

**How does carer management style influence the
performance of activities of daily living in people with dementia?**

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Key Points

- This is the first study to demonstrate that both intrinsic (apathy; global cognition) and extrinsic factors (carer styles) affects ADL performance.

- Carer styles when managing daily dementia problems affected people with dementia's ADL performance.
- People with dementia's level of apathy and carer use of criticism decreased ADL scores while their cognitive function and carer use of encouragement style improved ADL performance.
- Multi-components interventions targeting carer styles and apathy levels should be developed to support ADL performance.

Abstract

INTRODUCTION: People with Dementia (PwD)'s performance of activities of daily living (ADLs) has been associated with apathy, cognitive deficits, carers' depression and burden. However, it is not known if the carers' management style affects ADL performance, particularly alongside PwD's cognitive deficits and apathy. Thus, the aim of this study was to explore the contribution of intrinsic (cognition, apathy) and extrinsic (carer management styles) dementia factors to ADL performance.

METHODS: PwD (n=143) were assessed on global cognition (ACE-III); apathy (CBI-R); ADLs (Disability Assessment for Dementia-DAD). Carers' (n=143) criticism, encouragement and active-management styles were assessed with the Dementia Management Strategy Scale (DMSS). Multiple linear regression analysis investigated contributions of carer styles, cognition, apathy (independent variables) on ADLs (dependent variable).

RESULTS: The best model explaining the variance of the DAD scores included cognition ($\beta = 0.413$, $t_{(142)} = 4.463$, $p = 0.001$), apathy ($\beta = -0.365$, $t_{(142)} = -5.556$, $p = 0.001$), carer criticism ($\beta = -0.326$, $t_{(142)} = -2.479$, $p = 0.014$) and carer encouragement styles ($\beta = 0.402$, $t_{(142)} = 2.941$, $p = 0.004$) accounting for 40% of the variance of the DAD scores.

CONCLUSIONS: This novel study demonstrated that PwD's level of apathy and the carer's use of criticism negatively affected ADL performance while PwD's cognitive abilities and carer encouragement style improved ADL performance. These findings have critical implications for the development of novel multi-component non-pharmacological interventions to maintain function and delay disease progression in dementia, as well as direct relevance to current carers and families.

Introduction

People with dementia (PWD) present with gradual deterioration in the performance of activities of daily living (ADLs) [1]. Several intrinsic dementia factors have been associated with decline in daily tasks in several dementia subtypes [2-4]. Factors include decline in specific cognitive domains such as memory and executive function [5,6] and behavioural symptoms [2,3], for example apathy, the most common behavioural symptom reported in dementia [7]. However, intrinsic factors alone do not seem to fully explain the variance of ADL scores and some studies have found no association between PwD's level of cognition and ADL performance [4,8].

Extrinsic factors, such as carer-related characteristics [9], have also been associated with the PwD's performance of daily tasks. For example, female carers tend to report poorer ADL performance when compared with male family members [10]. Carers' mental health factors, such as carer depression and burden [10] have also shown to have a negative impact on the PwD's performance of ADLs. Thus, carers who are depressed and burdened tend to report more deficits in the PwD's daily tasks [10].

Another less investigated extrinsic factor that could affect the PwD's performance of daily tasks is the style that carers use when managing dementia-related problems. These management styles refer to the specific ways in which a family carer approaches dementia-related issues. Three carer's styles have been described in the literature, based on the strategies used by carers: *criticism*, which describes efforts to manage the patient by actions such as yelling, criticizing, threatening, and related behaviours. *Active management* includes actions to assist, engage, stimulate, and associated behaviours primarily directed toward modifying the environment or daily routine. *Encouragement* includes efforts to praise the individual, get them to discuss feelings or look on the bright side of

things [11]. Studies on the use of carer management styles in dementia have found correlations between the carer's use of criticism style with higher carer burden [11-13], while the use of encouragement style has been associated with carer's greater feelings of gain, which denotes a positive caring experience [13].

