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

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#### Abstract.

**Background:** Determining unmet need patterns and associated factors in primary care can potentially specify assessment batteries and tailor interventions in dementia more efficiently.

**Objective:** To identify latent unmet healthcare need patterns and associated sociodemographic and clinical factors. **Methods:** This Latent Class Analysis (LCA) includes n = 417 community-dwelling people living with dementia. Subjects completed a comprehensive, computer-assisted face-to-face interview to identify unmet needs. One-hundred-fifteen predefined unmet medical, medication, nursing, psychosocial, and social care needs were available. LCA and multivariate logistic regressions were performed to identify unmet needs patterns and patient characteristics belonging to a specific pattern, respectively.

**Results:** Four profiles were identified: [1] "few needs without any psychosocial need" (n = 44 (11%); mean: 7.4 needs), [2] "some medical and nursing care needs only" (n = 135 (32%); 9.7 needs), [3] "some needs in all areas" (n = 139 (33%); 14.3 needs), and [4] "many medical and nursing needs" (n = 99 (24%); 19.1 needs). Whereas the first class with the lowest number of needs comprised younger, less cognitively impaired patients without depressive symptoms, the fourth class had the highest number of unmet needs, containing patients with lower health status, less social support and higher comorbidity and depressive symptoms. Better access to social care services and higher social support reduced unmet needs, distinguishing the second from the third class (9.7 versus 14.3 needs).

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**Conclusions:** Access to the social care system, social support and depressive symptoms should be assessed, and the patient's health status and comorbidities monitored to more comprehensively identify unmet needs patterns and more efficiently guide tailored interventions.

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Keywords: Alzheimer's disease, dementia, latent class analysis, primary care, profiles, unmet needs

# INTRODUCTION

Dementia diseases are characterized by a progressive decline in cognitive abilities and impaired daily functioning [1]. Individuals often require extensive support and services to manage symptoms and coexisting diseases and maintain quality of life [2]. Therefore, people living with dementia (PlwD) often experience numerous unmet healthcare needs [3], including early and accurate diagnosis, care access, effective treatment options, social support, and palliative and end-of-life care [4, 5] that should be addressed by integrated, multi-professional approaches to improve an individual's live and healthcare delivery [5–8].

A common way to identify unmet needs is to administer standardized tools, such as the Johns Hopkins Dementia Care Needs Assessment (JHD-CNA) [9] or the Camberwell Assessment of Needs for the Elderly (CANE) [10], covering emotional well-being, health service access, managing neuropsychiatric symptoms, legal concerns, personal safety, general health care, daily activities domains, and education and information [4, 11-13]. However, these tools result in an imprecise identification of only a fraction of the unmet and met healthcare needs [4, 5, 11-13]. Other multimodal, comprehensive approaches are broader, identifying up to 16 unmet healthcare needs [14], but could be timeconsuming and burdensome for PlwD, especially when long assessments and tests are used to uncover as many unmet needs as possible.

So far, only one study has investigated profiles of care needs using the CANE in community-dwelling PlwD [15]. Four distinct need profiles were identified through latent class analysis, comprising a "no need" (41% of the sample), a "met psychological needs" (25%), a "met social needs" (19%), and an "unmet social needs" profile (15%). However, the CANE is neither comprehensive nor detailed enough to uncover all existing unmet needs, as represented by the results of this study, where only 15% of PlwD

had "unmet social needs" and all other "no needs" or "met needs", representing a somewhat unrealistic situation of community-dwelling PlwD.

Therefore, we developed an unmet need battery for PlwD on an extensive level. Identifying typical unmet need profiles with specific unmet needs combinations and profile-predicting factors can help specify unmet needs assessment batteries and more effectively tailor interventions focusing on broader need combinations. However, evidence of unmet needs patterns based on such comprehensive unmet needs assessment is currently lacking. Filling that gap by an exploratory latent class analysis and class prediction model was the main objective of this analysis.

## MATERIALS AND METHODS

#### Study design, setting, and recruitment

This cross-sectional, exploratory analysis was based on data derived from the German InDe-Pendent study "Advanced nursing practice and interprofessional dementia care"). This multicenter, cluster-randomized, controlled intervention study aims to reduce the number of unmet needs through an integrated model combining extended nursing roles with a redistribution of tasks between nurses and general practitioners (GPs) [16].

Study participants were recruited by GPs, neurologists and psychiatrists who are members of five physician networks in primary and specialized ambulatory care in three federal states of Germany. Inclusion criteria of PlwD were: screened positive for dementia (DemTect  $\leq 8$ ) [17] or being formally diagnosed with dementia, and living community-dwelling.

PlwD were informed about the study, invited to participate and asked to provide written informed consent (IC), as approved by the ethical committees (BB144/20; AS 81(bB)/2020; 2020-2081-zvBO). If patients could not provide IC, their legal representative was asked to provide written IC. Study enrollment and patient recruitment started on January 1, 2021 and ended on December 31, 2022. The present analysis was based on the data of 417 patients who completed the baseline assessment. The baseline assessment, which includes the assessment of unmet needs, was carried out immediately after the patient recruitment, in general, within one month after recruitment. The study is registered as a clinical trial (ClinicalTrials.gov Identifier: NCT04741932). Details of the study are described elsewhere [16].

