Hierarchical decline of the initiative and performance of complex activities of daily living in dementia

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Abstract

OBJECTIVES: Whilst basic activities of daily living hierarchically decline in dementia, little is known about the decline of individual instrumental activities of daily living (IADLs). The objective of this study was to assess initiative and performance deficits in IADLs in dementia.

METHODS: 581 carers completed the *revised Interview for Deteriorations in Daily Living Activities in Dementia 2* to rate their relative's everyday functioning.

RESULTS: Initiating and performing IADLs deteriorated hierarchically, whilst people with dementia were consistently most impaired in initiating *using the computer* and *managing finances*. Initiating *preparing a cold or hot meal* and *managing finances* were more impaired than their performance, whilst performing *maintaining an active social life* for example were more impaired than their initiative.

CONCLUSION: Findings can help identify the severity of dementia by understanding deficits in initiative and performance. This study has implications for the development of targeted interventions depending on the stage of dementia.

Keywords: dementia; activities of daily living; carers

Word count: 3425

Introduction

Dementia affects 46 million people world-wide[1], around 850,000 in the UK alone[2]. In an ageing society, this number is rising, so that finding effective ways to manage the disease is an important element in national dementia strategies[3,4].

One primary symptom is increased dependency in everyday activities. Although both complex instrumental activities of daily living (IADLs) and basic ADLs deteriorate in the early stages of dementia, people with dementia (PwD) experience greater levels of deficits with IADLs early on[5,6]. The majority of research focuses on global impairment in performing IADLs or ADLs[7-10], although examining individual activities can provide a better overview of the hierarchy of decline[11,12], and help in targeting assistance to PwD with specific activities. Recently, new scales have been developed, such as the Amsterdam IADL scale[14] or the IADL Profile which can also be used in aging[15], and comprise a greater number of activities. Recent research based on the *Interview for Deteriorations of Daily Living Activities in Dementia* (IDDD)[16] has highlighted how individual activities are differentially impaired in mild dementia only[17,18]. Moreover, using the IDDD and its derivative, the revised IDDD2 (R-IDDD2), allows for another distinction across everyday activities, the comparison between initiating and performing an activity.

The investigation of initiative and performance deficits in dementia is limited. Previous evidence is inconclusive as to which stage of an activity shows greater deterioration, with mixed populations including mild to moderate dementia or solely mild dementia[16,17,19,20]. A recent study reported that people in the mild stage of dementia were poorer at initiating *cleaning, doing repair work,* and *preparing a hot or cold meal*, whilst being poorer at performing *dressing* and *following current affairs*[5]. In particular, *preparing a hot meal, using the computer,* and *finance and medication management* were most impaired. All these investigations were based on the Interview for Deteriorations in Daily Living Activities for Dementia (IDDD), or a more recent version, the revised IDDD2 (R-IDDD2). Considering the hierarchical decline of ADLs and IADLs[21], without any separation between the activity stages, there is a clear evidence gap as to how initiative deficits vary across mild, moderate, and severe dementia, and at what stage they start developing.

The primary aim of this study was to explore the level of initiative and performance decline of individual IADLs across the stages of dementia in a large national sample. Little evidence exists on impairments of individual activities, particularly IADLs, with even less information on activity initiative. Based on evidence from mild dementia, it is hypothesised that initiating and performing activities vary significantly for some activities, such as *following current affairs* or *preparing a hot or cold meal*, although this trend is hypothesised to become smaller in the advanced stages with little to no variation due to greater levels of overall impairment. Improved knowledge on initiative and performance deficits across mild, moderate, and severe dementia can highlight the point at which interventions should target individual activities in those different stages, and can thus improve the focus of non-pharmacological treatments.

