people on the street
Dental	Preventive needs with regard to dental status Problems with dental prothesis	**self-developed assessment instrument:** last visit to the dentist more than 1 year ago and /or difficulties with dental prosthesis
Internal concomitant disease	Unmet need physical illness Abnormal blood pressure Abnormal pulse Diabetes supply material	**CANE** Section Physical health with serious problems; **self-developed assessment instrument**: if 1) unusual low blood pressure, or 2) low blood pressure and symptoms like ringing in the ears, or 3) low blood pressure should be checked out by a doctor, or 4) unusual high blood pressure, or 5) high blood pressure and symptoms like ringing in the ears, or 6) high blood pressure should be clarified by a doctor, or 7) unusual low pulse low, or 8) pulse low and symptoms like dizziness, or 9) pulse low and medical clarification, or 10) pulse quality irregular and weak, or 11) Blood glucose level and insufficient supply, or 12) Diabetic and no diary, or 13) Diabetic and nutrition problems, or 14) Diabetics and problems with injections or pumps, or 15) low blood sugar and eaten something for more than 1.5-2 hours
Neurological/ psychosomatic	Neurological abnormality Pain therapy	**Self-developed assessment instrument**: if 1) patient is in pain despite therapy, or 2) patient has pain weekly or more frequently, or 3) patient has moderate or severe pain; **EQ-5D** dimension pain/discomfort = moderate to extremely severe pain

Psychiatric	Unmet need psychotic symptoms and delirium Psychotic symptoms (depression/anxiety, sleep disorder) Psychotic abnormalities (aggression/agitation) Psychotic abnormalities (delusions/hallucinations) Psychotic abnormalities (stress, communication) Psychotic abnormalities (repetitive behavior, mobility/wandering) Psychotic abnormalities (uncooperative behavior) Unmet need mental stress Mild to moderate depression Severe depression Unmet need Intentional self-harm Unmet needs Behavioral problems and disorders	**CANE section psychotic symptoms** with serious problems; **CANE section psychological distress** with serious problems; **CANE section behavior** withserious problems; **GDS:** Score 5 -10 or 11-15; **self-developed assessment instrument for caregiver:** if 1) no interest/enjoyment in hobbies, or 2) depressed, sad, or 3) nervous, anxious, or 4) stubborn, or 5); believes he is being robbed, or 6) hear voices, see things, or 7) impulsive acting, or 8) wandering around, doing things over and over again, or 9) crying, whining, uncooperative behavior
Dermatological	Skin problems (edematous skin condition) Skin problems No/ insufficient wound care	**self-developed assessment instrument:** if 1) edematous skin condition, or 2) red itchy skin or rash, or 3) no or insufficient independent wound care
Addictive disease	Unmet need substance abuse and addiction Addiction disorder	**CANE** section alcohol = 2 (serious problems); **self-developed assessment instrument:** if alcohol consumption several times a week
Precaution	Slight risk for diabetes Moderate risk for diabetes High risk for diabetes Heart attack or stroke risk Lack of flu vaccine Geriatric rehabilitation (Check forecast and realistic goals)	**self-developed assessment instrument:** if 1) diabetes risk is about 17%, or 2) 33%, or 3) 50%, or 4) increased risk of heart attack and/or stroke >=3 risk factors are present, or 5) Dentist visit more than 1 year ago, or 6) consent to influenza vaccination, or 7) need for advice on thrombosis prophylaxis, or 8) Need for advice on aspiration prophylaxis, or 9) Need for advice on decubitus prophylaxis, or 10) Need for advice on deprivation prophylaxis, or 11) Need for advice on contracture prophylaxis, or 12) Advice needed for constipation prophylaxis, or 13) Need for advice on cystitis prophylaxis, or 14) unsafe driving behavior, drives a car with frontotemporal dementia, drives car and MMSE<20; **CANE** section inadvertent self-harm with serious problems
Information and clarification	Unmet need Information and education Information needs dementia	**CANE** section health and treatment information with serious problems; **self-developed assessment instrument:** if 1) dissatisfaction with dementia education, or 2) Clarification of dementia desired

