

# Tasks and Activities of an Effective Collaborative Dementia Care Management Program in German Primary Care

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## Abstract.

**Background:** Recent studies have demonstrated the efficiency of collaborative dementia care, which aims to improve post-diagnostic support. However, tasks carried out of such models are currently unknown, hindering its implementation.

**Objective:** To describe tasks of a collaborative model of dementia care, analyze the association between specific task subgroups and number of tasks with patients' and caregivers' characteristics and the impact of specific tasks on health-related quality of life (HRQoL).

**Methods:** The analysis was based on 183 persons with dementia (PwD) who received dementia care management conducted by dementia-specific qualified nurses. A standardized, computer-assisted assessment was used to identify patients' and caregivers' unmet needs. Tasks carried out to address unmet needs were documented, categorized, and descriptively analyzed. We used multivariate regression models to identify socio-demographic and clinical factors associated with a specific subgroup of tasks or a higher number of tasks.

**Results:** On average, 20.5 tasks were carried out per dyad (PwD and caregiver). 41% of tasks were categorized to cooperation with other healthcare providers, 39% to nursing care, and 19% to social support. Lower HRQoL and higher age, cognitive impairment, deficits in daily living activities, and depressive symptoms were significantly associated with a higher number of tasks. A higher number of cooperation tasks were associated with a higher gain in HRQoL.

**Conclusion:** Patients' characteristics and HRQoL significantly determine the intensity of collaborative care interventions. Variability of the intensity should be considered in developing future studies and in the implementation into routine care.

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## INTRODUCTION

The global prevalence and the economic impact of age-related diseases, such as dementia, present a significant public health challenge [1]. Currently, the number of people living with dementia worldwide is

estimated at 50 million, and it might reach 82 million in 2030 [2, 3]. The global cost of dementia treatment was estimated at \$818 billion in 2015, and it might rise to \$2 trillion in 2030 [4], which stresses dementia as a priority for health care systems worldwide [2, 3].

Studies about the comorbidities of aged people show that dementia is one of the prime contributing factors that lead to disabilities [5]. Despite the recent approval of aducanumab for Alzheimer's disease by

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the U.S. Food and Drug Administration, no curative treatment for people living with dementia (PwD) exists [6]. There is a need for new and more effective ways of dementia care to halt a crisis in health care [7, 8].

In the German health care system, all PwD and caregivers generally have access to evidence-based medical treatment, care, and support. Receiving dementia-specific medical treatments requires a formal dementia diagnosis while receiving legal support, and formal care requires a certain functional impairment that caused a need for care. However, care service providers, practitioners, and therapists are not well connected and coordinated to timely initiate treatment and care needed to address current unmet needs of PwD and caregivers. Therefore, patients and caregivers often do not know which services, treatment options, and care they should use and which are appropriate to improve the current situation. This causes an individual consideration of each case by a dementia-specific expert of the healthcare and social support system.

Several countries have introduced strategies to address the challenges by implementing collaborative models of care, aiming to improve case finding and post-diagnostic support within the different healthcare systems [9]. A systematic review of current evidence revealed that dementia case management approaches can positively impact, for example, reducing the risk of institutionalization [10, 11]. Following results from long-term studies, the institutionalization rate could be decreased by 28% [12, 13]. Furthermore, other studies revealed that the approaches could reduce caregiver burden [11] and improve patient's and caregiver's quality of life [11, 14]. Also, studies revealed that case management approaches could also significantly reduce neuropsychiatric symptoms of PwDs [11]. Several systematic reviews [12, 14, 15] and meta-analyses [10, 11] have already summarized the effectiveness of collaborative care management programs [10–12, 14].

Case and care management was also found to reduce health and social costs and increase the cost of unpaid care [16]. Michalowsky et al. [17] have provided empirical evidence about the cost-effectiveness of dementia care management, highlighting its benefits for public healthcare payers and patients.

Reilley et al. [11] underlined a substantial heterogeneity in the interventions [11, 18]. The wide range of interventions is highlighted in studies, which reported that only programs with a high intensity of interventions and a moderate integration level

reported medium effects on the outcomes [19, 20], whereby low-intensity programs reported insignificant effects or no effects at all [21–23]. None of the studies that reported case and care management interventions to improve the life of PwD and their caregiver [19, 20, 24] reported an overview of the tasks carried out to address the identified unmet needs and the association between patients characteristics and the intensity of the care management, measured by the number of tasks carried out. However, a detailed description of tasks carried out is necessary to reveal what factors are associated with higher or lower efficacy of collaborative care management approaches. Hence, this study aimed to analyze tasks carried out within safe, efficient, and cost-effective dementia care management for PwD and their caregivers and factors associated of specific tasks and the number of tasks carried out [17]. We furthermore aimed to assess the impact on specific tasks on patient-reported outcomes.