The interaction of cognitive deficits, apathy and extrinsic factors, such as the carer's management styles, is less known, because studies mainly focused on the investigation of intrinsic or extrinsic factors separately. In addition, to date, studies on how carer's styles when managing dementia-related problems can affect PwD's performance of daily tasks are missing. Elucidating the role of carer management styles within the context of the PwD's cognitive performance, apathy levels and everyday functioning would inform clinicians and researchers on the usefulness of different carer management strategies to support daily function. Additionally, novel carer-based interventions could be developed, targeting the optimal carers' styles to support ADL performance.

This study aimed to investigate the contribution of intrinsic dementia factors (global cognition and apathy) and extrinsic factors (carer management styles) to PwD's performance of ADLs.

Methods

This was an exploratory cross-sectional and observational study that was conducted as part of the TASKed project, a study funded by the Alzheimer's Society (led by the senior author), which has recruited 183 PwD and their family carers in the UK (n=366). The project was sponsored by the University of East Anglia, in Norfolk, England, and recruited participants from September/2016 until July/2019.

Participants

Out of 183 dyads from the parent TASKed project, 143 PwD were included in this study if they had a diagnosis of Alzheimer's disease (AD) [14] or Vascular dementia (VD) [15]. Inclusion criteria for the PwD also included living at home and be >40 years old and <90 years old.

Dementia diagnosis was obtained through copies of letters of diagnosis made by consultant neurologists or psychiatrists, depending on the memory clinics or mental health services to which the participant was linked to. This process was consented by the participant and approved by the REC. Exclusion criteria for PwD were: having a history of additional major psychiatric disorder, being unable to respond to single step commands and diagnosis of dementia secondary to head trauma, alcohol misuse or brain tumour. Carers needed to be fluent in English, be over 18 years old and have had to provide at least 7 hours of unpaid support each week. The primary carer was then defined by these criteria. All participants and their carers were assessed at their own home.

Ethical Considerations

The study was approved by the Health Research Authority in the UK (IRAS ID 199002, REC 16/LO/0544). Both the PwD and their carers provided written consent at the baseline visit. If the PwD lacked the capacity to consent to the study, appropriate measures were in place so that the carer could state what they thought the PwD's wishes would have been regarding their participation in this study.

Instruments

Carers completed demographic questionnaires for both the carer and the PwD, and they were interviewed using the following instruments.

ADLs were assessed using the *Disability Assessment for Dementia (DAD)* [16], an informant-based interview assessment widely used with people with AD and other dementias [3, 8] living in the community. The DAD includes both personal care tasks (Basic ADLs) and more complex tasks, such as meal preparation, household chores and going out (Instrumental ADLs). Non-applicable items (i.e. tasks never performed in the past) are excluded from the total score. Higher scores on the DAD denote better ADL performance.

Carer's management styles were evaluated using the *Dementia Management Strategies Scale (DMSS)* [11], a 28-item questionnaire that characterises three different styles of management: criticism (11 items), encouragement (8 items) and active management (9 items). The items measure the frequency by which the carer uses each style, when managing dementia-related problems, on a scale that ranges from 0 (never) to 4 (most of the time). Each style is scored independently in a continuous scale (criticism=up to 44; encouragement=32; active management=36). For this study, scores of each style were corrected to percentage to be able to make comparisons between styles. This percentage was obtained by dividing the score of each subscale by the sum scores of all items for each participant.

Carer's depression was assessed with the *Patient Health Questionnaire (PHQ-9)* [17], a self-complete scale that measures level of depression. The assessment comprises of 9 items that evaluates symptoms of depression over the last 2 weeks. The scale ranges from 0 (not at all) to 3 (nearly every day). Higher scores represents higher levels of depression, with scores higher than 15 considered moderately severe to severe depression, scores between 10-14 considered moderate depression and scores between 5-9 considered mild depression [17].