MEDICATIONAL CARE NEEDS

Dementia drug therapy	Screening for indication of anti-dementia drugs	**self-developed assessment/screening instrument:** Dementia diagnosis but no anti-dementia medication
Guideline-compliant dementia therapy	Review of guideline-compliant pharmacological therapy for dementia	**self-developed assessment/screening instrument for patient:** if Dementia diagnosis, delirious, aggressive behavior AND selected ATC Code; **self-developed assessment instrument for caregiver:** if sleep disorders in dementia AND selected ATC-Code
Potentially inadequate dementia therapy	Indication testing to avoid drug-related problems (Priscus-list)	PIM (Potentially inappropriate medication) according to **PRISCUS** – List (ATC codes)
Medication handling	Unmet need medication Improper storage of drugs Medication plan Medication dispenser Support medication administration	**Assessment/Observation by DCM during home visits:** if 1) no medication plan, but >3 medications. or 2) no medicine dispenser, but >3 medications, or 3) >3 medications and no support or forgotten several times, or 4) open storage of medication in any room; **CANE** section medication with serious problems

NURSING CARE NEEDS

Living environment	Unmet need living situation Lack of accessibility Lack of barriers bathroom Lack of emergency call Problems living situation	**CANE** section living conditions = 2 (serious problems); **self-developed assessment instrument for patient:** if 1) Apartment is not barrier-free and patient is wheelchair users, or 2) Bathroom is not barrier-free and patient is wheelchair users or has walking disabilities, or 3) no emergency call and patient is living alone, or 4) no emergency call and patient has a history of falls in the last 30 days, or 5) no emergency call and patient has fear of falling, or 6) no emergency call and patient has stroke or heart attack or diabetes; **QOL-AD** section living conditions (patient and caregiver) are bad or part/part
Housekeeping	Problems housekeeping Care degree adjustment Problems with making phone calls Problems with shopping	**CANE** section managing the household with serious problems; **self-developed assessment instrument for patient:** if 1) excessive demands (unkempt apartment), or 2) no independent food preparation and no support with food preparation, or 3) no help with household appliances and needed help with household appliances, or 4) needed help with household chores and noticeable impairment (BADL or moderate - severe dementia), or 5) unable to make phone calls independently and living alone, or 6) no shopping without problems and no support with shopping, or 7) not possible to consult a supply provider

Nutrition -	Unmet need nutrition Weight problems Chewing problems Problems with swallowing Problem with care of the stomach tube (PEG) Problems with drinking	**CANE** section nutrition with serious problems; **self-developed assessment instrument for patient:** if 1) patient lost at least 5 kg in the last 3 months, or 2) BMI is too high, or 3) patient has problems with chewing, or 4) problems with swallowing, or 5) patient receives tube feeding and takes care of his own tube, or 6) Drinking amount <1500ml
Body care	Unmet need body care Problems with body care Dressing problems Problems with the choice of clothes Problems with going to the toilet Inadequate foot care	**CANE** section personal care = 2 (serious problems); **self-developed assessment instrument:** if 1) patient or caregiver needed additional help in personal care or benefits of the statutory long-term care insurance or has care grade 1 max., or 2) patient needed additional help by 3) toilet, 4) showering, 5) washing, 6) hair care, 7) grooming beard, 8) brushing teeth, 9) nail care, 10) denture, 11) dressing, choosing clothes, or 12) has a deficient foot care
Mobility	Unmet need mobility Problems with mobility Unmet need increased risk for falls Risk for falls Mobility restriction in need of clarification	**CANE** section mobility/falls with serious problems; **self-developed assessment instrument:** if 1) Difficulty standing for long periods without any support or aids, or 2) Difficulty sitting for long periods of time without any support or aids, or 3) history of falls in the last 30 days, or 4) fear of falling, or 5) half-sided paralysis, or 6) facial paralysis, unknown to the doctor, or 7) frequent/constant dizziness, or 8) severe aphasia, or EPMS: Rigor, Tremor, Akinesis, or 9) Need/capable of rehabilitation, requirements met (in addition with **BADL Score** > 5 and TUG > 20 sec); **TUG**: needed time > 19sec or > 29 or < 30sec (Functionally relevant mobility impairment requiring clarification or pronounced mobility restrictions, usually need for intervention/aids)
Bladder and bowel function	Unmet need bladder and bowel function Problems with urinary continence Problems with incontinence material Problems with bladder emptying Problems with stool continence Problems with bowel emptying Problems with catheter Problems with stoma	**CANE** section continence= 2 (serious problems); **self-developed assessment instrument:** if 1) urinary incontinence during physical exertion, or 2) subject uses incontinence material, or 3) no medical prescription for incontinence material, or 4) insufficient absorbency of the incontinence material, or 5) difficulty urinating, or 6) stool incontinence, or 7) bowel movements weekly or less frequently, or 8) suspected diarrhea, or 9) unusual stool texture, or 10) help with going to the toilet necessary and no benefits from the statutory long-term care insurance, or 11) insufficient or independent supply of the catheter, or 13) insufficient or independent care of the stoma
Prevention	Risk for bedsores Lack of bedsore positioning material Unmet need unintentional self-harm	**self-developed assessment instrument:** if 1) >=3 decubitus risk factors are present, or 2) decubitus risk, but no positioning material; **CANE** (patient and caregiver) section self-harm = 2 (serious problems);

