

# Combinations of Service Use Types of People With Early Cognitive Disorders

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Original Study

## Combinations of Service Use Types of People With Early Cognitive Disorders



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### A B S T R A C T

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**Objectives:** Understanding which persons most likely use particular combinations of service types is important as this could lead to a better understanding of care pathways. The aim of this study is to identify combinations of service use within a sample of community-dwelling people with mild cognitive impairment (MCI) and dementia and identify factors related to these service use combinations.

**Methods:** A latent class analysis performed at baseline on a merged dataset ( $n = 530$ ) was used to classify care recipients based on following service use types: general practitioner visits, physiotherapist visits, hospital outpatient specialist visits, emergency room visits, hospital inpatient visits with stay over, day care visits, use of domestic homecare, use of personal homecare, and informal care on (instrumental) activities of daily living. Multinomial logistic regression was performed to identify factors associated with service use combinations using clinical characteristics of the care recipient and demographic characteristics of the care recipient and caregiver.

**Results:** Three service use classes were identified; a formal homecare class (10% of participants), an informal care class (46% of participants), and a low user class (44% of participants). Factors increasing the likelihood of being in the formal homecare class compared with the low service use class included a diagnosis of MCI or dementia, activities of daily living impairment, older age of the care recipient, and care recipient not living together with the caregiver.

**Conclusions:** Besides a diagnosis of MCI or dementia, other factors (activities of daily living impairment, age, and living situation) were associated with service use. We recommend using these factors alongside the diagnostic label for care indication.

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Alzheimer disease (AD) and associated dementia disorders have a great impact on people with dementia and their families. With a worldwide prevalence of 36 million<sup>1</sup> and related cost of \$604 billion,<sup>2</sup> dementia places a substantial burden on societies. Because of the progressive nature of the disease, people with dementia often require

increasing amounts of support on their cognitive abilities and activities of daily living (ADL) at home and often eventually in an institution.<sup>3,4</sup> Early diagnosis of dementia is considered important for access to treatment, support, and future care and life planning for persons with dementia and their caregivers.<sup>1,5</sup>

It is unclear what types of services are being used after a formal early diagnosis has been made. Understanding how clinical and demographic characteristics influence the use of care services is important to plan timely access to these types of care. Furthermore, because many different care providers are involved in the diagnostic process and care provision, insight in factors related to service use

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types could lead to better coordination of care between providers and informal caregivers.

Several studies examined service use of people with dementia and their caregivers. Overall, a diagnosis of dementia has been found to be a major determinant of service use<sup>6</sup> with increasing service use in more severe disease stages.<sup>6–8</sup> People with dementia use healthcare services (eg, specialist visits) more often than community services (eg, day care).<sup>9–11</sup> Factors associated with higher levels of service use have been found to be impaired ADL,<sup>6,7,12</sup> neuropsychiatric symptoms,<sup>4</sup> comorbidities,<sup>8</sup> not having a spousal caregiver,<sup>8,13</sup> caregiver and person with dementia not living together,<sup>13,14</sup> knowledge of available services,<sup>15–17</sup> caregiver's positive attitude toward service use,<sup>18</sup> higher caregiver burden,<sup>17</sup> higher number of skilled nursing facilities,<sup>19</sup> availability of public and private transportation,<sup>13</sup> higher educational level,<sup>8,13</sup> higher age, and not being married.<sup>6</sup> Factors for non-utilization of services have been found to be severity of cognition and a negative attitude of the person with dementia toward service use.<sup>17</sup> Furthermore, Beeber et al<sup>19</sup> showed that people with dementia and their caregivers tend to use a combination of different types (eg, using home health and home aide) rather than a single service type.

Studies on service use of people with mild cognitive impairment (MCI), often preceding dementia<sup>20</sup> are scarce. Although MCI according to the criteria is not severe enough to interfere with activities of daily living,<sup>21</sup> people with MCI showed to have higher medical costs and receive more informal care compared to people without MCI.<sup>22</sup> This finding suggests that informal care already starts before a person develops dementia.