#### Assessment of unmet needs

Specifically-qualified nurses (so-called Dementia Care Managers) conducted a standardized, computer-assisted, and algorithm-based unmet needs assessment within face-to-face interviews conducted at the participants' homes. To reduce the complexity and support the systematic identification of unmet needs, a computerized Intervention-Management-System (IMS) has been developed according to existing dementia-specific guidelines for evidencebased diagnostics and treatment of dementia, a review of current literature, meetings, and symposia with experts in the field and the scientific advisory board of DelpHi-MV study [18]. The unmet needs assessment was also tested and implemented in a primary care setting [14]. The IMS implemented in this study extends the previous system used in the DelpHi-MV and DCM:IMPact study [18, 19]. The principle of the unmet needs assessment is described elsewhere [14].

The IMS is a rule-based expert decision support system based on an array of validated questionnaires, tests, and further need-specific questions, matching PlwD individual responses to the computerized knowledge base. An unmet need was 1) identified automatically through the standardized survey (algorithm-based, predefined trigger conditions) by the system and confirmed by the nurse or 2) additionally identified by the nurse. For each questionnaire, trigger conditions were elaborated and defined, indicating a specific unmet need.

Unmet needs were categorized as follows: 1) medical care needs, 2) medication care needs, 3) nursing care needs, 4) psychosocial care needs, and 5) social legal support needs. The needs of caregivers were not taken into account due to the main objective of this paper, which is to focus on unmet needs patterns of PlwD. In total, n = 115 predefined needs exist.

An overview of the assessment instruments used, trigger conditions, and unmet needs is presented in Supplementary Table 1. The categories dental and dermatological unmet needs as well as needs related to addictive diseases were not considered due to too low observations (mean value < 0.1).

# Assessed sociodemographic and clinical variables

Age, sex, marital status, living situation (alone /not alone), education (less than ten years/ ten years/ more than ten years of school), financial problems (self-report: yes versus no) and presence of an informal caregiver (yes /no) were assessed. Furthermore, the following clinical measures were used: cognitive impairment according to the Mini-Mental State Examination (MMSE) [20], functional impairment according to the Bayer Activities of Daily Living Scale (B-ADL) [21], depression measures by the Geriatric Depression Scale [22], and social support according to the Social Support Questionnaire (F-SozU) [23]. Medical diagnoses (ICD-10 codes) and drugs taken (ATC codes) were retrieved from the medical records of the treating GPs' or specialists' practice, covering all documented ICD-10 diagnoses and drugs taken. The general health status was assessed by the EQ-5D-5L [24]. Functional impairment was also measured by the "long-term nursing care levels", ranging from one (slight impairment of independence) to five (severe impairments of independence), covering the need for care due to physical, mental and cognitive impairment. The longterm care levels determine the care services and/ or care benefits patients can receive, covered by longterm care insurance as part of the German social care system. Additionally, we assessed the body mass index (BMI) and healthcare utilization, especially GP and specialist visits (neurologists, psychiatrists).

## Statistical analyses

We summarized the variables that describe the sample and unmet needs using descriptive statistics. While there were complete data for unmet needs, missing data on covariates (up to 18% of PwD had missing values for covariate variables) were imputed using multiple imputations by chained equation [25].  $\chi^2$  and ANOVA tests were used to assess differences between groups.

Latent class analyses (LCA) were performed to predict unmet healthcare needs profiles, grouping PlwD into latent classes based on the number of unmet needs in the five need domains. Therefore, LCA was used to identify common combinations of unmet needs domains on a group level [26, 27]. LCA models were carried out as Poisson (number of unmet needs in each category) with log link, using maximum likelihood estimation with robust standard errors for two to six classes. For each of the k-class models (number of classes), the following criteria were examined: log-likelihood value (larger values indicate better fit), the sample size adjusted Bayesian and Akaike's information criterion (BIC, AIC; lower values indicate better fit), and the bootstrap likelihood ratio test showing differences between neighbouring models. Also, the lowest number of individuals per group (should be > 10%) was used to ensure that the LCA analysis produces reliable, stable, and interpretable results that can be generalized to the population of interest. Since LCA is a data-driven approach, we conducted a face validity check by visualizing the number of unmet needs categories over latent classes before model selection (see Supplementary Table 2) [26, 27].

To identify profile-predicting factors, we fitted a logistic regression model with the latent class group (dichotomously for each group) as the dependent variable and the sociodemographic and clinical variables listed above as independent variables. All statistical analyses were performed using STATA 16 [28]. We used the TRIPOD statement and checklist to report the LCA and FMM model development and application [29].

### Sensitivity analysis

While LCA was used to predict needs profiles by grouping PlwD into latent classes of unmet needs combinations with five need domains, we performed Finite Mixture Models (FMM) for clustering and density estimation of each individual unmet needs domain as a sensitivity analysis to estimate underlying probability density functions and identify natural groupings or clusters within each domain. This was done to extend and assess the robustness of the presented LCA results. FMM models were carried out as Poisson regression models adjusted for covariates. BIC, AIC were examined to assess model fit and selection of the number of underlying densities.

# RESULTS

# Sociodemographic and clinical factors

Table 1 presents the sociodemographic and clinical characteristics of the study sample.