## METHODS

### *Study design and sample characteristics*

This study uses primary data from the DelpHi-MV (“Dementia: life- and person-centred help in Mecklenburg-Western Pomerania”) trial, a GP-based, cluster-randomized, controlled intervention study, which was designed to test the efficacy and cost-effectiveness of a collaborative dementia care management compared to usual care. The design of the trial [25] and its demonstrated safety, efficacy [26], and cost-effectiveness [17] have been described elsewhere.

One hundred thirty-six general practitioners (GP) practices participated in the trial and were randomized to the intervention or control group. GP practices checked patients' eligibility for the trial ( $\geq 70$  years, living at home) and screened for dementia by application of a validated screening instrument (DemTect procedure) [27]. Thus, eligible patients do not necessarily need to have a formal dementia diagnosis but have to be screened positive for dementia. Consenting patients in the intervention group received dementia care management for six months. Patients from control GPs received care as usual [28]. The Ethics Committee of the Chamber of Physicians of Mecklenburg-Western Pomerania (registry number BB 20/11) approved the study protocol and documents for written informed consent (IC).

### Sample, participant flow

Six hundred thirty-four participants agreed to participate in the DelpHi-MV trial, and 516 started the baseline assessment. One hundred three participants were lost to the first follow-up, further 112 patients were excluded due to missing values, 118 patients were randomized to the control group not receiving the intervention and, therefore, excluded from this analysis. The final sample consists of  $n = 183$  PwD, who received the dementia care management for six months after an initial baseline assessment as a part of the intervention group.

For these 183 PwD, 173 informal caregivers participated in the trial. 95 (54.9%) of those caregivers lived in the same household with the PwD. Socio-demographic and clinical characteristics of the PwDs and the caregivers are shown in Table 1.

### Collaborative dementia care management intervention

Dementia care management is a model of collaborative care that aims to provide optimal and individualized treatment and care for PwD and their caregivers. The dementia care management intervention was developed based on current German guidelines for treatment, care in dementia diseases [29–31] as well as on empirical evidence and expert opinions. The intervention was targeted at the individual participant level and was delivered at each participant's home by nurses with dementia-specific qualifications. The main pillars of the intervention were the following: 1) management of treatment and care, 2) medication management, and 3) caregiver support and education. These pillars are associated with the following eight action fields having several foci: 1.1) indication check of antidementia drugs, 1.2) prevention of drug-related problems, 1.3) help with medication intake; 2.1) medical diagnosis and treatment, 2.2) technical assistance, 2.3) therapies, 2.4) social integration, 2.5) nursing care, 2.6) social and legal support; 3.1.) social integration of caregivers, 3.2) caregiver mental and physical health, 3.3) social and legal support of caregivers. A detailed description of the main pillars and action fields is published by Eichler et al. [30]. Every focus addresses a specific intervention module that constitutes the basis of the work for the Dementia Care Manager. These intervention tasks were documented by the nurses and analyzed in this paper.

Table 1

Socio-demographic and clinical characteristics of the total sample that received a complete dementia care management intervention ( $n = 183$ )

socio-demographic and clinical variables	
Age patient	
Mean (SD)	80.7 (5.4)
Sex patient, $n$ (%)	
Female	110 (60.1)
MMSE	
Mean (SD)	22.4 (4.8)
Severity of cognitive impairment <sup>1</sup> , $n$ (%)	
No indication of	41 (22.4)
Mild	96 (52.5)
Moderate to severe	46 (25.1)
Education, $n$ (%)	
No education	26 (14.2)
Basic	122 (66.6)
Higher	35 (19.1)
Living situation, $n$ (%)	
Alone	88 (48.1)
Dementia diagnosis <sup>2</sup>	
Yes, $n$ (%)	146 (79.8)
B-ADL	
Mean (SD)	4.0 (2.5)
Number of ICD-10 Diagnoses (PwD)	
Mean (SD)	13.6 (7.7)
Number of drugs taken (PwD)	
Mean (SD)	7.7 (3.6)
Physical health (SF-12)	
Mean (SD)	41.2 (10.8)
Mental health (SF-12)	
Mean (SD)	53.2 (9.1)
GDS	
Mean (SD)	3.3 (2.4)

<sup>1</sup>According to MMSE; <sup>2</sup> 79.8% of participants had a diagnosis for their dementia after screening (before screening rate was around 29%); MMSE, Mini-Mental State Examination, Range 0–30, higher score indicates better cognitive function; 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; SF-12, Short Form 12, summary scores range from 0 to 100, where higher scores indicate better health-related quality of life; ICD, International Statistical Classification of Diseases and Related Health Problems, SD, standard deviation; PwD, patient living with dementia.

