

Exploring the abilities of performing complex daily activities in dementia

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Exploring the abilities of performing complex daily activities in dementia: the effects of supervision on remaining independent

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ABSTRACT

Objectives: The aim of this study was to explore the remaining abilities of people with dementia (PwD) in performing daily activities.

Method: Informal carers of community-residing PwD were recruited across England via mail out and carer support groups. Carers completed the *revised Interview for Deteriorations in Daily Living Activities in Dementia 2* to rate the PwD's initiative and performance of daily activities. Six complex instrumental activities of daily living (IADLs) were selected: shopping, preparing a hot drink, using the telephone, preparing a cold meal, house work, and engaging in social activities, all of which were broken down into three sub-tasks. Data were analysed using Chi-square tests and linear regression analysis, assessing the contributions of hours of IADL care, hours of supervision, and dementia stage for each activity.

Results: 581 carers of people with mild, moderate, and severe dementia completed the questionnaire. The ability to perform individual activities deteriorated from mild to moderate to severe dementia, with PwD remaining the most able to perform subtasks of preparing a hot drink and a cold meal. Subtask performance varied across activities, with some better maintained than others across severity stages. Linear regression models showed that hours of supervising PwD explained a greater proportion of the variance of each IADL than IADL care hours.

Conclusion: PwD should be supervised to continue engaging in activities, thereby avoiding performing everything for the PwD. Findings can have implications for PwD living in nursing homes, and future research should explore the remaining IADL abilities of nursing home residents.

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Introduction

Increased dependency in everyday life is one of the primary symptoms of dementia (Stogman, Moser, & Klug, 2016). Providing care for such daily activities, including dressing and washing, is part of the 'fundamentals of care' for nursing staff (Kitson, Conroy, Wengstrom, Profetto-McGrath, & Robertson-Malt, 2010), and thus part of their regular care activities. Whilst the general often focus lies on the limitations in performing daily activities both in research and clinical practice (Beaver, Wilson, & Schmitter-Edgecombe, 2017; Moheb, Mendez, Kremen, & Teng, 2017), people with dementia are still able to perform activities, suggesting that the focus needs to shift to those remaining abilities for nursing staff to help people live a more fulfilled and active life for as long as possible.

Supporting people with dementia in conducting instrumental activities of daily living (IADLs) for as long as possible is an important aspect of their social health (Huber et al., 2011). The INTERDEM Social Health Taskforce together with the European Working Group of People with Dementia (Dröes et al., 2017) suggests that all three social health dimensions of *remaining independent*; *having the capacity to fulfil obligations*; and *taking part in social activities* are highly relevant and can be operationalised for people living with dementia.

By comparing different activities with one another, it appears that some activities decline earlier or faster than others. In particular, complex IADLs are found to deteriorate early on (Peres et al., 2008; Giebel, Challis, & Montaldi, 2017; Hsiao, Lu, Grill, & Teng, 2015), whilst more basic ADLs such as continence and feeding deteriorate to a greater degree in the later stages of dementia (Giebel et al., 2014; Reisberg et al., 1984). Despite limited evidence available, some IADLs appear to be maintained longer than others (Amjad, Roth, Samus, Yasar, & Wolff, 2016; Fieo & Stern, 2018). In particular, *finance management* skills deteriorate as one of the first activities (Peres et al., 2008), whilst PwD are reported to maintain activities of *preparing a cold meal* and *following familiar routes* for longer (Giebel, Sutcliffe, & Challis, 2017).