## PSYCHOSOCIAL CARE NEEDS

Social needs	Lack of free time activities Lack of social activity Unmet need Social interactions Unmet need partnership and relationship	**CANE** (patient and caregiver) section Social needs/contacts with serious problems; **CANE** (patient and caregiver) section social intimate relationships with serious problems; **self-developed assessment instrument**: if 1) Restricted leisure activities and loneliness score > 3, or 2) restricted leisure activities that train memory and loneliness score > 3, or 3) little or no activity outside the home and loneliness score > 3, or 4) calls too seldom with friends and family and loneliness score > 3, or 5) wants help with walking and social activity
Physical activity	Lack of physical activity	**CANE** (caregiver) section daytime activities with serious problems
Mental, physical, social activity	Unmet need mental, social and physical activities	**CANE** (patient and caregiver) section daytime activities with serious problems; **self-developed assessment instrument**: if 1) daily activities rarely or not at all

SOCIAL LEGAL SUPPLY NEEDS

Care directive	Missing advanced directives Missing Health Care Power of Attorney / General Power of Attorney	**self-developed assessment instrument**: if 1) no patient decree and able to give consent and max. mild dementia (MMSE <27)
Legal guardianship	Lack of fitness to drive Care directive Check the necessity of legal guardianship	**self-developed assessment instrument**: if 1) no General Power of Attorney and max. mild dementia (MMSE <27), or 2) no advanced directives on care and max. mild dementia (MMSE <27), or 3) no legal guardianship and severe dementia (MMSE <18)
Disabled persons pass	Adaptation disabled person's pass	**self-developed assessment instrument:** if no disabled person's pass is available and patient is disabled
Care grade adjustment	Care degree adjustment	**self-developed assessment instrument:** if help with household is required and impairment in **BADL** or moderate-severe (Alzheimer's) dementia
Finances	Unmet need Financial situation Problems with the financial Situation Unmet needs Benefits and subsidies Advice on stress at work Family and partnership counseling	**CANE** (patient and caregiver) *section financial situation*= 2 (serious problems); **CANE** (caregiver) *section financial support, grants* = 2 (serious problems); **DEMO**: if 1) patient does not get along well with available income, or 2) income is <1000€/month