Current evidence mainly focuses on associations with single types of service use. Only Beeber et al<sup>19</sup> focused on combinations of service types, although limited to community services. More research is needed to identify combinations of service types when incorporating a broader range of service types.

A better understanding of combinations and associated factors is important for timely access and coordination of care for people with MCI and dementia. This cross-sectional study, therefore, aims to identify subgroups of community-dwelling patients with MCI and dementia who share similar combinations of service use at their initial visit to a memory clinic using latent class analysis (LCA), and examine which clinical and demographic factors are related to these subgroups.

## Methods

### Design

A cross-sectional secondary data analysis was carried out on a merged dataset with data of 4 Dutch longitudinal studies with overlapping protocols: (1) the Leiden Alzheimer Research Netherlands (LEARN) study,<sup>23</sup> (2) the Clinical Course of Cognition and Comorbidity (4C) MCI study (Liao W, Hamel RE, Olde Rikkert MG, et al. Cohort profile: The Clinical Course of Cognition and Comorbidity in Mild Cognitive Impairment and Dementia [the 4C study]: Two complementary longitudinal, clinical cohorts in The Netherlands, unpublished data), (3) the 4C Dementia study<sup>24</sup> (data from Maastricht location only), and (4) the Dutch Flutemetamol study.<sup>25</sup> In all studies, patients were referred to the memory clinic of 1 of 4 academic hospitals (Maastricht, Leiden, Nijmegen, or Amsterdam) for evaluation of their cognitive complaints. They received an extensive clinical examination and the informal caregiver was asked to fill out a booklet with questions about service use, informal care, working situation and quality of life of themselves and the person with the memory disorder.

### Study Population

Inclusion criteria of the Clinical Course of Cognition and Comorbidity in Mild Cognitive Impairment (4C-MCI) and Clinical Course of

Cognition and Comorbidity in Dementia (4C-Dementia), LEARN, and the Dutch Flutemetamol study consisted of (1) a Clinical Dementia Rating score of 0–2; (2) a Mini-Mental State Examination (MMSE) score of  $\geq 10$ ; and (3) the availability of having a reliable proxy, further referred to as the informal caregiver.

Exclusion criteria were other neurologic diseases (ie, normal pressure hydrocephalus, Parkinson disease, Huntington disease, cognitive problems because of alcohol use, a cerebral vascular accident or transient ischemic attack less than 2 years ago, brain tumor, epilepsy, encephalitis); a psychiatric history less than 12 months ago (ie, major depression according to the Statistical Manual of Mental Disorders, 4th Edition); and suspicion of the participants not being able to have at least 1 follow-up.

In total, 1033 people participated in 4 studies: 304 in the LEARN study, 315 in the 4C MCI study, 329 in the 4C Dementia study, and 211 in the Dutch Flutemetamol study (some people participated in more than 1 study,  $n = 126$ ). Of all 1033 participants, 178 participated solely in 4C Dementia study in Amsterdam or Nijmegen of whom service use data was not obtained. Participants were excluded because of a diagnosis of subjective memory complaints ( $n = 199$ ), being institutionalized ( $n = 55$ ), having all clinical data or the syndrome diagnosis missing ( $n = 2$ ), or having all service use data missing ( $n = 104$ ). The final sample eligible for analyses comprised 530 community-dwelling people with MCI or dementia, further referred to as care recipients.