Breaking down activities into different sub-tasks, as opposed to a dichotomous perspective of being able and being unable, can help to highlight where exactly someone remains able to perform a task and where nursing staff can support a person targetedly. This is only gradually receiving more attention in research and clinical practice (Giovannetti, Schmidt, Gallo, Sestito, & Libon, 2006; Hartman, Goldenberg, Daumueller, & Hermsdoerfer, 2005) despite its potential benefits in helping people with dementia maintain independence for longer. Whilst the

majority of research only investigates the ability to perform an activity (Durant, Leger, Banks, & Miller, 2016; Peres et al., 2008), daily activities can be assessed on additional levels, such as planning and initiation (van Rossum & Koek, 2016; Wesson et al., 2017). One example of a sub-task analysis is breaking down *cleaning and doing household tasks* into 'washing up', 'setting the table', and 'forgetting it is time to do tasks' (Giebel, Challis, & Montaldi, 2017). It may be the case that people with dementia struggle with cleaning, but that there is one, or two, sub-tasks which are easier to maintain than others. This may be the case both for people with dementia living in the community and those living in nursing homes. Whilst generally activities are being taken over and performed for the person with dementia in the nursing home setting (den Ouden et al., 2015; 2017), residents may still be able to perform certain subtasks. In this situation, it is important to support the person to remain independent and carry on performing this activity for as long as possible, not only to keep the person active and engaged (Metzelthin et al., 2017), but also to maintain a high level of well-being and quality of life (Beerens et al., 2015). This knowledge can be employed in interventions both in the community and in the nursing home setting, by helping people with dementia with those subtasks that they experience difficulties with, and by enabling people to still perform those subtasks they are able to perform. Recent research suggests that people with dementia are able to benefit from specific interventions that help to re-learn specific daily activities (i.e. Voigt-Radloff et al., 2017). One such cognitive strategy is errorless learning, which has shown some positive results in the relearning of daily activities (de Werd, Boelen, Olde Rikkert, & Kessels, 2013).

Remaining independent in performing daily activities is an important factor contributing to increased levels of quality of life in dementia. This relationship has been observed in both community-residing (Giebel et al., 2014) and institutionalised people with dementia (Ballard et al., 2001; Beerens et al., 2016; Chan, Slaughter, Jones, & Wagg, 2015). Being involved to a greater extent in active, expressive, and social activities, such as playing a game, engaging in sports, or doing household chores, in nursing home residents was shown to be associated with higher levels of quality of life (Beerens et al., 2016). In contrast, engaging in more passive activities, such as watching television or sitting, which happens frequently in nursing homes (den Ouden et al., 2015), was linked to reduced levels of well-being. This suggests that not only in the community, but also in institutional long-term care, PwD need to be enabled to engage in meaningful daily activities.

The aim of this study was to explore performance of subtasks of daily activities in dementia in greater depth. These subtasks were selected based on (a) their association with the person with dementia's quality of life (QoL); (b) their slower rate of decline compared to other IADLs; and (c) PwD potentially being able to perform these tasks in both their own home and in nursing homes based on existing literature. Highlighting the subtasks that people with dementia remain able to perform, as opposed to stating a dichotomous picture of being able and being unable, can help nurses in designing better interventions to prolong those abilities for as long as possible, both in the community and in the nursing home setting.

Method

This was a cross-sectional mail out study across England. Data were collected between October 2015 and May 2016.

Participants

To be eligible for the study, carers had to be an informal (non-paid) carer, and the person they cared for had to have a diagnosis of dementia diagnosed formally by a clinical specialist and live in the community. The diagnosis was provided by the carers and confirmed, where possible, with the National Health Service Trusts by contacting the respective Trusts after a questionnaire was returned. No exclusions were applied on the dementia sub-type diagnosis.

The sample size was calculated using G-Power software. The aim was to collect data on approximately 200 people with mild, 200 with moderate, and 200 with severe dementia. Post-hoc power calculations with an effect size of 0.5 and a significance value at $p < .05$ indicated a power of 1, implying a 100% likelihood of correctly rejecting the null hypothesis and concluding there to be a real effect.