Method

Participants and recruitment

Carers (18 years or older) of people at any stage and type of dementia living in the community were identified through memory clinics and community based mental health services at 10 NHS sites. The study was adopted onto the National Institute for Health Research portfolio and registered on the Join Dementia Research Network, (a UK-based research register for PwD, carers, and healthy volunteers to participate in dementia research), to increase access to eligible carers. Data were collected between October 2015 and May 2016. In addition, the researcher (CG) attended six ethnically-diverse carer groups across England.

Materials

Everyday functioning was assessed with the R-IDDD2[5]. The R-IDDD2 contains 17 initiative and 20 performance activities. Each activity can be rated on a scale from '0' to '4' (never; seldom; sometimes; often; always difficulties). On the performance scale, each impaired activity can be rated further based on three sub-tasks provided. For example, *using the telephone* can be broken down into 'confusion whilst calling someone', 'forgetting numbers previously known', and 'general difficulties using the telephone'. In addition, the R-IDDD2 contains questions about the duration of caring responsibility, in years and hours per day, as well as the duration of symptom presentation. This provides an estimate of the severity of dementia where no data are available on the PwD' level of cognitive functioning. The R-IDDD2 and its predecessor the IDDD are psychometrically sound[5,20].

Carer well-being was measured using the General Health Questionnaire 12 (GHQ-12)[22] and the Adult Carer Quality of Life Questionnaire (AC-QoL)[23]. The GHQ-12 measures recent psychological distress, which includes the ability to concentrate, confidence, and problem management. A maximum score of 36 can be obtained, with higher scores indicating greater psychological distress. The AC-QoL is a 40-item questionnaire that assesses eight areas of carer QoL, including support for caring, caring choice, and ability to care. Each item is rated as '*never*', '*some of the time'*, '*a lot of the time'* and '*always*' by the carer, which equates to a score of between '0' and '3' depending on the question. Higher scores indicate a higher QoL.

The QoL of PwD was measured using the Quality of Life in Alzheimer's Disease Proxy version (QoL-AD)[24]. The QoL-AD comprises 13 items including social relationships, finances and mood. A maximum score of 52 can be obtained, with higher scores indicating better QoL.

Procedure

Ethical approval was obtained through proportionate review by the Bristol NRES Committee South West (Ref: 15/SW/0271) prior to the study. Staff at the Trusts either distributed the questionnaire with a freepost return envelope to carers of PwD; or sent the questionnaire to the carers by post. If a pack

was not returned within three weeks, staff contacted the carers to see if they required any assistance in completing the questionnaire or to answer any questions they may have. If carers had mislaid the pack, staff would send out a replacement.

The second mechanism of recruitment was via six dementia carer support groups. Carers completed the questionnaire after their written informed consent was obtained by the researcher (CG). Questionnaire completion took approximately 20 to 30 minutes.

Data analysis

Demographic characteristics were collected, and general information, scores on well-being scales and initiative and performance ratings of individual activities were calculated. These were analysed separately for mild, moderate, and severe dementia, and for the overall sample.

The severity of dementia was determined using data from a previous large European study of the transition of PwD living in the community into long-term care facilities, the *RightTimePlaceCare* programme[25]. This data-set which comprised 1,223 cases, classified PwD into mild, moderate, and severe dementia based on their score on the Standardised Mini-Mental State Examination[26]. A score of 24 to 20 indicated mild dementia, 19-10 moderate, and 9 to 0 severe dementia. These cut points have been utilised in other literature[27]. Frequency analysis and ANOVA with Bonferroni posthoc correction were employed to measure the ranges and significant variations in: symptom duration; hours of ADL care, hours of IADL care, and supervision across dementia severity. Single linear regression analysis was performed to analyse the level at which the four stated variables predicted dementia severity. ANOVA with Bonferroni correction showed significant variations in the duration of symptoms between mild and severe cases ($F(2,819)=5.810$, $p<.05$); variations in hours of ADL care between all three stages ($F(2,1034)=33.456$, $p<.001$); variations in hours of IADL care between mild and severe and moderate and severe dementia ($F(2,1035)=10.114$, $p<.001$); and variations in hours of supervising the PwD between all three stages ($F(2,996)=19.405$, $p<.001$). Single regression analyses showed that all four variables independently significantly predicted dementia severity.