### Measures

Demographic characteristics of the care recipients included gender, age, and years of formal education. Demographic characteristics of the informal caregivers included gender, age, years of formal education, living situation, and working situation. Clinical measures of the care recipients included a diagnosis of MCI or dementia (because of AD or other cause), cognitive functioning measured by the MMSE, with lower scores representing more severe cognitive problems,<sup>26</sup> behavioral problems measured by the neuropsychiatric inventory (NPI), with higher scores indicating increased severity<sup>27</sup>; and functional abilities of ADL measured by the disability assessment for dementia (DAD), with lower scores indicating increased disabilities on performing ADL.<sup>28</sup>

Measures of service use were derived through a comprised questionnaire filled out by the informal caregiver.<sup>23</sup> This questionnaire consisted of the Resource Utilization in Dementia Lite<sup>29</sup> and additional questions, which measured service use on general practitioner (GP) visits, physiotherapy visits, psychologist visits, community mental health team visits, emergency room visits, hours of personal or nursing home care, hours of domestic home care, days of day care at nursing home, care home or community center, being admitted to a nursing home or care home, hospital outpatient specialist visits (any-type eg, geriatrician, urologist), hospital inpatient visits with stay overnight, hospital inpatient visits without stay overnight, hours of informal care of activities in daily living (ADL; eg, dressing), and hours of informal care of instrumental ADL (IADL; eg, cooking). In the questionnaire it was asked if and how often the care recipient, or the informal caregiver because of the problems of the patient, used these services within a recall period of 3 months. A copy of the booklet can be provided upon request.

The following service use variables were included for further analyses: GP visits, physiotherapy visits, emergency room visits, personal home care, domestic home care, day care visit, hospital outpatient specialist visits, hospital inpatient visits with overnight stay and informal care ADL, and informal care IADL. Psychologist visits, community mental health team visits, and hospital inpatient visits without stay-over were excluded because data were only obtained in a subsample.

**Table 1**  
Demographic and Clinical Characteristics of Patients With MCI and Dementia and Their Informal Caregivers at First Visit to Memory Clinic Using Nonimputed Data

Demographics	MCI (n = 198, 37%) Mean (SD) Range	Dementia (n = 332, 63%) Mean (SD) Range	Missing (%)	Significance*
<b>Patient</b>				
Age, years	69.7 (8.8) 50–89	69.5 (10) 41–91	0	.763
Gender, male (%)	61%	53%	0	.080
Years of education	10.9 (3.6) 6–17	11.0 (3.7) 6–17	0	.729
MMSE	26.3 (2.6) 18–30	23.0 (3.4) 13–30	1	.000
DAD	86.6 (13.8) 38–100	75.2 (23.7) 0–100	13	.000
NPI, total score	14.0 (14.5) 0–76	19.2 (17.9) 0–88	37	.004
<b>Informal caregiver</b>				
Age, years	62 (11.7) 17–86	61.7 (10.8) 22–90	3	.763
Gender, male (%)	35%	36%	1	.894
Years of education	11.4 (3.1) 6–17	11.7 (3.2) 6–17	4	.279
Lives together with patient (%)	76%	72%	2	.351
Having a paid job (%)	36%	43%	2	.105

\*Independent *t* test for continuous data and Pearson  $\chi^2$  test for proportions.

### Statistical Analyses

LCA was conducted to identify combinations of service use types. LCA is used to detect the smallest number of latent classes by grouping individual care recipients into categories based on similarities in service use types. This was done by starting with a 1-class model and stepwise increasing the number of classes. The estimation of the number of classes was based on information criteria, likelihood ratio tests using the three step approach,<sup>30</sup> entropy score, and researcher's interpretation. The Bayesian Information Criterion<sup>31</sup> considers the model with the lowest value to be the superior model. The Lo-Mendell-Rubin test<sup>32</sup> examined if the estimated model fitted significantly better than the model with 1 class less<sup>33</sup> using a *P* value of .05. Entropy scores, ranging from 0 to 1, were used as an indicator of classification certainty using a cut-off score of >0.80. All class models were eventually reanalyzed using a parametric bootstrapped likelihood ratio test.<sup>34</sup> This test is considered more robust than the Lo-Mendell-Rubin test<sup>35</sup> and should be significant at a *P* value level of .05. Above all, interpretation of the meaningfulness of the latent class model was conclusive. The LCA was performed using Mplus v 7.3 (Muthén & Muthén, Los Angeles, CA).<sup>36</sup>

Of the 530 participants, 63.4% had complete service use data, 33.4% had 1–3 missing variables, and 3.2% had more than 3 missing variables on service use. For the LCA, missing values on service use data were handled by the latent class analyses in Mplus 7.3 through the default option.