People with dementia were categorised into mild, moderate, and severe dementia stages based on data rules derived from a European data set on the transition between community and nursing home residency, the *RightTimePlaceCare* project (Verbeek et al., 2011). In the *RightTimePlaceCare* project, people with dementia categorised into mild dementia with a Mini-Mental State Examination score of 24–20; moderate dementia with a score of 19–10; and severe dementia with a score of 9 to 0. Each group was assessed for their ranges in symptom duration, hours of ADL care, hours of IADL care, and hours of supervision, in order to create data rules to apply to and categorise people with dementia from the present dataset. Further details on this categorisation process are published elsewhere (Giebel, Sutcliffe, & Challis, 2017).

Materials

Carers completed the *revised Interview for Deteriorations in Daily Living Activities in Dementia 2* (R-IDDD2), which assesses the initiative and performance of 17 and 20 daily activities, respectively. This scale is based on the original IDDD (Teunisse, Derix, & Derix, 1991), which has good psychometric properties but was argued to lack additional activities (Voigt-Radloff et al., 2012). Hence, the R-IDDD2 was designed in a two-step process (Giebel, Challis, & Montaldi, 2016; Giebel, Challis, & Montaldi, 2017), and was found to have high internal consistency for its initiative [basic ADLs $\alpha = 0.894$; IADLs $\alpha = 0.934$] and performance scale [basic ADLs $\alpha = 0.858$; IADLs $\alpha = 0.959$] (Giebel, Challis, & Montaldi, 2017).

Each activity can be rated on a scale from '0' (never any difficulties/lacking motivation) to '4' (always difficulties/lacking motivation). Each activity on the performance sub-scale comprises three sub-tasks, which can be rated using the same scale. The sub-tasks are to be completed if the overall activity (e.g. *finance management*) is rated between '1' and '4'. The total score for the two scales are derived from the number of completed activities.

For this investigation, only those complex IADLs were chosen which (a) were found to be linked very strongly to the person with dementia's quality of life (Giebel & Sutcliffe, 2018); (b) were found to deteriorate less than other IADLs (Giebel, Sutcliffe, & Challis, 2017); and (c) were considered feasible to address in both home care and nursing home settings, thereby excluding activities such as using the computer and driving. As a result, six activities were included: (1) engaging in social activities and maintaining an active social life; (2) cleaning; (3) preparing a hot drink, (4) shopping, (5) using the telephone, and (6) preparing a cold meal, so that the total score could range from 0 to 24.

Demographic characteristics on the PwD's and carer's age, gender, and ethnicity, dementia subtype, relationship with carer, time since first symptoms, time since caring, as well as hours of informal IADL care, informal ADL care, and supervision were also reported.

Procedure

Ethical approval was provided by the Bristol NRES Committee South West (Ref: 15/SW/0271). There were two different methods for completing the questionnaire. The primary strategy involved staff at 10 National Health Service Trusts across England distributing the questionnaire to interested carers, who could take the questionnaire home and return it completed via a free-post envelope. Staff approached carers at the memory clinic visit with their relative with dementia; at Trust dementia carer support groups; and telephoned those that did not come into the clinic. Each questionnaire had an ID from the individual Trust, so that the research team could inform the Trusts regularly about returned questionnaires. Those carers who had not returned the questionnaire after three weeks were followed up by staff via telephone. All Trusts also had access to the *JoinDementiaResearch* register of carers who were interested in taking part in research.

The secondary strategy involved a member of the research team (CG) attending six different culturally-mixed carer support groups across the North of England, at which carers completed the questionnaire. The groups lasted approximately one hour and written informed consent was obtained prior to completing the questionnaire.