Supplementary Material 1. Fit statistic for Latent Class Models of Unmet Healthcare Needs Profiles based on Poisson Regression Models (Family) with Log Link and Face Validity oft the Three-Class-Model and the Four-Class-Model
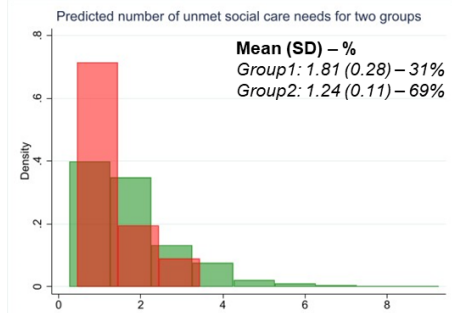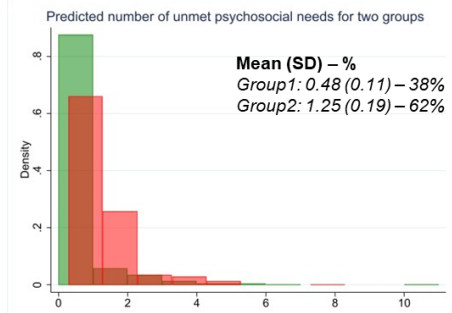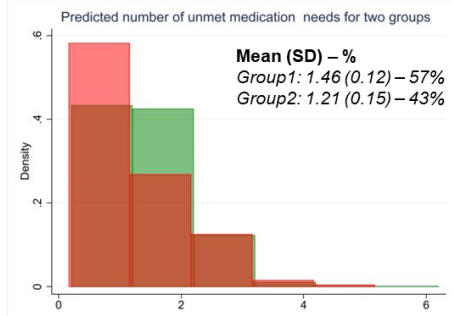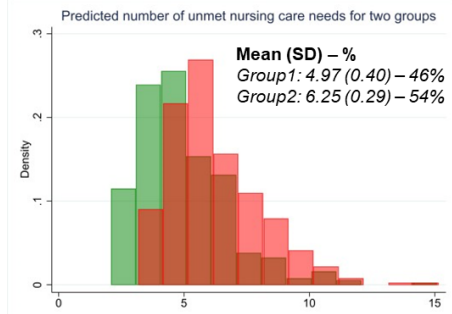
Parameter	Number of classes					
	1	2	3	4	5	6
N free parameters	5	11	17	23	29	35
Log likelihood	-3.778	-3.682	-3.661	-3.652	-3.645	-3.640
BIC	7.587	**7.431**	**7.426***	**7.444**	7.464	7.491
AIC	7.567	7.387	**7.357**	7.351	**7.349***	**7.350**
Likelihood ratio test	-	**<0.001**	**<0.001**	**<0.001**	**<0.001**	**<0.001**
Lowest n per group	**415 (100%)**	**160 (38%)**	**111 (27%)**	**57 (14%)**	39 (9%)	20 (5%)
Face Validity Check			***	***		
Selected Model				***		
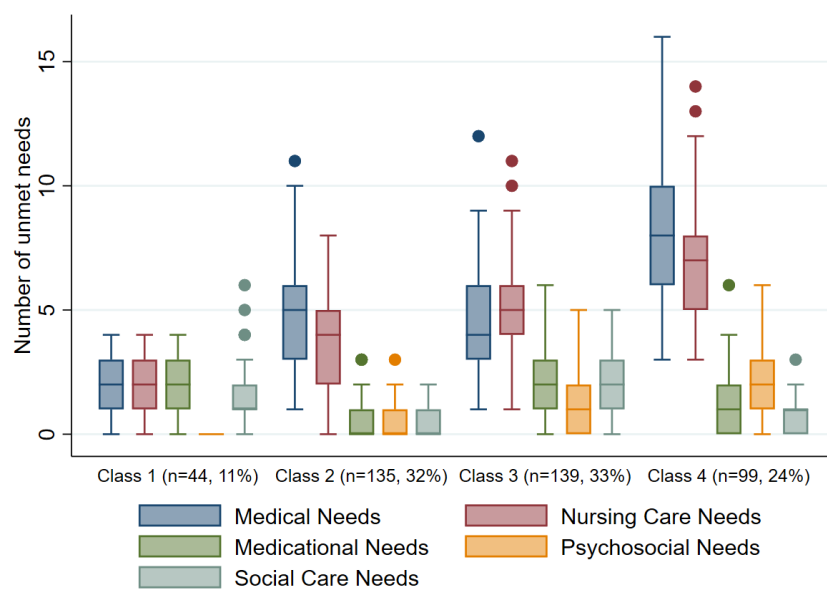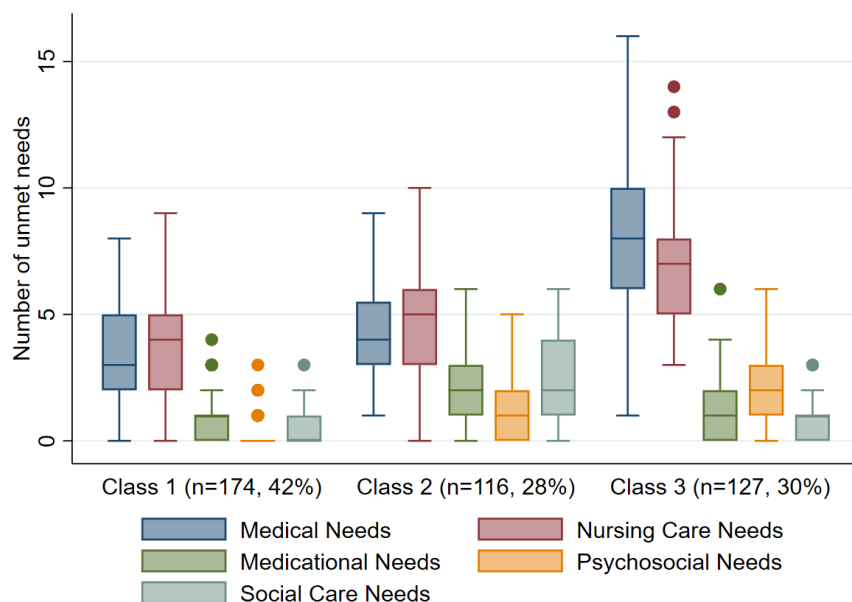
Differences between models: Class 2 and 3 of the "four-class-model" are nearly similar to the first and second class of the "three-class-model", respectively. The third class of the "three-class-model" is divided into a healthier, less depressive sample with a very low number of unmet needs (class one in the "four-class-model", and a less healthy, more depressive sample with a very high number of drugs.