# Number of unmet needs and associated sociodemographic and clinical factors

The mean number of unmet needs was 13 (range: 0-31). Only one PlwD (0.2%) had no unmet need, 92% seven or more, and ten percent more than 20 unmet healthcare needs.

The distribution of the unmet needs across the five subcategories is shown in Table 2. The majority of unmet needs were "medical care needs" and "nursing care needs" (4.8 per PlwD, respectively), fourfold more often than "medication care needs" (1.4 per PlwD), "social, legal supply needs" (1.1) and "psychosocial care needs" (1.0 per PlwD). Psychiatric needs, like psychotic symptoms and abnormalities, delirium, mental stress, depression, and behavioural problems (1.3 per PlwD), were the most common individual needs.

# Latent profiles of unmet healthcare needs

Based on model fit criteria and face validity, the four-class model was considered superior, assigning PlwD to one out of four classes based on the largest possibility of membership. The following class membership distribution was observed: n = 57 (13.7%) in class one; n = 131 (31.4%) in class two and class three, respectively; n = 98 (23.5%) in class four.

The four profiles were labelled according to the number of unmet needs in the respective four categories as follows:

- (1) "Few needs without any psychosocial needs", where patients have the lowest number of unmet needs (mean: 7.4), the highest education and health status and lowest long-term care grade severity, functional impairment, number of drugs taken and number of comorbidities.
- (2) "Some medical & nursing needs only", where patients had on average 9.7 needs in total, the highest long-term care grade severity and functional impairment but also the highest long-term level of nursing care coverage, and the highest social support.
- (3) "Some needs in all areas", where patients had on average 14.3 unmet needs, a high functional and the highest cognitive impairment but also the largest proportion of patients without a long-term level of nursing care coverage.
- (4) "Many medical & nursing care needs", where patients have the highest number of unmet needs (mean 19.1), the lowest education and

| Demographics   |             |
|--|-------------|
| Female sex, n (%)  | 233 (55.9)  |
| Age, mean (SD)   | 80.6 (6.9)  |
| Living alone, n (%)  | 167 (40.1)  |
| Marital status (married), n (%)                                    | 217 (52.4)  |
| Presence of informal caregiver, n (%)                              | 383 (96.0)  |
| Education, n (%)   |             |
| <i>No school-leaving qualification or &lt; 10 years of schools</i> | 240 (59.9)  |
| Secondary school (= 10 years)                                      | 94 (23.4)   |
| High school or higher (>10 years)                                  | 67 (16.7)   |
| Clinical variables   |             |
| Cognitive impairment (MMSE), mean (SD)                             | 17.3 (7.5)  |
| Mild (MMSE>20), n (%)  | 65 (15.6)   |
| Moderate (MMSE 10–19), n (%)                                       | 165 (39.6)  |
| Severe (MMSE 0–9), n (%)   | 187 (44.8)  |
| Functional impairment (B-ADL), mean (SD)                           | 5.8 (2.3)   |
| Depression (GDS), mean (SD)  | 3.7 (2.8)   |
| Yes $(GDS > 6)$ , $n (\%)$   | 51 (12.2)   |
| Social inclusion (F-Sozu), mean (SD)                               | 3.9 (0.5)   |
| Long-term care grade / level of nursing care coverage, n (%)       |             |
| No   | 138 (33.1)  |
| 1  | 34 (8.2)    |
| 2  | 98 (23.5)   |
| 3  | 94 (22.5)   |
| 4–5  | 53 (12.7)   |
| Number of drugs taken, median (IQR)                                | 6 (4–9)     |
| Number of ICD-10 diagnoses, median (IQR)                           | 8 (4–14)    |
| Body-Mass-Index, mean (SD)   | 26.0 (4.3)  |
| Health status (EQ-5D-5 L index), mean (SD)                         | 0.74 (0.23) |
| Healthcare utilization   |             |
| GP visit during last 3 months (yes), n (%)                         | 364 (87.3)  |
| Neurologists visit during last 3 months (yes), n (%)               | 127 (30.5)  |

Table 1 Sociodemographic and clinical characteristics of the study sample (n = 417)

MMSE, Mini-Mental State Examination; 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  $\geq$  6 indicates depression; GP, general practitioner; ICD-10, International Classification of Diseases; EQ-5D-5 L, index values ranged between 1 – 0.661, higher indices indicate better health.

health status, and the highest depression score, number of drugs taken and comorbidity.

A description of unmet needs patterns and patients' sociodemographic and clinical variables are shown in Table 3 and Fig. 1. However, subcategories of needs with significant differences between classes were shown only in Table 3, which means that unmet needs categories that did not differ significantly across latent classes were hidden.

#### Predictors of unmet needs pattern membership

Younger and non-depressed patients who are not receiving treatment by a specialist (neurologist, psychiatrist) had a high chance of belonging to the first class, "few needs without any psychosocial care need". Needs profile class two membership ("some medical & nursing needs only") was predicted by having a long-term nursing care level (representing better access to social and nursing care services) and higher social support. Having "some needs in all areas" (class 3) was associated with a missing long-term level of nursing care (representing restricted access to social and nursing care services) and a higher cognitive impairment. Finally, depressed patients with low health status, increased comorbidity, and less social support had a higher chance of belonging to the fourth class with the highest number of unmet needs, especially medical and nursing care needs. The results of the multivariate analyses are presented in Table 4.