Data analysis

Data were analysed using SPSS Version 24, and the significance level α was set at 0.05. Demographic characteristics and activity performances were analysed using frequency analysis. Linear regression analysis was performed to assess the contributions of hours of care on the level of functioning. For this purpose, 12 regression models were performed due to the collinearity of the two independent variables of hours of supervision and hours of IADL care. Each overall activity (making tea/coffee; shopping; using the telephone; preparing a cold meal; cleaning/doing house work; maintaining an active social life) was entered as the outcome variable in two regression models, with one model including hours of IADL care and dementia stage, and one model including hours of supervision and dementia stage as independent variables. Dementia stages

of moderate and severe dementia were clustered together, by computing a binary 'dementia stage' variable ('0' = mild; '1' = moderate/severe). This was due to the different samples sizes of mild ($n = 272$), moderate ($n = 170$), and severe ($n = 139$) dementia, in order to create two groups with a similar sample size. In addition, people with moderate and severe dementia get admitted into a care home due to their deteriorating symptomatology, so that this group is representative of people needing to access a care home. To account for multiple testing, a Bonferroni correction was calculated, by dividing the p value by 12. This resulted in a new significant value of $p \leq 0.004$.

Results

In total, 581 carers of people with dementia completed the survey, of which 272 were caring for a person with mild, 170 for a person with moderate, and 139 for a person with severe dementia, based on the specific categorisation criteria. Carers were on average 68 (± 11.5) years old, and primarily female (67.0%). People with dementia were on average 76 (± 8.5) years old, and primarily male (53.4%). The large majority of carers and PwD was white Caucasian (95.2% both). Carers were primarily spouses (75.9%) or adult children (19.8%) of the PwD, and 82.6 per cent were the sole carers. The number of hours carers spent assisting with ADLs [$F(2,565) = 262.502, p < .001$], with IADLs [$F(2,564) = 140.752, p < .001$], and supervising the PwD with daily activities [$F(2,549) = 371.341, p < .001$] was significantly higher in the moderate and severe group compared to the mild group, and higher in the severe vs. moderate group.

Subtask performances across dementia severity

Table 1 shows the proportion of people with mild, moderate, and severe dementia who were able to perform subtasks for preparing a hot drink, shopping, using the telephone, preparing a cold meal, cleaning and housework, and engaging in social activities and maintaining an active social life either with no assistance or seldom. Overall, the proportion of people being able to perform these sub-tasks deteriorated from mild to moderate to severe dementia, with preparing a hot drink and preparing a cold meal being the most well maintained IADLs at any stage of dementia.

Within each activity, certain sub-tasks were maintained better than others. For *making a hot drink*, more than half of the people with mild dementia were able to perform all subtasks, most of whom applied the correct order when preparing a hot drink and remembered that they had recently made a tea or coffee. Less than a quarter of people in the moderate stages were able to remember where things were stored, and there was little variation between subtasks in the severe stage.

For *going shopping*, around half of people with mild dementia could remember what they had placed in their trolley and could find their way around the supermarket without getting lost. In the moderate stages, not getting lost in the supermarket was the best maintained sub-task (30%), whilst there were no significant variations between subtasks in the severe stage.

Table 1. Subtask performances in mild, moderate, and severe dementia.

IADL	Subtasks	Mild dementia (n = 272)	Moderate dementia (n = 170)	Severe dementia (n = 139)
Preparing a hot drink	Remembering order of making a hot drink	160 (67.8%)	54 (34.6%)	20 (16.3%)
	Remembering where things are stored	144 (56.7%)	36 (23.5%)	16 (12.6%)
	Remembering having recently made a hot drink	150 (61.8%)	48 (32.7%)	20 (16.4%)
Shopping	Remembering what is already in the trolley	103 (50%)	30 (21.9%)	10 (9.4%)
	Not getting lost in the aisles	101 (49.2%)	40 (29.2%)	8 (7.2%)
	Remembering where items are in the shop	83 (38.3%)	25 (18.3%)	5 (5.5%)
Using the telephone	Not getting confused whilst calling someone	110 (49.3%)	31 (20.4%)	16 (13.3%)
	Not forgetting numbers previously known	76 (33.2%)	15 (8.7%)	8 (6.8%)
	No general difficulties	87 (34.6%)	20 (12.4%)	9 (7.2%)
Preparing a cold meal	Not only prepares very simple meals	137 (57.4%)	31 (22.4%)	17 (14.4%)
	Able to find items to prepare meal with	140 (62.0%)	37 (26.8%)	16 (13.5%)
	Correct order of meal preparation	155 (68.6%)	37 (27.0%)	17 (15.3%)
Cleaning/ house work	Washing up/cleaning as well as before	107 (45.4%)	32 (18.0%)	12 (10.2%)
	Setting the table correctly	132 (61.1%)	37 (25.3%)	16 (14.3%)
	Remembering it is time to do tasks	92 (41.8%)	27 (19.1%)	8 (12.6%)
Maintaining active social life/ Engaging in hobbies	Remembering what happened at last social event	58 (23.7%)	17 (11.5%)	5 (4.1%)
	Remembering key aspects of a hobby	85 (36.3%)	22 (15.5%)	11 (9.7%)
	Settling into a hobby	79 (31.7%)	25 (16.4%)	12 (9.7%)