Dementia care managers [25], specifically-qualified nurses [32], carried out the intervention for six months in various intensities, depending on the individual case. The nursing professionals in Germany generally undergo a three-year training program on a non-academic level. The qualification of the nurses for this study was based on an add-on qualification, enhancing nurses' competencies to care for PwD and caregivers within German primary care [33]. Based on a comprehensive standardized assessment,

the dementia care manager identified with the help of a computerized Intervention-Management-System (IMS) all existing social, medical, psychological, pharmaceutical, and nursing care needs of the PwD and their caregivers and generated an individual and tailored intervention plan and tasks that have to be carried out to address each identified unmet need [28, 33, 34].

#### *Documentation of care management tasks*

Identified needs were validated in interprofessional case conferences with a neurologist, a nursing professional on a master's degree, a psychologist, and a pharmacist. Validated needs were then discussed face-to-face with the treating GP, which resulted in individual intervention task lists. These lists of tasks needed to address all unmet needs of each PwD and caregiver were used for this analysis. The dementia care managers carried out all tasks in close cooperation with the caregiver, the GP, and various health care and social service professionals within the intervention period of six months.

Throughout the intervention, various contacts between PwD and their caregivers and the care manager took place either through contacts via telephone or visits at the patient's home. The intensity of the dementia care management was measured by the number of tasks carried out to address PwDs and caregivers' unmet needs. A higher intensity of the intervention for PwD and caregiver was defined for this analysis as a higher number of tasks provided by the care manager.

According to the average of 8.77 (SD 5.04) unmet needs of the PwDs and the caregiver [35], a substantial amount of different interventions were needed to address these needs. The DCM was not restricted to the initial list of tasks, as new tasks could be added based on additional unmet needs in the intervention. More information about the intervention and the "Delphi-standard" is presented in Eichler et al. [28].

#### *Assessment of socio-demographic and clinical data*

Socio-demographic data (age, gender, living situation, education) of the PwD and the caregiver and clinical variables were assessed at baseline before the intervention started. The living situation were assessed as living alone or living not alone. Education of the PwD was categorized into the following groups: no (without a school-leaving

qualification), basic (eight years of school education), and higher (more than eight years of school education). Also, the following clinical variables were assessed: cognitive impairment according to the Mini-Mental State Examination (MMSE) [36], comorbidity according to the number of ICD-10 (International Statistical Classification of Diseases and Related Health Problems) diagnoses listed in the GP's files [37], drugs taken (prescribed medication (Rx) and non-prescriptive "over the counter" drugs (OTC)), depression according to the Geriatric Depression Scale and deficits in daily living activities according to the Bayer Activities of Daily Living Scale (B-ADL). Furthermore, Health-Related Quality of Life (HRQoL) was assessed with the 12-Item Short-Form Health Survey (SF-12), a generic, multidimensional instrument that measures the physical and mental dimensions of HRQoL [38]. The SF-12 was used to assess the impact of specific tasks on patient-reported outcomes.

We used the following cut-off points of the respective instruments to evaluate differences in the number of intervention tasks carried out for different stages of cognitive impairment (mild: >20 and moderate to severe (0–19) according to the MMSE, functional impairment (no (>28), mild (18–27) and severe, (<10) according to the B-ADL); depression (score  $\geq 6$  indicates depression according to the Geriatric Depression Scale); and HRQoL (low (<20), moderate (20–40) and high (>40) according to the SF-12).

#### *Data preparation: Categorization of tasks*

We categorized the needs-based intervention tasks into the following categories: 1) medical and nursing care; 2) social and legal support; and 3) cooperation with other healthcare providers. The first category included all interventions related to direct patient support, including nursing care, medication, care aids, monitoring, and adjustment of care arrangements like the initiation of day care, outpatient care, and respite services. Moreover, the care manager provided all educational support to inform the PwD and the caregiver about dementia and comorbidities, behavioral problems, prophylactics, emergency support, possibilities of care and support, and applications for refunding were categorized to this group of interventions.

The second category included all tasks concerning advice and actions relating to the appropriate level of care, i.e., "Pflegegrad" in German (=based on a

five-point scale from very low to very high) to address the PwD's need of care. The care level determines the level of support accessible from the social system and the respective entitlement to reimbursement of cost. The second category includes interactions concerning the degree of disabilities, like applications, adjustments, or topics relating to the severely disabled card, and all actions and advice concerning documents like the patient decree, power of attorney, and the patient's will.