Conditional probabilities, or probabilities of using specific services given class membership, were plotted alongside their class proportion. Conditional probabilities were classified as low (0%–40%), moderate (41%–69%) and high, 70%–100%.<sup>37</sup>

Next, it was tested if class membership was associated with demographic and clinical characteristics. This was done by a multinomial logistic regression model on the saved individual most likely class membership in SPSS v 22 (IBM Corporation Armonk, NY).<sup>38</sup> Because of the explorative nature of the study, first univariate analyses were performed to select independent variables. Significant variables (*P* < .10) with less than 25% missing values were used in the multivariable analyses. Furthermore, collinearity between independent variables was assessed. The multinomial logistic regression was performed in a block wise fashion, starting with the syndrome and etiology diagnosis, then including the clinical characteristics MMSE, NPI, and DAD score, and the final block contained the informal caregivers' demographics age, gender, years of education, living situation and working situation. Model improvement was examined based on the significance (*P* < .05) of the  $\chi^2$  change.

Missing values on clinical and demographic characteristics were imputed through a multiple imputation procedure. In total 10 imputations were performed.

### Results

Baseline characteristics are displayed in Table 1. Most patients had a diagnosis of dementia (63%), of which 65% had dementia because of AD. The mean age of the care recipients was 70 years in the MCI group and 70 years in the dementia group. More than one-half of them were male (61% for MCI and 53% for dementia). The informal caregivers of the persons with MCI and dementia had a mean age of 62 years (MCI) and 62 years (dementia), of whom less than one-half were male (35% for MCI and 36% for dementia). The *t* tests and  $\chi^2$  tests showed

**Table 2**  
Service Use of Patients With MCI and Dementia and Service Use of Their Informal Caregivers Because of the Problems of the Care Recipient, at First Visit to Memory Clinic Over a Recalled Period of 2 Weeks to 3 Months

Service Use Visits Past 3 Months	MCI (n = 198)			Dementia (n = 332)		
	N (%) Users	Median (Range)	Missing (%)	N (%) Users	Median (Range)	Missing (%)
GP	153 (77)	2 (1–20)	1	243 (73)	2 (1–30)	3
Physiotherapist	50 (25)	6 (1–48)	4	72 (22)	6 (1–26)	2
Hospital outpatient	157 (79)	2 (1–15)	1	241 (73)	3 (1–19)	2
Inpatient stay over	9 (5)	2 (1–9)	3	12 (4)	3 (1–21)	3
Emergency room	15 (8)	1 (1–4)	4	25 (8)	1 (1–3)	5
Day care	1 (1)	7 (–)	2	12 (4)	15.5 (0.66–48)	3
Domestic homecare*	23 (12)	3.1 (0.33–11.25)	1	59 (18)	3.4 (1–9.38)	2
Personal homecare*	18 (9)	6 (0.37–14)	2	27 (8)	5.75 (1–19.38)	2
Informal care ADL*	43 (22)	7 (0.03–112)	7	122 (37)	7 (0.03–112)	2
Informal care IADL*	78 (39)	7 (0.10–112)	8	209 (63)	7 (0.07–112)	1

\*Hours per week instead of visits past 3 months.