Note: Displayed are percentage of people able to perform subtask within each severity group either without any difficulties or seldom with difficulties.

For *using the telephone*, the majority of people were able to hold a phone conversation without getting confused in the mild stages, which was the best maintained sub-task through the different severity stages.

For *preparing a cold meal*, the vast majority of people with mild dementia experienced no problems or seldom when performing this activity, and had particularly few problems with the order of the meal preparation. In moderate dementia, fewer people were able to prepare simple meals whilst relatively more of them were able to find items for meal preparation and ensure the correct order of tasks. Between 13 and 15% of people with severe dementia were still able to perform certain subtasks of cold meal preparation.

For *cleaning and doing house work*, over half of people with mild dementia were able to set the table correctly, which remained the best maintained subtask in moderate dementia also. Between 10 and 14% of people with severe dementia remained able to perform cleaning and household tasks, including washing up as well as before the dementia, and remembering it was time to do a task.

For *maintaining an active social life and engaging in hobbies*, more people were able to continue taking part in their hobbies across all three stages of dementia than remembering what happened at the last social event they attended. Besides *shopping*, *maintaining an active social life* represented the greatest difficulty for people with severe dementia, with only four to 10 per cent of people experiencing no difficulties or seldom, as reported by their carers.

Factors associated with IADL performance

Linear regression analyses showed that dementia stage was significantly related to all six IADLs (see Table 2). Taking into account the adjusted Bonferroni correction of $p < 0.004$, hours of IADL care was not found to be a significant predictor for any activity, whereas hours of supervision significantly predicted *preparing a hot drink* and *using the*

telephone. Going *shopping* almost reached statistical significance ($p = 0.006$). Dementia stage and hours of supervision explained consistently a slightly larger proportion of the variance of the six activities than regression models including hours of IADL care. Of all activities, *preparing a cold meal* and *making a hot drink* had the largest variance explained ($R^2 = .269$; $R^2 = .237$).

Discussion

This study focused on the remaining abilities of people with dementia, and not their difficulties, and is one of the first studies to show that people at different stages of dementia, including advanced dementia, are still able to perform certain daily activities and tasks. By exploring IADL performance in a more detailed fashion through the breakdown of individual activities, this study showed that people with dementia maintained certain subtasks better than others. For example, both in the earlier and in the more advanced stages, people with dementia showed remaining skills, such as knowing the correct order in which to make a hot drink as opposed to knowing where things are stored to prepare the hot drink. This suggests a greater need for actively supporting PwD with those subtasks they are still able to perform. In particular, considering a growing body of evidence showing that PwD are able to re-learn and maintain their daily functioning skills via occupational therapy and cognitive interventions (i.e. Graff et al., 2006; Voigt-Radloff et al., 2017), it is important to highlight those areas of maintained functioning, so that people with dementia can receive targeted support where required, and be encouraged to continue those tasks.