PwD's disease stage was based on the *Frontotemporal Dementia Rating Scale* (FRS) [18], a 30-item questionnaire which assesses dementia stage. Each item can be scored as 0 (all the time and sometimes) and 1 (never). The FRS rates the severity of the dementia as very mild, mild, moderate, severe, very severe and profound. For this study, we have grouped our sample in three stages only: Mild (very mild and mild), Moderate and Severe (severe, very severe and profound) and logit scores were used for the statistical analyses. The FRS has shown to be sensitive to disease progression also in AD [19].

PwD's global cognition was measured using the *Addenbrooke's Cognitive Examination-III* (ACE-III) [20], an internationally recognised dementia screening tool that evaluates global cognitive skills in five domains: language, attention, memory, verbal fluency and visuospatial abilities. The maximum score is 100, and higher scores indicate better cognitive functioning. The ACE-III's recommended cut offs are 88 (sensitivity=1.0; specificity=0.96) and 82 (sensitivity=0.93; specificity=1.0) [20].

PwD's level of apathy was assessed with the *Cambridge Behavioural Inventory-Revised version* (CBI-R) [21]. The CBI-R evaluates behavioural symptoms in people with dementia, including apathy, sleep and changes in eating behaviour. Behaviours are assessed according to a frequency scale ranging from 0 (never), to 4 (constantly). Higher scores represent higher frequency of behavioural change. The apathy subscale of the CBI-R was used in this study to obtain the PwD's level of apathy. Scores were converted to a percentage.

Data Analyses

Statistical Analyses were performed using the Statistical Package for the Social Sciences programme (SPSS version 25). The level of statistical significance was set at 5% ($p < 0.05$).

To characterise the sample, descriptive statistics were performed for demographics and clinical variables. To investigate possible differences between dementia stage, data was compared using independent samples *t* tests for the clinical variables (cognition, apathy and ADLs).

To investigate the role of the intrinsic dementia (cognition and apathy) and extrinsic (three carer management styles) factors in the variance of the PwD's performance of ADLs (DAD, total score), a multiple linear regression analysis was performed.

Results

Sample size was calculated based on a multiple linear regression analysis allowing for five predictors (cognition, apathy and the three-carer management styles variables) in the model. In order to detect a medium effect size (Cohen's $f^2=0.15$) [22] with 95% power at 5% significance level, the minimum sample size required was estimated to be $n=138$.

The descriptive statistics of demographics and clinical variables for all participants are shown in Table 1. The majority of PwD were male (62.9%), lived with their family and were married. Their average age was 78 years ($M=78.73$, $SD=7.33$). The majority had a diagnosis of AD (81.1%) followed by VD (18.9%). Figure 1 compares the PwD's level of cognition, apathy and ADL performance, by dementia stage.

-Insert Table 1-

-Insert Figure 1-

Carers were mostly female and were 73 years old on average ($M=73.08$, $SD=10.57$). The majority of carers were spouses reporting mild depressive symptoms (Table 1). Carers reported using an active management style more often (51%) than encouragement style (46.2%) and they reported seldom-use of criticism strategies (61.5%) (Figure 2).

-Insert figure 2-

What is the impact of cognition, apathy and carer management styles to the PwD's performance of ADLs?

To understand the contribution of cognition, apathy and the three carer management styles (criticism, encouragement and active management) to ADL performance, these variables were included in the regression analysis, using the DAD total score (ADL performance) as the dependent variable.

The best model that explained the highest variance on the DAD included PwD's level of cognition ($\beta = 0.413$, $t_{(142)}=4.463$, $p=0.001$), PwD's apathy level ($\beta = -0.365$, $t_{(142)}=-5.556$, $p=0.001$), carer's use of criticism style ($\beta = -0.326$, $t_{(142)}=-2.479$, $p=0.014$) and carer's use of encouragement style ($\beta = 0.402$, $t_{(142)}=2.941$, $p=0.004$). This model explained 40% of the variance of the ADL performance ($R^2=0.40$, $F=18.359_{(5,137)}$, $p<0.001$). Active management was the only factor that did not significantly contribute to the variance in ADL performance. Results of the regression analysis are displayed in table 2.