**Table 3**  
Fit Statistics for Different Latent Class Models

	1 Class	2 Class	3 Class	4 Class	5 Class	6 Class
Log likelihood	-2189.865	-2026.110	-1988.720	-1973.734	-1961.322	-1950.937
BIC	4442.459	4183.950	4178.172	4217.202	4261.380	4309.610
Entropy	n/a	0.754	0.892	0.905	0.890	0.842
LMR	n/a	.0000	.0039	.0257	.5562	.4642
BLR	n/a	.0000	.0000	.0128	.1333	.4286

BIC, Bayesian Information Criterion; BLR, bootstrap likelihood ratio test; LMR, Lo-Mendell-Rubin test; n/a, not applicable.

significant differences on the clinical variables MMSE, DAD, and NPI score between people with MCI and dementia (Table 1).

Table 2 summarizes the usage of services. Three cases showed extreme values of 168 hours per week for informal care ADL and IADL and were, therefore, transformed to 112 hours per week. During the recall period of 3 months, more than one-half of the participants visited their GP (77% MCI, median visits = 2; 73% dementia, median visits = 2) and visited outpatient specialist services (79% MCI, median visits = 2; 73% dementia, median visits = 3). Other services were used less frequently, except for the informal care IADL. More than one-half of the people with dementia used informal care IADL (63%), with a median of 7 hours per week.

**LCA**

The results of the model selection criteria (Table 3) indicated that the 3-class model was superior to the other models. The 3-class model showed the lowest Bayesian Information Criterion value, a significant Lo-Mendell-Rubin test ( $P < .05$ ) and bootstrap likelihood ratio test ( $P < .05$ ), and had a high entropy score (0.892). Furthermore, the 3 classes resulted in meaningful interpretation by showing qualitative and quantitative difference in type and frequency of service use among classes (Figure 1). GP visits and outpatient visits showed a high probability in all three classes. Probably most of these visits entailed a referral to the memory clinic. Class 1 contained 10% of the participants ( $n = 54$ ). Members of class 1 had a high probability of visiting the GP, outpatient visits, receiving informal care for IADL and using domestic homecare, a moderate probability of using personal homecare, and receiving informal care for ADL, but a low probability of visiting physiotherapist, inpatient visits, emergency room visits, and day care

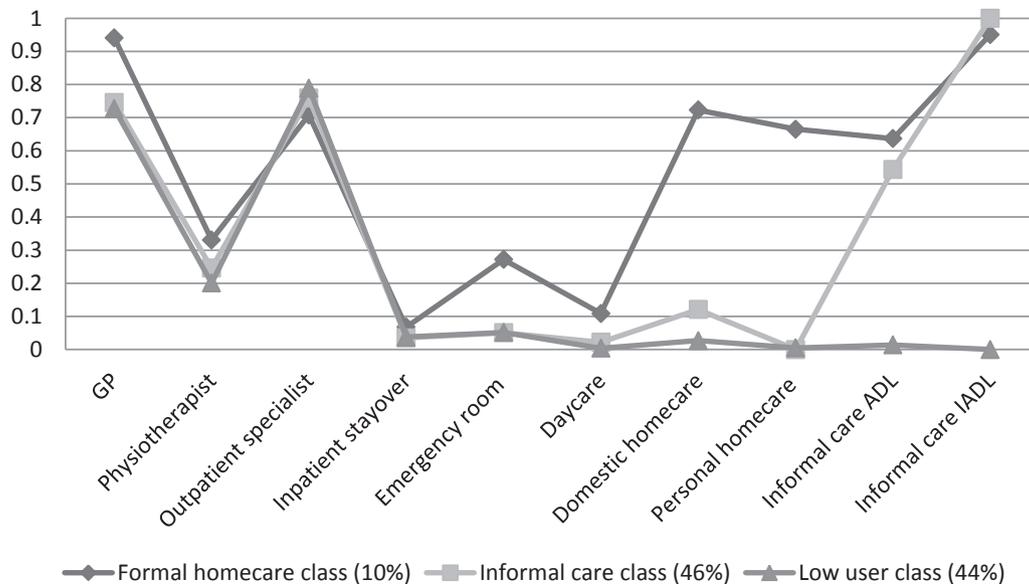
visits. Class 1 was, therefore, labeled as the “formal homecare” class. Class 2 contained 46% of participants ( $n = 242$ ). Members of class 2 had a high probability of visiting the GP, outpatient visits and receiving informal care for IADL, a moderate probability of receiving informal care for ADL, but a low probability for using the other service use types. Class 2 was labeled as the “informal care” class. Class 3 contained 44% of participants ( $n = 234$ ) and showed a high probability of visiting the GP and outpatient specialists, and a low probability of using the other service use types. Despite the high probability of visiting the GP and outpatient specialists, class 3 was labeled as the “low-user” class.