Comparing the effects of hours of IADL care and supervision on IADL performance for example by nursing staff supports the notion of helping and guiding PwD to complete an activity by themselves as opposed to simply but-tering a piece of toast for (and not with) them. To date, little research has addressed the benefits of supervision as

Table 2. Linear regression models exploring the impact of hours of care and dementia severity on functioning.

DV	IVs	Standardised β	R squared	P values
Preparing a hot drink	(1) H of IADL care (2) dementia stage	.056 .442	.219	.185 .000
Preparing a hot drink	(1) H of Supervision (2) dementia stage	.166 .365	.237	.001 .000
Shopping	(1) H of IADL care (2) dementia stage	.106 .339	.171	.051 .000
Shopping	(1) H of Supervision (2) dementia stage	.126 .358	.182	.006 .000
Telephone	(1) H of IADL care (2) dementia stage	.084 .418	.212	.046 .000
Telephone	(1) H of Supervision (2) dementia stage	.151 .364	.225	.002 .000
Cold meal	(1) H of IADL care (2) dementia stage	.050 .479	.253	.238 .000
Cold meal	(1) H of Supervision (2) dementia stage	.128 .428	.269	.010 .000
Cleaning/ house work	(1) H of IADL care (2) dementia stage	.047 .374	.157	.295 .000
Cleaning/ house work	(1) H of Supervision (2) dementia stage	.095 .348	.172	.069 .000
Active social life	(1) H of IADL care (2) dementia stage	.072 .280	.101	.112 .000
Active social life	(1) H of Supervision (2) dementia stage	.122 .248	.115	.022 .000

an alternative to direct care, whilst care in general focuses primarily on completing tasks for the person with dementia (den Ouden et al., 2015; den Ouden et al., 2017; Kuk, den Ouden, & Zijlstra, 2017). However, there is growing evidence on enabling people with dementia and older adults in performing activities, as opposed to completing activities for them (i.e. King, Parsons, Robinson, & Jorgensen, 2012; Resnick, Galik, Vigne, & Payne Carew, 2016). Recent research into breakfast activities in nursing homes has shown that staff are frequently completing activities (such as pouring a drink) for residents (den Ouden et al., 2017). However, staff should instead be more engaging with residents and thus increase their approach to supervising and guiding residents in doing activities themselves, where possible. This is supportive of the notion of Function Focused Care, which is grounded in the ethos of enabling nursing home residents to engage in activities rather than care staff performing the activities for them (Resnick, Galik, Gruber-Baldini, & Zimmerman, 2011; Resnick, Galik, & Boltz, 2013). Function Focused Care has been found to be successful in supporting residents with dementia in performing activities (Galik, Resnick, Hammersla, & Brightwater, 2014), which suggests that focusing on the remaining abilities of PwD is an important avenue to pursue. Considering the impact of deteriorating daily functioning on nursing home admission (Verbeek, 2015), it is important to support PwD at the earliest opportunity in the right way to stay independent for as long as possible.

Levels of support and supervision obviously vary between community- and nursing home-residing PwD. Whilst PwD still live in their own home, they are more independent and may require guidance and support for more complex activities, such as finance management or preparing a hot meal. Also, PwD may wish to be supported in more complex hobbies which may not be available in a nursing home setting, such as going to a pottery class or playing golf. Research by King et al. (2012) on restorative home care approaches further supports the benefits of re-enabling older adults, as their intervention showed significant improvements in quality of life compared to usual home care. In contrast, once the PwD moves into a nursing home, the ability to perform a range of IADLs will have deteriorated. Staff need to provide more full care with previously able IADLs, and shift their attention to provide supervision to IADLs which are still less affected and where PwD are still able to perform some parts of the activities, such as *making a hot drink* and *preparing a cold meal*, as this study shows. As observed by den Ouden et al. (2017), staff could for example encourage residents at breakfast