-insert table 2-

The contribution of each of the variables to the ADL performance model varied. For each point that the PwD scored on the CBI-R apathy subscale, which denotes increase level of apathy, their ADL performance (DAD) decreased by 3%. PwD's performance of ADLs also decreased by 3% for each

point that the carer scored on the criticism subscale (DMSS). On the other hand, for each point that the PwD scored for better cognition (ACE-III) their ADL performance increased by 4%, and for each point that the carer scored on the encouragement subscale (DMSS), the PwD's performance of ADLs increased by 4%.

Preliminary analyses were performed to ensure that assumptions of normality, multicollinearity, linearity and homoscedasticity were met. Outliers were also checked using Mahalanobis and Cook's distances. No independent variables were highly correlated, thus, our data did not show multicollinearity or singularity. This was also confirmed with Tolerance and VIF, as these values were all within accepted limits. For our sample, Mahalanobis distance scores (MD=20.43) were just below its critical value of 20.52 for five independent variables [23], and Cook's distance value were below one ($D_i = 0.13$) thus, we can conclude that no outliers were found within the data. Residual and scatter plots indicated that the assumptions of normality, linearity and homoscedasticity were all met.

Discussion

This is a novel study investigating how the combination of intrinsic and extrinsic dementia factors can affect PwD's performance of ADLs. Carer's use of criticism style decreased ADL performance while encouragement style improved task performance, confirming the key role that carers have when supporting PwD in the performance of daily tasks. In addition, better global cognition increased ADL performance while apathy had the opposite effect, confirming previous studies [2, 3, 24-26].

The use of encouragement style increased ADL performance. Encouragement strategies are based on an emotional support approach, since they include ways of encouraging the PwD to have a positive attitude in relation to their circumstances such as, for example, motivating the PwD to discuss their emotions and feelings, showing the PwD physical affection and keep up with friends. The fact that the more encouraging the carer was improved ADL performance suggests that a positive atmosphere, where the PwD is listened and prompt to express themselves, provides a more favourable environment that supports ADL performance. Using this style was also associated with positive carer outcomes in the past. For example, a study that looked at the relationship between the carer management styles and carer-related measures found that the use of encouragement predicted perception of positive gain in Asian carers [13], increasing the carer's positive feelings of the caring experience. As such, our study also contributes to the knowledge that implementing positive strategies when caring for someone with dementia will influence the carer's wellbeing while having an effect on the PwD's performance of ADLs.

Criticism style was the least chosen style among our carers, with the majority of them reporting that they seldom used it. Still, this style negatively affected PwD's performance of ADLs. The criticism style is based on strategies where the carer, for example, blames the PwD for having created difficulties and asks the PwD to stop doing things that cause worry, and also the use of yelling and threatening. Even though our carers reported that they were rarely critical towards the PwD, the fact that these strategies still affected ADL performance shows that a critical environment is not conducive to the task performance of the PwD. On the other hand, the use of criticism was found to be associated with increase carer's use of home and social services in a previous study [12]. This supports our findings by linking the use of criticism strategies, which leads to poor PwD's performance of ADLs and may result in the need for greater external help. In addition, in previous studies, the use of criticism style has been linked with higher carer burden [11-13] - and carer

burden has been associated with poor ADL outcomes [10]. Future studies could include both measures of carer burden and carer management style, to further understand how these extrinsic carer-related factors may further influence PwD's performance of ADLs.

In our sample, the majority of our carers identified themselves as adopting strategies that belong to the active management style. This style is characterised by a dynamic involvement by the carer in relation to the PwD's needs. As such, a carer who uses active management strategies will be the one who is constantly arranging and adapting the environment, thereby stimulating the PwD and will also notice when to do things when the PwD is no longer capable of. Although these carers are actively involved in the PwD's daily routine, interestingly this was the only style that did not contribute to the variance of the PwD's performance of daily tasks. A possible reason for this variable not to contribute in the statistical model may be that carers who are deeply involved with the PwD's daily activities have an accurate knowledge of the type of support the PwD needs in their daily routine, overlapping strongly with the ADL performance.