**Multinomial Logistic Regression**

The method of using the most likely class as outcome in further analyses was appropriate to use because entropy score was high.<sup>39</sup> Univariate analyses showed no significant results for the predictor variables age of the informal caregiver, gender of the informal caregiver, gender of the care recipient, informal caregiver’s years of education, and working situation of the informal caregiver. NPI was missing in 37% of the cases and, therefore, excluded for this analyses. Complete case analysis ( $n = 317$ ) was performed including NPI. Results showed that NPI was not significant ( $P = .154$ ).

Table 4 shows the results of the multinomial logistic regression in terms of pooled odds ratios (ORs). Every block showed a significant improvement compared with the previous block.

Results of the final block showed that a higher age of the care recipient [OR 1.11; confidence interval (CI) 1.06–1.16] increased the likelihood of being in the formal homecare class compared with the low user class, whereas a higher score on the DAD (OR 0.94; CI



**Fig. 1.** Conditional probabilities (y-axis) and class proportions (x-axis).

**Table 4**  
Pooled ORs From Multinomial Logistic Regression Predicting Class Membership

	Overall Group Differences	Group Comparisons		
	P Value	Formal Homecare Class vs Low User Class	Informal Care Class vs Low User Class	Formal Homecare vs Informal Care Class
Gender, male*	>.05	0.93 (0.41–2.07)	0.94 (0.62–1.43)	0.98 (0.46–2.11)
Age*	<.01	1.11 <sup>†</sup> (1.06–1.16)	1.01 (0.98–1.03)	1.10 <sup>†</sup> (1.05–1.15)
Years of education*	>.05	0.91 (0.81–1.02)	0.95 (0.90–1.01)	0.96 (0.85–1.07)
Diagnosis	<.01			
AD vs MCI		0.48 (0.18–1.29)	1.84 <sup>‡</sup> (1.13–2.99)	0.26 <sup>‡</sup> (0.10–0.68)
Other NDD vs MCI		1.31 (0.47–3.61)	2.16 <sup>‡</sup> (1.22–3.83)	0.61 (0.23–1.57)
MMSE	>.05	0.96 (0.85–1.09)	0.97 (0.91–1.04)	0.99 (0.86–1.11)
DAD	<.01	0.94 <sup>†</sup> (0.92–0.96)	0.97 <sup>†</sup> (0.95–0.98)	0.97 <sup>†</sup> (0.95–0.99)
Living situation <sup>§</sup>	<.01	0.18 <sup>†</sup> (0.08–0.44)	0.73 (0.43–1.22)	0.25 <sup>†</sup> (0.11–0.56)

ORs are presented with 95% CI.

\*Of care recipient.

<sup>†</sup> $P < .01$ .

<sup>‡</sup> $P < .05$ .

<sup>§</sup>Living together.

0.92–0.96) and living together (OR 0.18; CI 0.08–0.44) decreased this probability. The likelihood of being in the informal care class compared with the low user class is decreased by a higher score on the DAD (OR 0.97; 0.95–0.98) and increased by having a diagnosis of AD vs MCI (OR 1.84; CI 1.13–2.99) or dementia because of other causes vs MCI (OR 2.16; CI 1.22–3.83).

Although the entropy score was high, we additionally performed multinomial logistic regression weighted by the individuals' maximum class membership probability to account for uncertainty in class allocation. Findings showed no deviating results between the most likely class method and the weighted method.