time to take slices of bread and show them where the butter and cheese are. If necessary, staff can show them how to hold utensils and perform the action for residents to replicate. In addition, staff can ensure that everything required for the activity is in plain view and reachable, so that this does not become a barrier. Small-scale, homelike residential facilities may be one way to promote staff in providing more supervisory and less full care to PwD, as these settings are also shown for residents to have higher levels of functioning than residents in standard nursing homes (Verbeek et al., 2012). For example, this setting could enable PwD better in continuing to go to the shop and buy small items. This would support PwD in engaging in active activities, such as going to the shop, whilst avoiding and reducing the amount of engaging in only passive activities, such as watching the television, for which PwD do not need to engage in any particular steps in order to perform the activity. Therefore, overall the focus of care in dementia needs to be placed on enabling PwD to perform an activity and making the activity as easy as possible.

One crucial feature of enabling people to continue maintaining their skillsets and performing I/ADLs throughout dementia, where possible, is the underlying motivation to engage in those activities (Hjelle, Tuntland, Forland, & Alvsvag, 2017; Jeon et al., 2018). These are individual and thus require a person-centred care approach (Ballard et al., 2018), which could be achieved for example with creating life stories (McKeown, Clarke, Ingleton, Ryan, & Repper, 2010). If PwD have never prepared a hot meal, then they are unlikely to pick this skill up post diagnosis. Different social activities however can be particularly tailored to an individual's preferences, so that supporting PwD to continue engaging with their hobby both in the community environment and in the nursing home setting can be beneficial to their well-being. Enabling PwD to engage in meaningful activities and staying active has been shown in a variety of studies to be linked to improved quality of life (Beerens et al., 2016; Fernandez-Mayoralas, Rojo-Perez, Martinez-Martin, Prieto-Flores, & Rodriguez-Blazquez, 2015). This is in line with the concept of social health in dementia as outlined by INTERDEM (2017), with having meaningful activities and remaining independent representing some of the cornerstones. Considering that maintaining and raising quality of life in dementia is one of the global priorities for dementia (Alzheimer's Disease International, 2016), supervising and enabling PwD to continue completing IADLs is one way of achieving this goal.

Limitations

This study has some limitations. Data on everyday functioning in this study were provided by informal carers, and thus by proxies. This may vary from self-reports by PwD, and also from direct observational performances. However, Rueda et al. (2015) showed that proxy reports of daily functioning were more associated with objective symptoms of the condition compared to self-reports. Dementia diagnosis was similarly provided by carers, but confirmed where possible after questionnaire completion with the relevant NHS Trust. For those carers completing the questionnaire in support groups, this was not possible, yet recruiting carers via support groups is a frequent recruitment method to overcome potential gatekeeping issues in NHS Trusts. Moreover, in this study, PwD were categorised based on their hours of care which were associated with their MMSE categorisation in a previous study, whilst no cognitive data were available such as the Clinical Dementia Rating Scale. Whilst this is a potential shortcoming, PwD were categorised into severity stages based on data from a previous large-scale European study, and two independent raters rated and discussed all severity stage allocations based on category rules obtained from the European study. It is also important to mention that whilst the tool used in this study, the R-IDDD 2, is novel and requires further validity and reliability testing, the R-IDDD2 has already been tested in a large sample of PwD in a previous study (Giebel, Challis, & Montaldi, 2016), and was found to have high internal consistency.

Conclusions

Findings from this study suggest the need for care staff, both in home care and in nursing home settings, to supervise and allow PwD to complete daily activities and sub-tasks that they are able to perform, as opposed to making a hot drink or doing housework for them. Whilst this study focused on community-residing PwD, there are implications also for care staff in nursing home settings and suggestions on how to change the provision of the fundamentals of care provided by nursing staff. Future research in this setting should establish the levels of remaining abilities in performing IADLs and ADLs, soon after admission, in case the care culture of performing tasks for residents increases the level of deterioration and thus reduces functioning and QoL.

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