Supplementary Figure 1. Finite Mixture Models (Poisson) results

Associated Factors within Finite Mixture Models:

Predicted number of unmet medical needs for two groups

Mean (SD) – %
Group1: 4.69 (0.19) – 69%
Group2: 6.06 (0.37) – 31%
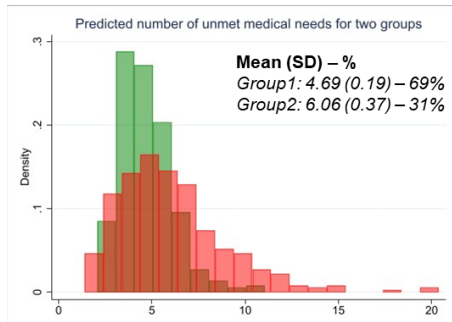
- Lower number of Diagnoses (b=0.011; SE=0.01;p=0.002), lower EQ-5D-5L health state (b=-0.47; SE=0.17;p=0.007), no financial problems (b=0.22; SE=0.11;p=0.045), and a lower cognition (b=0.02; SE=0.01, p=0.004) decreases the number of medical care needs in group 1
- Financial problems (b= -0.37; SE=0.14;p=0.008), living alone (b=0.29; SE=0.14;p=0.037), missing regular general practitioner visits (b=-0.48; SE=0.20;p=0.0021), a lower EQ-5D-5L health state (b=-0.57; SE=0.26, p=0.029), a higher age and (b=0.03; SE=0.01;p=0.009) lower social support (b=0.37; SE=0.16; p=0.016) increases the number of medical care needs in group 2

Predicted number of unmet nursing care needs for two groups

Mean (SD) – %
Group1: 4.97 (0.40) – 46%
Group2: 6.25 (0.29) – 54%

- A higher BMI (b=0.03; SE=0.01;p=0.006) increases the number of nursing care needs in group 1
- Missing regular general practitioner visits (b=-0.30; SE=0.15;p=0.0042) and a lower EQ-5D-5L health state (b=-0.58; SE=0.18, p=0.001) increases the number of nursing care needs in group 2

Predicted number of unmet medication needs for two groups

Mean (SD) – %
Group1: 1.46 (0.12) – 57%
Group2: 1.21 (0.15) – 43%

- A higher education (b=0.64; SE=0.20, p=0.002), no financial problems (b=-0.43; SE=0.21, p=0.044) reduces the number of unmet medication needs in group 1
- Living alone (b=1.01; SE=0.31, p=0.001) increases the number of medication needs

Predicted number of unmet psychosocial needs for two groups

Mean (SD) – %
Group1: 0.48 (0.11) – 38%
Group2: 1.25 (0.19) – 62%

- A better EQ-5D-5L health state (b=-2.80; SE=1.22, p=0.022), better social support (b=-2.43; SE=0.86, p=0.005), a higher BMI (b=0.09; SE=0.04, p=0.015) and being not treated by a Neurologist (b=1.31; SE=0.51, p=0.011) reduces the number of psychosocial needs in group 1
- A lower social support (b=-0.50; SE=0.17; p=0.001), lower education (b=-0.50; SE=0.21, p=0.013) and without regular general practitioner treatment (b=-0.71; SE=0.21, p=0.001) increases the number of psychosocial needs in group 2

Predicted number of unmet social care needs for two groups

Mean (SD) – %
Group1: 1.81 (0.28) – 31%
Group2: 1.24 (0.11) – 69%

- A higher number of medication (b=0.11; SE=0.05, p=0.016) increases the number of social care needs in group 1
- Having access to the social care system by a care grade (b=-0.88; SE=0.17, p=0.001) reduces the number of social care needs in group 2.