The third category included those tasks aimed at integrated care in collaboration with speech, occupational and physiotherapists, and other non-physician specialists, as well as feedback to the GP with respect to differential diagnoses, adjusting medication, and rehabilitation programs.

#### *Statistical analyses*

Descriptive and univariate statistics were calculated to depict all tasks carried out within the collaborative dementia care management. To assess which PwDs' socio-demographic and clinical characteristics were associated with a higher number of intervention tasks needed to address the PwD's and the caregiver's unmet needs, multivariate Poisson Regression Models with random effects for the GP were fitted. Additionally, we analyzed the association between the number of tasks in each subcategory with patients' and caregivers' socio-demographic and clinical variables. All models were adjusted for the mentioned socio-demographic and clinical variables of the PwD and the caregiver. A sensitivity analysis used an interaction term to evaluate differences between patient-caregiver gender combinations, representing the four possible gender combinations (i.e., female and male patients versus female and male caregiver).

Furthermore, multivariate Poisson Regression models were used to assess the impact of specific tasks and the number of tasks carried out on the change of patient-reported outcome (i.e., health-related quality of life). Therefore, we calculated the change in the mental and physical SF-12 value by the difference between the one-year follow up values (after receiving the intervention) and the baseline score (before starting the intervention) and included these values within the multivariate models that were adjusted for patients and caregivers socio-demographic and patients clinical and HRQoL baseline scores. Statistical analyses were conducted with the STATA statistical packet [39].

## **RESULTS**

### *Socio-demographic and clinical characteristics*

Patients were on average 80.7 years old, above-average female (60.1%), and mildly functionally (B-ADL: 4.0) and cognitively (MMSE: 22.4) impaired. Part of the patients was not cognitively impaired according to the MMSE (score 27–30). The MMSE is less sensitive for detecting milder forms of cognitive impairment (43%) than the DemTect procedure (80–100%), which was used to screen PwD for dementia in this study. According to the MMSE, this led to patients who were screened positive for dementia but showed no cognitive impairment. However, this does not mean that these patients did not have dementia

PwDs HRQoL was moderate and lower in the physical dimension (41.2) as compared to the mental dimension (53.2). PwDs caregivers were on average younger (64.9 years, SD 12.6) and more likely female (73.2%,  $n = 134$ ). The socio-demographic and clinical characteristics are depicted in Table 1.

### *Description of tasks*

In total, 3,747 tasks were provided to the 183 PwD or their caregivers to address all identified unmet needs. The largest proportion of the tasks was categorized to cooperation with other health-care providers (41.1%,  $n = 1,541$  tasks), followed by nursing care (39.7%,  $n = 1,486$ ) and social and legal support (19.2%,  $n = 720$ ).

On average, 20.5 (SD 7.2) tasks were needed to carry out the entire dementia care management: On average, 8.7 (SD 3.7, range: 2–21) for the cooperation with other healthcare providers, 8.1 (SD 4.0, range: 1–29) for nursing care, and 3.9 (SD 2.1, range: 1–11) for social and legal support. An overview of dementia care management tasks and corresponding frequencies are shown in Table 2.

Univariate analyses revealed that a higher number of dementia care management tasks occurred in older PwD (80–90 years versus < 80 years: 22.2 versus 19.1), in PwD having severe deficits in daily living activities (no versus severe: 17.0 versus 22.2), a higher depression (no versus severe: 20.2 versus 25.3) and a lower mental (high versus low: 20.4 versus 23.8), and physical quality of life (high versus low: 19.1 versus 25.5). Furthermore, more tasks were documented when caregivers were female (21.4 (SD 7.1) versus 18.9 (SD 7.4) for male