It is worth noting that the application of strategies that carers use when dealing with dementia-related problems may be shaped by their level of education or knowledge about dementia. Future studies could include these variables to understand how the carer's level of training and understanding of the disease may influence the strategies that they use daily.

PwD's increased level of apathy had a detrimental effect on PwD's performance of daily tasks, which is in agreement to previous research in apathy in AD [2, 25, 26]. For example, an American study [25] found that apathy uniquely contributed to PwD's performance of ADLs, while apathy and PwD's sleep disorders were found to contribute to ADL performance more recently [2]. In relation to

cognition, previous studies had varied results in relation to its contribution to ADL performance. In this study, PwD's higher level of cognition improved ADL performance. A review on the cognitive contributions to everyday performance [27] found that greater global cognition was positively associated with better everyday function in people with AD [27]. Other studies [4,8], however, did not demonstrate such association between cognition and ADL performance, possibly because they focused on rarer forms of dementia such as frontotemporal lobar degeneration phenotypes, with smaller samples.

One limitation of this study was the inability to control for dementia stage because the instrument used to determine dementia severity (FRS) includes questions on ADL performance (DAD). In addition, another limitation was that our sample was largely comprised by PwD in the moderate and severe stages of the disease. Strengths of our study included an appropriately powered sample size, and novel focus on combining variables that were not investigated altogether in a single study. Future studies with people in the mild stages of dementia could provide a better overview of the effect of the aforementioned factors on ADL performance of PwD in the mild stage. Studies that use observation of the PwD and their carer while they complete a standardised ADL task would further elucidate how the interactions between them and use of different strategies facilitate or hinder PwD's task performance.

This study has several implications. Firstly, it showed how the use of different carer styles contributed to the PwD's performance of ADLs. Clinicians may need to consider the identification of the carer's style when using informant-based questionnaires to evaluate performance of ADLs. This could help clinicians identify possible effects of carer styles on the PwD's performance of daily tasks, allowing them to offer appropriate support to their clients and families. In addition, our study suggests that the use of encouragement style should be advised to carers when supporting people

with dementia in their daily tasks and other dementia-related issues. A relevant implication for researchers is the opportunity to develop and test non-pharmacological multicomponent intervention programmes that focus on the style that carers adopt when dealing with dementia-related problems and apathy management. By targeting these strategies, novel carer-based interventions could maintain function and delay the dementia's progression, while also having a positive effect on carer wellbeing.

In summary, our results revealed that both intrinsic and extrinsic dementia factors contributed to ADL performance, confirming the need for clinicians and researchers to address these factors concomitantly. Although PwD's everyday performance still depends to a great extent on their cognitive and behavioural functioning, the strategies that carers use when dealing with dementia-related issues can be targeted in order to improve PwD's performance of ADLs.