#### Sensitivity analysis – finite mixture models

Based on AIC and BIC, the FMM revealed no unobserved densities of two or more than two underlying subpopulations within each unmet need

|                                     |             | ,          |                   |       |
|-------------------------------------|-------------|------------|-------------------|-------|
|                                     | yes (%)     | mean (SD)  | CI <sup>95%</sup> | Range |
| Total                               | 416 (99.8%) | 13.1 (5.1) | 12.5-13.5         | 0-31  |
| Medical care needs                  | 414 (99.3)  | 4.8 (2.8)  | 4.5-5.0           | 0-16  |
| Dementia diagnostic                 | 314 (75.3)  | 1.0 (0.7)  | 0.9-1.1           | 0-3   |
| Visual and audio diagnostic support | 159 (38.1)  | 0.5 (0.8)  | 0.5 - 0.6         | 0-3   |
| Internal concomitant disease        | 161 (38.6)  | 0.5 (0.7)  | 0.4-0.6           | 0–4   |
| Neurological/psychosomatic          | 192 (46.0)  | 0.6 (0.7)  | 0.5-0.6           | 0-2   |
| Psychiatric                         | 229 (54.9)  | 1.3 (1.6)  | 0.5-0.6           | 0–8   |
| Precaution                          | 198 (47.5)  | 0.6 (0.8)  | 0.6-0.7           | 0–3   |
| Information and clarification       | 89 (21.3)   | 0.3 (0.5)  | 0.2-0.3           | 0-2   |
| Medication Care Needs               | 296 (71.0)  | 1.4 (1.3)  | 1.2-1.5           | 0-6   |
| Anti-dementia drug treatment        | 211 (50.6)  | 0.5 (0.5)  | 0.4-0.6           | 0-1   |
| Potentially inadequate medication   | 51 (12.2)   | 0.1 (0.3)  | 0.1-0.2           | 0-1   |
| Medication handling                 | 162 (38.9)  | 0.7 (1.0)  | 0.6-0.8           | 0-5   |
| Nursing Care Needs                  | 408 (97.8)  | 4.8 (2.4)  | 4.5-5.0           | 0-14  |
| Living environment                  | 269 (64.5)  | 0.8 (0.8)  | 0.8 - 1.0         | 0–4   |
| Housekeeping                        | 260 (62.4)  | 0.7 (0.7)  | 0.7 - 0.8         | 0–3   |
| Nutrition                           | 294 (70.5)  | 1.0 (0.8)  | 0.9 - 1.0         | 0-5   |
| Body care                           | 270 (64.8)  | 1.2 (1.1)  | 1.1-1.3           | 0-4   |
| Mobility                            | 270 (64.8)  | 1.0 (1.0)  | 0.9-1.1           | 0–4   |
| Psychosocial Care                   | 217 (52.0)  | 1.0 (1.2)  | 0.8-1.1           | 0-6   |
| Social interaction                  | 146 (35.0)  | 0.5 (0.9)  | 0.4-0.6           | 0–4   |
| Physical activity                   | 87 (20.9)   | 0.2 (0.4)  | 0.2-0.2           | 0-1   |
| Mental activity                     | 87 (20.9)   | 0.2 (0.4)  | 0.2-0.3           | 0-1   |
| Social Care Needs                   | 302 (72.4)  | 1.1 (1.2)  | 1.0-1.2           | 0-6   |
| Care directive                      | 58 (13.9)   | 0.2 (0.5)  | 0.1-0.2           | 0-2   |
| Legal guardianship                  | 148 (35.5)  | 0.5 (0.7)  | 0.4-0.5           | 0-3   |
| Disabled persons pass               | 96 (23.0)   | 0.2 (0.4)  | 0.2-0.3           | 0-1   |
| Care grade adjustment               | 96 (23.0)   | 0.2 (0.4)  | 0.2-0.3           | 0-1   |

Table 2 Unmet needs of patients (n = 417)

domain. However, the domains of unmet nursing and medical needs tend to differentiate between two underlying densities. The factors associated with the groups with higher or lower unmet needs were comparable to the results of the pattern-predicting factors based on the LCA analysis.

#### DISCUSSION

This is the first study that provided empirical evidence about unmet needs patterns and profilepredicting factors of community-dwelling PlwD based on a comprehensive needs assessment. PlwD had, on average, thirteen unmet needs, especially medical and nursing care needs, which also represented the highest proportion of possible unmet needs of the implemented intervention management system. Using the LCA method, four main profiles were identified, ranging from a class with "few needs without any psychosocial need" over groups of "some medical and nursing care needs only" and "some needs in all areas" to "many medical and nursing needs". The class with the lowest needs (class one) comprised especially younger patients without depressive symptoms. This group was also less cognitively impaired and had a higher general health status than the other classes. The second class had, on average, still less than ten unmet needs and were represented by patients having significantly more likely a long-term nursing care level, which can be seen as access to social care services, like home care and day and night care, and significantly higher social support by family and friends. The third class had considerably more needs than class two (mean: 14.3 versus 9.7), containing people without a long-term level of nursing care, even though their cognitive impairment was significantly higher. The fourth class had the most unmet needs, containing patients with significantly lower health status, less social support and a higher number of comorbidities and depressive symptoms.