Table 2  
Tasks of dementia care management

Task categories und subtasks	Number (%) of tasks carried out in total	Number (%) of PwD receiving these tasks	Mean number (SD) of task per PwD
Total	<b>3,747 (100%)</b>	<b>183 (100%)</b>	<b>20.5 (7.2)</b>
Medical and nursing care <sup>1</sup>	<b>1,486 (39.7%)</b>	<b>183 (100%)</b>	<b>8.1 (4.0)</b>
Nursing and support	383 (10.2%)	182 (99.5%)	2.1 (1.4)
Medication management	290 (7.7%)	178 (97.3%)	1.6 (0.9)
Care aids	151 (4.0%)	67 (36.6%)	0.8 (2.2)
Housing alteration	28 (0.7%)	21 (11.5%)	0.2 (0.5)
Handling comorbidities	77 (2.1%)	48 (26.2%)	0.3 (0.8)
Prophylactics	216 (5.8%)	130 (71.0%)	1.2 (1.0)
Emergency preparations	103 (2.7%)	81 (44.3%)	0.6 (0.8)
Caregiver advice	238 (6.4%)	113 (61.7%)	1.3 (1.4)
Social legal support <sup>1</sup>	<b>720 (19.2%)</b>	<b>183 (100%)</b>	<b>3.9 (2.1)</b>
Adaption of Care level	185 (4.9%)	116 (63.4%)	1.0 (1.0)
Mandate	297 (7.9%)	126 (68.9%)	1.6 (1.4)
Disability services	40 (1.1%)	31 (16.9%)	0.2 (0.5)
Other social legal advice	198 (5.3%)	174 (92.1)	1.1 (0.5)
Cooperation with other healthcare providers	<b>1,541 (41.1%)</b>	<b>183 (100%)</b>	<b>8.7 (3.7)</b>
Non-physician Therapist	8 (0.2%)	8 (4.4%)	0.04 (0.2)
Medical specialist	115 (3.1%)	69 (37.7%)	0.6 (1.0)
Rehabilitation	139 (3.7%)	101 (55.2%)	0.8 (0.8)
General practitioner	1,279 (34.1%)	183 (100%)	6.9 (4.4)
Diagnosis: adaption, education, therapy	720 (19.2%)	180 (98.4%)	3.9 (1.6)
Medication management	419 (11.2%)	166 (90.7%)	2.2 (1.9)
Prophylactics	140 (3.7%)	105 (57.4%)	0.8 (0.9)

<sup>1</sup>Education, counselling, and implementation.

caregivers). The number of tasks over different socio-demographic and clinical characteristics is shown in Table 3.

#### *Association between patient's socio-demographic and clinical characteristics and the number of tasks carried out*

Table 4 presents the results of the regression models. PwDs mental and physical HRQoL were the main factors significantly negatively associated with the number of tasks carried out. A lower HRQoL was associated with a higher number of tasks. Also, female sex of the informal caregiver but none of the interaction terms of all gender combinations were significantly associated with an increased number of tasks carried out. Furthermore, a higher number of drugs taken and daily living deficits of the PwD as well as a lower education of the PwD were significantly associated with a higher intensity of the intervention, represented by a higher number of tasks carried out to address the identified unmet needs.

Considering solely medical and nursing care tasks, higher age of the patient, comorbidity, number of drugs taken and deficits in daily living, as well as a lower HRQoL and female sex of the caregiver, were associated with a higher number of provided

tasks. Concerning the cooperation with other healthcare providers, a higher cognitive impairment and depression, as well as a lower physical HRQoL were associated with a higher intensity of the dementia care management intervention.

#### *Impact of tasks on patient-reported outcomes*

Table 5 presents the results of the impact of the total number of tasks or the specific categories on patients' mental and physical HRQoL. Only a higher number of cooperation tasks with other healthcare providers were significantly associated with a greater improvement in mental and physical HRQoL. Neither the total number of tasks carried out nor one of the different task categories were significantly associated with improving patients' HRQoL.

## DISCUSSION

This analysis revealed that most of the tasks carried out were related to cooperation with other healthcare providers and nursing care, highlighting the importance of inter-professional coordination and nursing care in primary dementia care. The overall number of tasks needed to address all existing unmet needs of patients and caregivers were high and affected by the following factors: age, caregiver sex, number of drugs

Table 3

Number of tasks over different socio-demographic and clinical characteristics ( $n = 183$ )

Socio-demographic and clinical variables	Mean (SD) number of tasks carried out
Age, $n$ (%)	
< 80	19.1 (5.9)
80 – 90	22.2 (7.7)
> 90	19.3 (11.9)
Sex patient, $n$ (%)	
Female	21.3 (7.8)
Male	20.0 (6.2)
Cognitive impairment (MMSE), $n$ (%)	
Mild (20–30)	20.8 (6.9)
Moderate to severe (0–19)	20.5 (8.1)
Education, $n$ (%)	
No education	21.2 (6.2)
Basic	20.5 (7.4)
Higher	21.4 (7.3)
Living situation, $n$ (%)	
Alone	21.2 (7.1)
Not alone	20.3 (7.3)
Physical deficits (B-ADL), $n$ (%)	
No deficits (< 2.0)	17.2 (6.6)
Moderate deficits (2.0 – 5.0)	22.1 (6.3)
Severe deficits (> 5.0)	22.2 (7.8)
Number of ICD-10 Diagnoses (PwD), $n$ (%)	
< 5	21.7 (11.0)
5 – 10	21.1 (7.3)
11 – 15	20.6 (6.8)
> 15	20.2 (7.2)
Number of drugs taken (PwD), $n$ (%)	
0 – 3	22.7 (9.0)
4 – 6	21.3 (7.3)
7 – 10	19.3 (7.3)
> 10	22.2 (5.4)
Receiving formal care	
yes	21.9 (7.4)
no	20.4 (7.2)
Physical health (SF-12), $n$ (%)	
Low (< 20)	25.5 (5.0)
Moderate (20 – 40)	22.5 (7.4)
High (> 40)	19.1 (6.8)
Mental health (SF-12), $n$ (%)	
Low (< 20)	–
Moderate (20 – 40)	23.8 (9.5)
High (> 40)	20.4 (6.8)
Depression (GDS), $n$ (%)	
No depression	20.2 (6.9)
Mild depression	23.8 (6.9)
Severe depression	25.3 (19.2)