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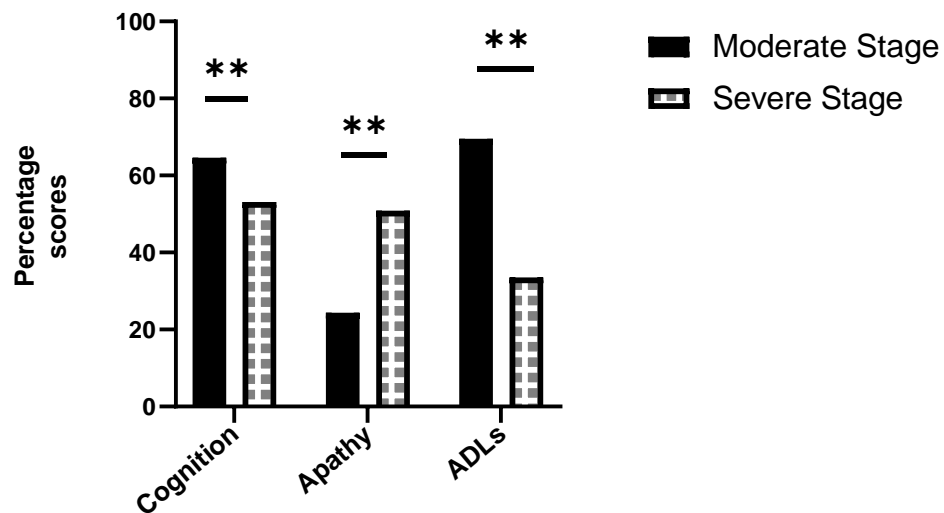
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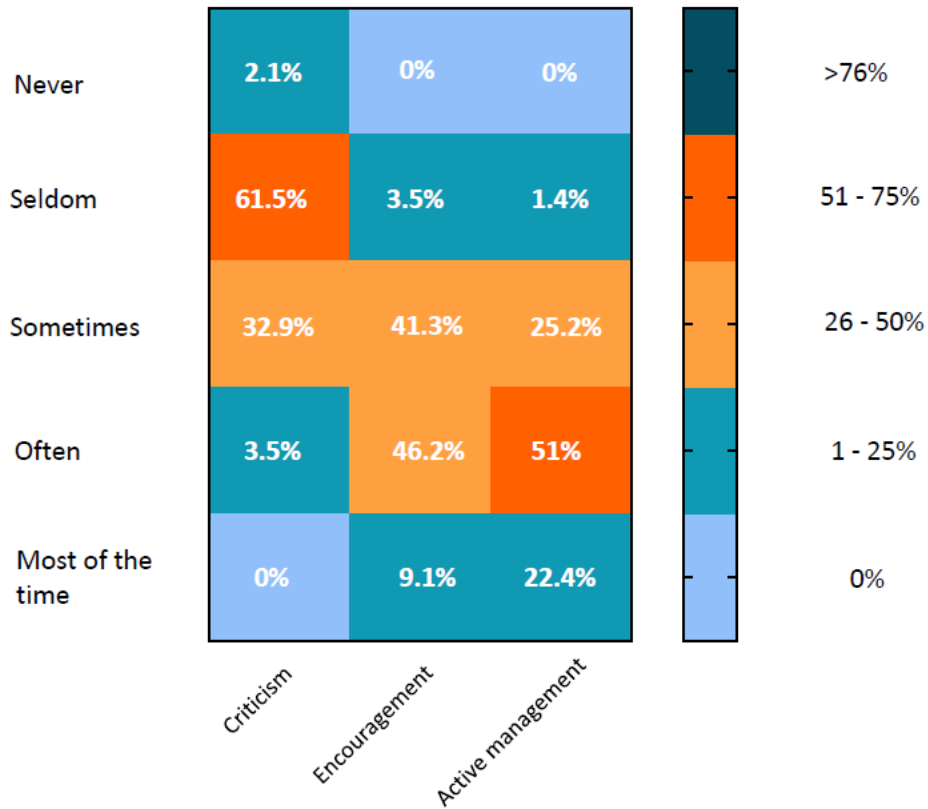
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Figure 1. Bar graphs showing comparison of level of cognition, apathy and ADL performance of people with dementia, grouped by dementia stage [moderate (n=56) vs severe (n=77)]. People in the mild stage of dementia were excluded from this comparison, due to the small numbers in the sample (n=10).



*Cognition was assessed with the ACE-III (Addenbrooke's Cognitive Examination, third edition) (Scores 0-100, higher scores denote more preserved cognitive abilities); apathy was measured with the CBI-R (Cambridge Behavioural Inventory-Revised) (0-100%, higher scores denote higher levels of apathy); ADLs were measured with the DAD (Disability Assessment for Dementia) (0-100%, higher scores denote better ADL performance). **t test, statistically significant difference ($p < 0.01$).*

Figure 2. Heat map reporting the frequency with which carers reported the use of different strategies while managing dementia-related problems, as described by the three-carer management styles based on the DMSS: criticism, encouragement and active management.



Carer management styles were assessed using the DMSS (Dementia Management Strategies Scale). The scale ranges each strategy using this graduation: 0 (never used the strategy), 1 (seldom), 2 (sometimes,) 3 (often) and 4 (most of the time).