Janssen et al. [15] demonstrated latent needs profiles based on the CANE, where only 15% of PlwD had "unmet social needs" and all other "no needs" or "met needs". The CANE is a valid assessment tool in PlwD with acceptable psychometric properties [30, 31]. However, due to the very low number of unmet needs, the unmet needs patterns identified using the CANE do not represent the real-life situation of

|  | Description of unmet needs classes                                 |  |  |  |  |  |  |  |
|--|--|--|--|--|--|--|--|--|
| Parameter/ classes                                       | Class 1 "Few<br>needs without<br>psychosocial<br>needs" $(n = 57)$ | Class 2 "Some<br>medical & nursing<br>needs only"<br>(n = 131) | Class 3 "Some<br>needs in all<br>areas"<br>(n = 131) | Class 4 "Some<br>needs in all areas,<br>but many medical<br>& nursing needs"<br>(n = 98) |  |  |  |  |
| Unmet Needs <sup>1</sup> , mean (SD)***                  | 7.4 (2.6)  | 9.7 (2.7)  | 14.3 (3.1)   | 19.1 (3.9)   |  |  |  |  |
| Medical care***  | 1.8 (1.1)  | 4.3 (1.9)  | 4.3 (2.0)  | 7.8 (2.8)  |  |  |  |  |
| Dementia diagnostic***                                   | 0.9 (0.6)  | 0.8 (0.7)  | 1.1 (0.7)  | 1.1 (0.7)  |  |  |  |  |
| Neurological/psychiatric***                              | 0.4 (0.6)  | 1.7 (1.3)  | 1.5 (1.5)  | 3.4 (2.1)  |  |  |  |  |
| Information/clarification***                             | 0.2 (0.5)  | 0.7 (0.9)  | 0.6 (0.9)  | 1.0 (1.1)  |  |  |  |  |
| Internal concomitant diseases***                         | 0.4 (0.6)  | 1.6 (1.2)  | 1.4 (1.4)  | 2.9 (1.8)  |  |  |  |  |
| Medication***  | 1.7 (1.1)  | 0.5 (0.7)  | 2.0 (1.3)  | 1.6 (1.3)  |  |  |  |  |
| Anti-dementia drug treatment***                          | 0.6 (0.5)  | 0.3 (0.5)  | 0.6 (0.5)  | 0.6 (0.5)  |  |  |  |  |
| Storage & intake***                                      | 1.0 (1.1)  | 0.1 (0.5)  | 1.2 (1.2)  | 0.8 (1.0)  |  |  |  |  |
| Potentially inadequate medication*                       | 0.1 (0.4)  | 0.1 (0.2)  | 0.1 (0.3)  | 0.2 (0.4)  |  |  |  |  |
| Nursing care***  | 2.5 (1.6)  | 4.1 (1.9)  | 4.8 (1.9)  | 7.1 (2.4)  |  |  |  |  |
| Living enviroment***                                     | 0.9 (0.8)  | 1.4 (0.9)  | 1.7 (1.1)  | 2.2 (1.3)  |  |  |  |  |
| Nutrition***   | 1.3 (0.9)  | 1.9 (1.2)  | 2.0 (1.2)  | 3.2 (1.6)  |  |  |  |  |
| Mobility***  | 0.3 (0.5)  | 0.7 (0.8)  | 1.1 (0.9)  | 1.7 (1.0)  |  |  |  |  |
| Psychosocial***  | 0.0 (0.0)  | 0.3 (0.5)  | 1.1 (1.1)  | 2.1 (1.3)  |  |  |  |  |
| Social interaction***                                    | 0.0 (0.0)  | 0.2 (0.4)  | 0.6 (0.9)  | 1.2 (1.1)  |  |  |  |  |
| Physical activity***                                     | 0.0 (0.0)  | 0.1 (0.3)  | 0.2 (0.4)  | 0.4 (0.5)  |  |  |  |  |
| Mental activity***                                       | 0.0 (0.0)  | 0.1 (0.2)  | 0.3 (0.5)  | 0.4 (0.5)  |  |  |  |  |
| Social care***   | 1.3 (1.3)  | 0.4 (0.5)  | 2.1 (1.3)  | 0.6 (0.7)  |  |  |  |  |
| Legal guadianship***                                     | 0.6 (1.3)  | 0.2 (0.4)  | 1.4 (1.5)  | 0.3 (0.5)  |  |  |  |  |
| Disabled person pass***                                  | 0.4 (0.5)  | 0.1 (0.4)  | 0.3 (0.5)  | 0.1 (0.3)  |  |  |  |  |
| Care grade adjustment***                                 | 0.2 (0.5)  | 0.1 (0.2)  | 0.4 (0.5)  | 0.2 (0.4)  |  |  |  |  |
| Demographics   | . ,  |  |  | ``´  |  |  |  |  |
| Age, mean (SD)   | 79.5 (6.7)   | 81.5 (6.7)   | 79.8 (7.5)   | 81.1 (6.1)   |  |  |  |  |
| Sex (female), n (%)                                      | 33 (58%)   | 73 (56%)   | 73 (56%)   | 54 (55%)   |  |  |  |  |
| Living alone, n (%)                                      | 28 (49%)   | 45 (34%)   | 55 (42%)   | 39 (40%)   |  |  |  |  |
| Caregiver available (yes), n (%)                         | 54 (96%)   | 125 (96%)  | 115 (91%)  | 89 (91%)   |  |  |  |  |
| Education (lowest), n (%)*                               | 28 (49%)   | 77 (60%)   | 68 (54%)   | 67 (74%)   |  |  |  |  |
| Financial problems (yes), n (%)                          | 11 (20%)   | 20 (16%)   | 31 (24%)   | 16 (17%)   |  |  |  |  |
| Health service visits                                    | 11 (20%)   | 20 (10%)   | 51 (21/0)  | 10(17,0)   |  |  |  |  |
|  | 10 (9601)  | 114 (8707)   | 116 (2007)   | 95 (9701)  |  |  |  |  |
| GP last 3 mo. (yes), n (%)<br>NB last 3 mo. (yes), n (%) | 49 (86%)<br>6 (10%)  | 114 (87%)<br><b>48 (37%)</b>                                   | 116 (89%)<br><b>40 (31%)</b>                         | 85 (87%)<br>33 (34%)   |  |  |  |  |
| NP last 3 mo. (yes), n (%)                               | 0 (10%)  | 40 (37%)   | 40 (31 %)  | 33 (34 %)  |  |  |  |  |
| Clinical characteristics                                 |  |  |  |  |  |  |  |  |
| Long-term care grade, mean (SD)***                       | 1.6 (1.3)  | 2.0 (1.4)  | 1.3 (1.3)  | 2.0 (1.5)  |  |  |  |  |
| Long-term care grade (yes), n (%)***                     | <b>39 (68%)</b>  | <b>99</b> (76%)  | 74 (56%)   | <b>67 (68%)</b>  |  |  |  |  |
| EQ-5D-5L-index, mean (SD)***                             | 0.84 (0.1)   | 0.76 (0.2)   | 0.79 (0.1)   | 0.59 (0.3)   |  |  |  |  |
| B-ADL, mean (SD)*  | 5.4 (2.0)  | 6.1 (2.4)  | 5.5 (2.1)  | 6.1 (2.4)  |  |  |  |  |
| F-Sozu, mean (SD)***                                     | 3.9 (0.3)  | 4.0 (0.4)  | 3.8 (0.5)  | 3.7 (0.5)  |  |  |  |  |
| GDS, mean (SD)***  | 2.3 (1.6)  | 3.3 (2.3)  | 3.3 (2.2)  | 5.4 (3.6)  |  |  |  |  |
| MMSE, mean (SD)  | 17.4 (7.1)   | 17.7 (8.0)   | 17.0 (7.0)   | 17.0 (7.7)   |  |  |  |  |
| BMI, mean (SD)*  | 24.9 (3.1)   | 26.0 (4.4)   | 25.8 (3.9)   | 26.8 (5.1)   |  |  |  |  |
| ICD-10 diagnoses, mean (SD)***                           | 7.8 (7.9)  | 10.2 (7.9)   | 9.5 (7.4)  | 15.0 (12.4)  |  |  |  |  |
| Drugs taken, mean (SD)***                                | 5.7 (3.3)  | 6.8 (3.5)  | 6.0 (3.2)  | 8.1 (4.0)  |  |  |  |  |