<sup>1</sup> According to MMSE; <sup>2</sup> after screening (before screening rate was around 29%); MMSE, Mini-Mental State Examination.; 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; SF-12, Short Form 12, summary scores range from 0 to 100, where higher scores indicate better health-related quality of life; ICD, International Statistical Classification of Diseases and Related Health Problems, SD, standard deviation; PwD, patient living with dementia.

taken, comorbidity, education, deficits in daily living and cognition, depression, and subjective perception of mental and physical health of PwD. Furthermore, a higher number of collaborating tasks with different health care providers, like general practitioners, were associated with an improvement of patients' HRQoL. Therefore, this analysis adds essential evidence to socio-demographic and clinical factors determining the intensity of collaborative care in dementia diseases.

Regarding the negative association between tasks carried and patient education, a few previous studies found that educational programs efficiently increase drug adherence in lower-education populations [40]. This finding could explain that less educated people may need more educational interventions to address specific unmet needs in their dementia care and increase adherence to the given treatment and care plan. Previous analyses [41] also revealed that PwD with polypharmacy (more than five drugs regularly taken) more likely suffer from drug-related problems and receive potentially inappropriate medication and low-value care [42, 43]. This, in turn, can result in higher hospitalization rates, lower quality of life (QoL), and thus a more increased need for interventions to address this variety of unmet needs [41]. Our analysis confirmed these findings, demonstrating that PwD with higher rates of medical drug use often requires more interventions than those with a lower number of medications. Furthermore, provided intervention tasks in the category of nursing support related to PwD medications included, i.e., the provision of a medication dispenser or initiation of outpatient care service to assist the PwD to adhere to their regular medication scheme. This underlines the increased number of tasks provided for this patient subgroup. Future research might want to look in more detail on the influence of PwDs' and caregivers' education as well as polypharmacy on unmet healthcare needs and the appropriate intervention intensity in order to improve post-diagnostic support of this vulnerable patient subgroup.

Also, a study of Almqvist et al. [44] found significant differences in the caregiver burden related to the sex of the caregiver. Female caregivers are more likely to have a higher subjectively perceived caregiver burden and more often report health problems, a lack of positive outlook and limitations of social support, including conflicts with other family members compared to male caregivers [44]. They are also more likely to have higher risks of depression compared to informal male caregivers [45]. This could partly

Table 4

Multivariate analysis of the association between patients and caregivers' socio-demographic and clinical variables determining the number of tasks needed to address identified unmet needs

b (CI)	All tasks (total) <sup>1</sup>	Medical and nursing care <sup>2</sup>	Social & legal support <sup>3</sup>	Cooperation with other healthcare providers <sup>4</sup>
	<i>b</i> (SE)	<i>b</i> (SE)	<i>b</i> (SE)	<i>b</i> (SE)
Patients age	0.01 (0.01)	<b>0.02 (0.01)**</b>	0.01 (0.01)	-0.01 (0.01)
Caregivers age	-0.01 (0.01)	-0.01 (0.01)	-0.01 (0.01)	-0.01 (0.01)
Patients sex (Ref. female)	0.02 (0.05)	-0.13 (0.09)	-0.03 (0.13)	0.10 (0.07)
Caregiver sex (Ref. female)	0.10 (0.04) <sup>†</sup>	0.12 (0.09) <sup>†</sup>	0.04 (0.12)	0.08 (0.07)
Interaction caregiver's patient sex <sup>5</sup>	0.01 (0.01)	0.01 (0.01)	0.01 (0.01)	0.01 (0.01)
Education				
<i>No versus low</i>	-0.09 (0.05) <sup>†</sup>	-0.07 (0.11)	-0.11 (0.13)	-0.06 (0.08)
<i>No versus high</i>	-0.02 (0.06)	0.12 (0.13)	-0.03 (0.12)	0.04 (0.09)
Living situation (Ref. alone)	0.02 (0.04)	0.06 (0.08)	-0.01 (0.11)	-0.03 (0.06)
Comorbidity (ICD-10 Diagnoses)	0.01 (0.01)	-0.01 (0.01) <sup>†</sup>	-0.01 (0.01)	0.01 (0.01)
Dementia diagnosis (Ref. yes)	0.04 (0.05)	0.04 (0.10)	0.02 (0.12)	-0.04 (0.07)
Cognitive impairment (MMSE)	0.01 (0.01)	0.01 (0.01)	-0.01 (0.01)	<b>0.02 (0.01)*</b>
Number of drugs taken	-0.01 (0.01) <sup>†</sup>	-0.02 (0.01) <sup>†</sup>	-0.02 (0.01)	0.01 (0.01)
Physical health (SF-12)	<b>-0.01 (0.01)***</b>	<b>-0.01 (0.01)*</b>	-0.01 (0.01)	<b>-0.01 (0.01)**</b>
Mental health (SF-12)	<b>-0.01 (0.01)**</b>	<b>-0.01 (0.01)***</b>	-0.01 (0.01)	-0.01 (0.01)
Deficits in daily living activities (B-ADL)	<b>0.02 (0.01)*</b>	0.02 (0.02) <sup>†</sup>	-0.02 (0.03)	0.01 (0.01)
Depression (GDS)	-0.01 (0.01)	-0.01 (0.02)	-0.03 (0.02)	<b>0.03 (0.01)*</b>
Intercept	3.27 (0.39)***	1.37 (0.81)***	2.13 (1.01)	2.21 (0.57)***