## Discussion

This study identified 3 classes of service use in a memory clinic population with a diagnosis of MCI and dementia. Classes mainly differentiated between the service types formal homecare (domestic and personal homecare), and informal care (ADL and IADL) and were, therefore, labeled as the “formal homecare class,” “informal care class,” and the “low user class.” The largest class was the informal care class (46% of participants), and the smallest class the formal homecare class (10% of participants). Care recipient and informal caregiver not living together, older age of the care recipient, and a more impaired score on the DAD scale were strongly related to the formal homecare class. A diagnosis of dementia and impaired DAD score were strongly related to the informal care class.

We did not find any significant results in the univariate analyses for informal caregivers age, gender, and years of education on service use combinations, which is comparable to findings of Robinson et al.<sup>7</sup> Gender of the care recipient was also not significant in the univariate analyses, although other studies found that gender is related to service use.<sup>6,40</sup> We excluded NPI scores as a predictor in the main analyses. Other research indicated that behavioral changes are an important factor associated with social, healthcare, and informal care costs.<sup>4</sup> However, NPI scores showed no significant result ( $P = .154$ ). One explanation for this might be a lack of variability because of the low NPI scores in our sample mainly in the subgroup of people with mild dementia. However, Herrmann et al.<sup>41</sup> found that even in a mildly impaired community-dwelling population NPI showed to be an important cost driver.

Living situation was significantly associated with being in the formal homecare class (ie, they were less likely to live together with their informal caregiver compared with the informal care class and low user class). This is not surprising given the fact that caregivers

who do live together with the care recipient often substitute activities that normally would be done by the formal care system.<sup>14,42</sup>

Furthermore, a higher care recipient's age was related to a higher likelihood of using formal homecare services, which is comparable to the findings of Beeber et al.<sup>19</sup>

Bergvall et al.<sup>12</sup> showed in their study that ADL measured by the DAD rather than cognition measured by the MMSE are the main predictor for informal care, which is comparable to our findings.

Lastly, as expected, care recipients with a diagnosis of dementia were more likely to use informal care compared with care recipients with MCI. However, diagnosis was not related to using formal homecare in addition to informal care. This can be explained by the fact that other factors such as high care recipient age, impaired ADL functioning, and whether the care recipient and caregiver lived together showed a strong relation with service use and reflect the heterogeneity of care needs within the diagnostic syndrome categories of MCI and dementia.

This study has some limitations. First, this study was based on cross-sectional data and, therefore, determining causality or the ability to predict service use is limited. Second, service use was measured using a self-report questionnaire, which is less reliable than data retrieved by a face-to-face interview,<sup>19</sup> and caregivers may have been unaware about services that were used.<sup>43</sup> A third limitation is the use of a limited number of predictors. Including a broader range of demographic (eg, availability of nursing facilities), social (eg, attitude toward service use), and clinical predictors (eg, presence of comorbidities) is recommended for future studies as these have been shown to be related with service use.

## Implications for Practice and Research

Our results showed that next to the syndrome diagnosis of MCI or dementia, age of the care recipient, ADL impairment, and living situation were also related to service use combinations. These findings confirm previous research and emphasize the importance to take these factors into account during the diagnostic process as these may improve to care planning. Future research should examine combinations of service use longitudinally, which makes it possible to actively prepare and plan the future need for services. A detailed understanding of the probability and interaction of care services over time could provide care professionals with the necessary information to form an individualized care plan and prepare persons with memory complaints for their future care need. Such information could also be of value for the coordination of care services to ensure uncomplicated transitions between care providers.

## Conclusions

This study showed that ADL impairment, not living together with the caregiver, and a higher age of the care recipient increased the likelihood of receiving formal home care in memory clinic visitors with MCI and dementia. ADL impairment and having a dementia diagnosis increased the likelihood of receiving informal care. Therefore, these factors are relevant to take into account in addition to the diagnosis for care planning.

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