Table 3 Description of unmet needs classes

MMSE, Mini-Mental State Examination; 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; F-Sozu, Social Support Questionnaire, higher score indicates higher social support; GDS, Geriatric Depression Scale, sum score 0–15; score  $\geq 6$  indicates depression; EQ, EQ-5D-5 L, higher values indicate better health status; GP, General Practitioner; NP, Neurologists & Psychiatrists; Group differences were assessed by using oneway anova analyses (continuous variables) or  $\chi^2$  Test.(proportional variables), \*p < 0.05), \*\*p < 0.01, \*\*\*p < 0.001; <sup>1</sup>subcategories of needs with significant differences between classes were shown only.

community-dwelling PlwD [15, 31], underlining the importance of more comprehensive assessments. Our results suggest that, based on a comprehensive assessment, heterogeneous groups of latent unmet need profiles could be determined and profile-associated sociodemographic and clinical factors identified. Low depressive symptoms were mainly associated with the "no need" profile in the study of Janssen et al. [15], which is in line with previous research [13] and our results. We found that low depressive symptoms

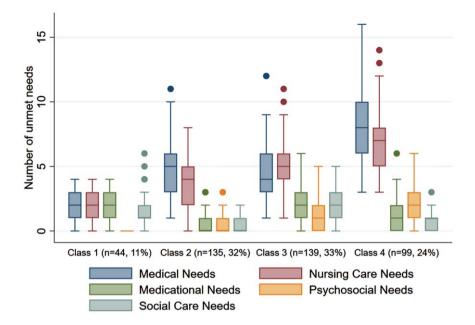


Fig. 1. Box-plots of the number of unmet needs for each category over identified latent classes.

were the main factor associated with membership in class one, represented by the lowest number of unmet needs. Contrary to this, a high depression score was associated with a class four membership, where patients had the highest number of unmet needs. Depression is highly prevalent in dementia diseases [32, 33] and is linked with the number of unmet needs. A review by Parker et al. [34] revealed that effectively addressing depression has the highest potential throughout non-pharmacological interventions to optimize patient-reported outcomes. Also, the GDS score could be an expression of an unsatisfied care situation. Therefore, our analysis underlined the importance of identifying, monitoring and appropriately handling depressive symptoms in dementia.