\*\*\* $p < 0.001$ , \*\* $p < 0.01$ , \* $p > 0.05$ , <sup>†</sup> $p < 0.1$ ; <sup>1</sup>183 observations, 49 cluster: Wald  $\chi^2(15) = 82.8$ ,  $p < 0.001$ ; <sup>2</sup>183 observations, 49 cluster: Wald  $\chi^2(15) = 76.3$ ,  $p < 0.001$ ; <sup>3</sup>183 observations, 49 cluster: Wald  $\chi^2(15) = 8.4$ ,  $p < 0.909$  (non-significant model); <sup>4</sup>183 observations, 49 cluster: Wald  $\chi^2(15) = 66.7$ ,  $p < 0.001$ ; <sup>5</sup>included in separate multivariate models as sensitivity analyses; b, non-standardized beta-coefficient.

Table 5

Multivariate analysis of the association between the number of tasks needed to address identified unmet needs and the effect of patients' mental and physical health

b (CI)	All tasks (total)	Medical and nursing care <sup>2</sup>	Social & legal support <sup>3</sup>	Cooperation with other healthcare providers
	<i>b</i> (SE)	<i>b</i> (SE)	<i>b</i> (SE)	<i>b</i> (SE)
Change of physical health (SF-12)	0.01 (0.01) <sup>1</sup>	-0.01 (0.01) <sup>2</sup>	0.01 (0.01) <sup>3</sup>	<b>0.01 (0.01)***4</b>
Change of mental health (SF-12)	0.01 (0.01) <sup>5</sup>	-0.01 (0.01) <sup>6</sup>	0.01 (0.01) <sup>7</sup>	<b>0.01 (0.01)***8</b>

Models were adjusted for the following covariables: Patients and caregiver age, patients and caregiver sex, education, living situation, comorbidity, dementia diagnosis, cognitive impairment, number of drugs taken, deficits in daily living activities, depression; \*\*\* $p < 0.001$ , \*\* $p < 0.01$ , \* $p > 0.05$ , <sup>†</sup> $p < 0.1$ ; <sup>1</sup>183 observations, 49 cluster: Wald  $\chi^2(15) = 75.5$ ,  $p < 0.001$ ; <sup>2</sup>183 observations, 49 cluster: Wald  $\chi^2(15) = 75.5$ ,  $p < 0.001$ ; <sup>3</sup>183 observations, 49 cluster: Wald  $\chi^2(15) = 10.9$ ,  $p < 0.816$  (non-significant model); <sup>4</sup>183 observations, 49 cluster: Wald  $\chi^2(16) = 74.1$ ,  $p < 0.001$ ; <sup>5</sup>183 observations, 49 cluster: Wald  $\chi^2(16) = 75.6$ ,  $p < 0.001$ ; <sup>6</sup>183 observations, 49 cluster: Wald  $\chi^2(16) = 75.5$ ,  $p < 0.001$ ; <sup>7</sup>183 observations, 49 cluster: Wald  $\chi^2(16) = 10.8$ ,  $p < 0.823$  (non-significant model); <sup>8</sup>183 observations, 49 cluster: Wald  $\chi^2(16) = 74.4$ ,  $p < 0.001$ ; b, non-standardized beta-coefficient.