Table 1. Demographic characteristics and clinical variables of the full sample and grouped by dementia stage. Mild group not included in the comparison of demographic variables due to its small sample size. SD in brackets.

	Carers (n=143)	PwD (n= 143)	Mild (n=10)	Moderate (n=56)	Severe (n=77)	Moderate vs Severe
Age (in years)	73.08 (10.57) [†]	78.73 (7.33)	79 (6.86)	78.86 (7.43)	78.6 (7.41)	ns
Gender (Male %)	30.9	62.9	50	57.1	68.8	ns
Education (in years)	12.79 (2.78)	12.28 (2.62)	12.8 (3.01)	12.52 (2.8)	12.04 (2.44)	ns
Length of Symptoms	N/A	3.94 (3.09) [†]	2.44 (1.23)	3.27 (2.67)	4.6 (3.36)	*
Cognition (ACE-III)	N/A	58.49 (17.73)	64.3 (13.57)	63.79 (12.2)	53.88 (20.2)	**
ADLs (DAD)	N/A	50.63 (24.5)	86.99 (14.43)	68.23 (14.28)	33.11 (15.35)	**
Apathy (CBI-R)	N/A	37.93 (27.56)	15.5 (24.31)	23.03 (22.01)	51.67 (24.03)	**
Marital Status (%)						
Married	N/A	81.8	90	80.4	81.8	ns
Widowed	N/A	11.2	10	12.5	10.4	ns
Other	N/A	7	-	7.2	7.8	ns
Living Situation (%)						
With Family	N/A	90.2	100	85.7	92.2	ns
Alone	N/A	9.8	-	14.3	7.8	ns
Relationship to PwD (%)						
Spouse	81.8	N/A	90	78.6	83.1	ns
Children	12.6	N/A	10	16	10.4	ns
Other	5.6	N/A	-	5.4	6.5	ns
Depression (PHQ-9)	5.41 (4.72)	N/A	3.00 (4.32)	4.36 (3.67)	6.51 (5.17)	**

Global cognition was assessed with the ACE-III (Adenbrooke's Cognitive Examination, third edition); ADLs (Activities of Daily Living) were measured with the DAD (Disability Assessment for Dementia), apathy was measured with the motivation subscale of the CBI-R (Cambridge Behavioural Inventory-Revised) (Frequency score: 0-100%); Carer depression was assessed using the PHQ-9 (Patient Health Questionnaire-9). Carer management styles were identified using the DMSS (Dementia Management Strategies Scale). Independent Sample t-test was used for continuous variables. X² Test was used for categorical variables. Statistically significant difference *p<0.05; **p<0.01. † Missing data for both the length of symptoms (n=128/143) and carers' age (n=142/143).

Table 2. Independent variables (carer or person with dementia) included in the multiple regression analysis. Dependent variable: ADL Performance (N=143).

DAD (ADL performance)	Coef (β)	<i>t</i> -statistic	<i>p</i>	95% CI	
				Lower	Upper
PwD Cognition (ACE-III)	0.413	4.463	0.001	4.079	10.569
PwD Apathy (CBI-R)	-0.365	-5.556	0.001	-13.64	-6.479
Carer Criticism (DMSS)	-0.326	-2.479	0.014	-7.927	-0.892
Carer Encouragement (DMSS)	0.402	2.941	0.004	2.040	10.417
Carer Active Management (DMSS)	-0.083	-0.612	0.541	-5.978	3.151

Note. $F_{(5,137)}=18.36$, $p<0.001$, $R^2=0.40$;

PwD: people with dementia; ADL performance was measured with the DAD (Disability Assessment for Dementia); cognition was assessed with the ACE-III (Addenbrooke's Cognitive Examination, third edition); apathy with the CBI-R (Cambridge Behavioural Inventory-Revised). Carer criticism, encouragement and active management are the three carer's styles described in the DMSS (Dementia Management Strategies Scale).