Comparing the second with the third class, an important factor was the existence (OR 2.08, class two) or non-existence (OR 0.43, class three) of a long-term level of nursing care, which can be seen as a formal prerequisite for nursing and social care services access. Looking at the difference in the number of unmet needs in these two profiles, there was no difference in medical and nursing care needs, but there were fewer medication care needs, primarily due to more occasional needs in storage and (unassisted) intake in class two. Problems with drug intake can't be addressed without having a long-term level of nursing care in Germany, where home care services then take over, helping cognitively impaired patients with the proper intake and storage of drugs. This is especially important in PlwD, who often take more than five drugs (polypharmacy), which is associated with potentially inappropriate [35] and low-value medication [36]. This can result in adverse events, like hospitalizations, reduced quality of life, and higher healthcare costs. Therefore, it is fundamental to establish access to social and nursing care services for PlwD as early as possible. In addition, social care needs represent an important area to be targeted in the early stage of dementia diseases [31, 37]. Social care needs especially occurred in the first and third classes, where patients were less cognitively impaired. This is understandable since applying for long-term level of nursing care as a prerequisite for access to receive social and nursing care services and initiating a patient decree and an attorney is always initiated first, even though the initiation is often too late or could be earlier in routine care.

Previous studies revealed an association between unmet needs and health-related quality of life [8, 38–42], social support, and patients' comorbidity [43]. All of these align with our findings, represented by PlwD with the highest unmet needs (class 4). In this profile class, especially psychiatric and neurological needs, due to a higher depression score, as discussed above, nutrition, personal care needs, and a huge number of psychosocial care needs were prevalent. According to the latter, it seems plausible that

| Parameter/ classes               | Class 1 "Few<br>needs without<br>psychosocial | Class 2 "Some<br>medical & nursing<br>needs only" | Class 3 "Some<br>needs in all areas"<br>(n = 131) | Class 4 "Many<br>medical & nursing<br>needs" (n=98) |
|----------------------------------|---|---|---|---|
|                                  | needs" $(n=57)$                               | (n=131)   | OR (SE)   | OR (SE)   |
|                                  | OR (SE)                                       | OR (SE)   |   |   |
| Demographics                     |   |   |   |   |
| Age                              | 0.94 (0.02)*                                  | 1.04 (0.02)                                       | 0.98 (0.02)                                       | 1.02 (0.02)   |
| Sex (Ref. male)                  | 0.90 (0.36)                                   | 1.09 (0.28)                                       | 0.95 (0.25)                                       | 1.06 (0.36)   |
| Living alone (Ref. not alone)    | 1.30 (0.52)                                   | 0.87 (0.23)                                       | 1.00 (0.24)                                       | 0.93 (0.32)   |
| Caregiver availability (Ref. no) | 1.55 (1.45)                                   | 1.15 (0.69)                                       | 0.74 (0.36)                                       | 1.10 (0.68)   |
| Education                        |   |   |   |   |
| Medium (10 yrs., Ref. < 10 yrs.) | 1.24 (0.52)                                   | 1.11 (0.34)                                       | 1.26 (0.36)                                       | 0.47 (0.20)   |
| High (>10 yrs., Ref. < 10 yrs.)  | 0.88 (0.49)                                   | 1.13 (0.39)                                       | 1.35 (0.40)                                       | 0.58 (0.27)   |
| Financial problems (Ref. yes)    | 1.22 (0.60)                                   | 1.20 (0.38)                                       | 0.66 (0.19)                                       | 1.02 (0.41)   |
| Health service visits            |   |   |   |   |
| GP visit last 3 mo. (Ref. no)    | 1.74 (1.08)                                   | 1.17 (0.49)                                       | 1.24 (0.47)                                       | 0.45 (0.22)   |
| NP visit last 3 mo. (Ref. no)    | 0.15 (0.08)***                                | 1.82 (0.51)                                       | 0.93 (0.25)                                       | 1.02 (0.35)   |
| Clinical characteristics         |   |   |   |   |
| Long-term care grade (Ref. no)   | 0.88 (0.38)                                   | 2.08 (0.62)**                                     | 0.43 (0.11)***                                    | 1.02 (0.36)   |
| Health status (EQ-5D-5 L index)  | 9.50 (13.6)                                   | 3.10 (3.19)                                       | 4.77 (3.37)                                       | 0.03 (0.02)***                                      |
| Functional impairment (B-ADL)    | 0.97 (0.09)                                   | 1.03 (0.07)                                       | 0.93 (0.05)                                       | 1.07 (0.08)   |
| Social support (F-Sozu)          | 0.84 (0.42)                                   | 3.27 (1.05)***                                    | 0.67 (0.20)                                       | 0.37 (0.13)**                                       |
| Depression (GDS)                 | 0.79 (0.08)**                                 | 1.00 (0.06)                                       | 0.97 (0.05)                                       | 1.18 (0.07)**                                       |
| Cognitive impairment (MMSE)      | 1.02 (0.03)                                   | 1.00 (0.02)                                       | 0.96 (0.02)*                                      | 1.01 (0.02)   |
| Body-Mass-Index (BMI)            | 0.95 (0.04)                                   | 0.98 (0.03)                                       | 1.00 (0.03)                                       | 1.04 (0.03)   |
| Comorbidity (# ICD-10 diagnoses) | 0.92 (0.03)                                   | 0.98 (0.02)                                       | 0.98 (0.02)                                       | 1.06 (0.02)***                                      |
| Polypharmacy (# drugs taken)     | 0.99 (0.06)                                   | 1.04 (0.04)                                       | 0.97 (0.03)                                       | 0.97 (0.04)   |