be confirmed in this analysis. Female caregivers' sex was associated with a higher intensity of the intervention, represented by a higher number of tasks carried out. However, after adjusting for the four possible interaction terms, none of the caregiver-patient gender-specific combinations were significantly associated with the number of tasks carried out in the care management intervention, demonstrating the uncertainty of the presented association between female gender and tasks carried out. It could be possible that women perceive or reflect the burdens of informal care and support PwD more intensely

than males. This gender difference could result in a situation where female caregivers have more unaddressed needs to relieve the burden of informal care by initiating caregiver support programs and more professional care for the PwD [44, 45]. A previous analysis by Eichler et al. that was based on the same study population revealed no significant association between patients' gender and the number of unmet needs [36]. However, the gender of the caregiver was not included in this analysis. However, further research is needed to evaluate gender-specific differences in support of PwD and informal caregivers,

which carries the chance to improve intervention programs, like models of collaborative care.

The prevalence of physical inactivity, limitations in activities of daily living, and polypharmacy were related to the diagnosis of dementia [46]. Cognitive decline is closely related to functional impairment. Therefore, it seems consistent that we found a higher number of tasks in PwD with more significant deficits in daily living. This could be explained by a higher need for care, resulting in a more complex treatment and care situation. PwDs being in an advanced stage of dementia diseases need more professional home care and day and night care and, ultimately, institutional care. To ameliorate this often challenging situation, more intervention tasks need to be provided, further to the existing care of a GP and other healthcare workers.

A higher number of tasks for cooperation was associated with PwDs' mental health, HRQoL, cognitive impairment, and depression. Non-pharmacological interventions are preferred initial approaches to manage and improve PwD daily life [47]. This would explain the higher intensity of the care management for these subgroup of patients [47, 48]. It should also be mentioned that this study was conducted to address the unmet needs of PwD and their caregivers by qualified nurses in close cooperation with the GP. The nurse and the GP initiated further treatments, monitoring, and cooperation. It is not surprising that this cooperation requires coordination and communication between the different stakeholders involved.

Also, the number of nursing care tasks was associated with a higher age of the PwD, which could be an interaction effect with the cognitive and functional impairment of the patients, also resulting in a higher need for care and support [21, 49–52]. Previous studies revealed that PwD with higher age and functional and cognitive impairment benefit most from collaborative care programs [53]. However, implementation research is needed to evaluate how PwDs with a more increased need for collaborative care can be identified under routine care conditions.

This analysis underlined the complexity of collaborative models of care in dementia, demonstrating that socio-demographic and clinical factors should be noticed early on and be monitored to increase the efficacy and cost-effectiveness of collaborative care. So far, there is limited evidence to compare and reflect the results from this study. Therefore, more research is needed to identify and precisely describe the content design and specific form of collaborative models of care in dementia diseases and to evaluate

the association of PwDs' and caregivers' characteristics and existing unmet needs and the interventions required to meet their unmet needs.

### *Limitations*

The DelpHi trial was conducted with a sample of mostly mildly cognitive impaired primary care patients living community-dwelling that were screened positive for dementia, which limits the generalizability of the presented study results. The dementia care management was implemented in the primary care setting with PwD and their caregivers in a rural area with a moderate level of infrastructure. Results might differ in other regions and settings, like inpatient or hospital care as well as suffering from other diseases.

The inclusion criterion of the study was a positive screening result for dementia, regardless of the specific dementia subtype. Results can differ throughout the different dementia subtypes as well as for other parameters that could not be considered here. Also, the screening procedure could cause false-negative cases. Only 38% of positively screened patients received a formal dementia diagnosis previous to the screening, and 69% received a formal diagnosis after the positive screening outcome by the treating GP. However, diagnoses were not finally evaluated. Therefore, false-positive cases are possible, which limits the generalizability of the presented results. The provision of a specific task may require various activities and sometimes multiple visits, the number of tasks does not readily translate into a measure for the overall time demand of the intervention.

The comparability of the results is limited because the number of tasks somewhat depend on the respective definitions of the needs surveyed. The degree of detail in the discrimination between different tasks will likely differ to some extent between studies.

### *Conclusions*

Interprofessional and person-centered care represent the main components of collaborative dementia care. This analysis adds important evidence to the complexity and intensity of collaborative care in dementia and demonstrates socio-demographic and clinical factors affecting the number of tasks of collaborative dementia care. Patients and caregiver characteristics significantly determine the number of tasks carried out within a collaborative model of care, which means that specific case-finding procedures could be beneficial to identify PwDs and caregivers

having a high need for intensive collaborative care management.

## DISCLOSURE STATEMENT

Authors' disclosures available online (<https://www.j-alz.com/manuscript-disclosures/21-5656r2>).

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