Table 4 Factors associated with patients class affiliation (multivariate analysis)

Logistic regression model with random effects for physician networks; MMSE, Mini-Mental State Examination; 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  $\geq 6$  indicates depression; Class 1 Model: LR  $\chi^2(18)$ : 56.47, Prob >  $\chi^2$ :<0.001, R2:0.189.; Class 2 Model: LR  $\chi^2(18)$ : 50.57, Prob >  $\chi^2$ :0.001, R2:0.111.; Class 3 Model: LR  $\chi^2(18)$ : 43.15, Prob >  $\chi^2$ : 0.001, R2:0.093.; Class 4 Model: LR  $\chi^2(18)$ : 109.58, Prob >  $\chi^2$ :<0.001, R2:0.274.

psychosocial care needs increase at this advanced disease stage, demonstrating another central component of high-quality dementia care, which is to make sure that PlwD can live at home for as long as possible [44, 45]. Clinicians and primary care physicians should use caution in relying on PlwDs' general health status, depressive symptoms and social support in an advanced stage of dementia diseases, emphasizing the importance of tailored intervention to address these individual needs. This is vital to improve the living and care situation of patients in the respective stages of the disease.

Our analysis also demonstrated that unified need profiles could be used as a reference for the most common needs combinations that can be distinguished. Collaborative care models emerged as safe, effective, cost-effective solutions to identify and address unmet needs within tailored interventions [46, 47]. Services of the long-term nursing care insurance, social support, general health status, comorbidity and depressive symptoms should be monitored within these collaborative care approaches to specify unmet needs assessment batteries and tailor interventions more efficiently to improve PlwDs living situation and optimize healthcare delivery. However, longitudinal analyses are urgently needed to reveal to what extent the identified unmet needs patterns can be addressed by these tailored interventions and how far the situation of PlwD and the healthcare delivery can be improved in distinct unmet need profile groups.

## Limitations

The used assessment is based on self-reporting of PlwD, which limits the generalizability of trigger conditions since PlwDs cognitive impairment could affect the validity and completeness of data. There could be further undetected unmet needs, rendering the number of detected unmet needs an underestimation. Therefore, the comparability of our results to the findings of other studies is limited. The computerized unmet needs assessment was specifically developed in the context of the InDePendent intervention [16]. Hence, while it allows for a comprehensive needs assessment study, this context could limit the comparability and reproducibility of the presented results.

Additionally, this analysis was based on crosssectional data. Even though "predictors" (sociodemographic and clinical variables) and unmet needs were assessed simultaneously, it is impossible to draw causality conclusions from the association between the sociodemographic or clinical variables and belonging to one of the four latent classes. Therefore, further longitudinal data and analyses would be needed to clarify or confirm the causality between the profile-predicting factors of the latent classes. Also, some of the predictors were limited. For example, we used a simple count of documented ICD-10 diagnoses as a comorbidity index. Using a defined comorbidity index, like the Carlson Comorbidity score, would be more suitable to demonstrate the health status and. therefore, better to assess the association between patients' comorbidity and belonging to one of the four latent classes.

# AUTHOR CONTRIBUTIONS

Bernhard Michalowsky (Conceptualization; Formal analysis; Funding acquisition; Methodology; Project administration; Validation; Visualization; Writing – original draft; Writing – review & editing); Anika Rädke (Project administration; Validation; Writing - review & editing); Annelie Scharf (Project administration; Writing - review & editing); Franka Mühlichen (Project administration; Writing - review & editing); Maresa Buchholz (Writing – review & editing); Moritz Platen (Validation; Writing - review & editing); Fabian Kleinke (Data curation; Project administration; Writing - review & editing); Peter Penndorf (Data curation; Project administration); Stefanie Pfitzner (Data curation; Project administration); Neeltje van den Berg (Writing - review & editing); Wolfgang Hoffmann (Funding acquisition; Methodology; Supervision; Validation; Writing - review & editing).

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# **CONFLICT OF INTEREST**

Bernhard Michalowsky is an Editorial Board Member of this journal but was not involved in the peer-review process of this article nor had access to any information regarding its peer-review.

All other authors have no conflict of interest to report.

# DATA AVAILABILITY

Data is not available.

#### SUPPLEMENTARY MATERIAL

The supplementary material is available in the electronic version of this article: https://dx.doi.org/ 10.3233/JAD-240025.

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