The resulting data rules by which cases in the present study were categorised into mild, moderate, and severe dementia were initially tested on 30 cases in the *RightTimePlaceCare* data set. Categorising PwD in the present study relied primarily on data provided on hours of care, and also on the duration of symptoms, since recent literature[28] shows a significant association between total caregiving time and dementia severity. Two researchers (CG, CS) independently rated all 604 cases of the present study, and those ratings were compared for inter-rater reliability using Cohen's[29] kappa statistic. Any disagreements were discussed and a second rating was conducted. Any remaining disagreements in ratings were resolved through discussion.

Cohen's kappa statistics indicated good agreement ($kappa=0.655$, $p<.001$) in the first, and very good agreement ($kappa=.849$, $p<.001$) in the second rating round between the two independent reviews of the dementia stage. The remaining discrepancies were resolved through discussion to achieve a complete agreement.

In the present data set, ANOVA, with Bonferroni post-hoc correction, was employed to analyse differences in the scores of the initiative and performance ratings, between the three cognitive stages of dementia. Paired samples t-tests were used to analyse within-group variations (mild, moderate, and severe dementia), in initiating and performing activities. The extent to which initiative deficits predict performance deficits was explored using linear regression modelling. Bivariate correlation analysis was used to calculate the associations between the GHQ-12, AC-QoL, and the QoL-AD with individual activities on the initiative and performance scales. Construct validity of the R-IDDD2 was calculated using Cronbach's alpha.

Where the total score for an activity was missing, but scores on one or all three sub-activities were available, the median of the sub-activity scores was calculated for the overall activity score. For hours caring for ADLs, IADLs, or supervising, a maximum of 16 hours per day were employed where carers stated 24-hour care. This procedure was also used in previous published studies[30]. Statistical significance was set at $p<.05$ across all tests. All analyses were performed using SPSS Version 22.

Results

Overall, 604 carers completed questionnaires. Of these, 45 questionnaires were obtained through attending carer support groups, with attendance ranging from five to 10 carers per group. Of those recruited via NHS Trusts, 213 (35 per cent) were recruited via the Join Dementia Research Network. Of the total sample, 23 cases were excluded due to missing data for symptom duration and/ or number of hours of care, resulting in 581 cases in total. Using the previously specified severity ratings, 272 cases were classified as mild dementia, 170 as moderate and 139 as severe dementia.

Table 1 shows the demographic characteristics of the sample. In the overall sample, the majority of carers were female and White Caucasian, spouses or adult children, and on average 68 (+/-11) years old. Carers tended to be the sole carers of the PwD and lived with them. The majority of PwD were male, White Caucasian, and on average 76 (+/-9) years old. The most prevalent type of dementia was Alzheimer's disease (52 per cent), followed by vascular dementia (14 per cent) and mixed dementia (16 per cent). On average, carers had noticed symptoms of the dementia for 4.4 (+/-3.0) years, whilst caring for the PwD for 2.9 (+/-2.4) years. Carers spent the majority of caring on supervising their relative with dementia.

ANOVA with Bonferroni correction indicated that carer age was significantly lower in mild and moderate compared to severe dementia ($F(2,577)=8.262$, $p<.001$). There were significantly fewer single carers in the mild dementia group than in the moderate and severe group ($\chi^2=52.770$, $p<.01$), and significant variations in the relationship with a larger proportion of children and fewer spouses caring for people with mild dementia ($\chi^2=24.267$, $p<.001$).

Carer distress was significantly lower in mild dementia compared to moderate and severe dementia ($F(2,568)=20.594$, $p<.001$). Carer QoL was significantly higher in mild dementia compared with moderate and severe dementia ($F(2,513)=12.315$, $p<.001$). PwD QoL was rated by carers as

significantly lower in severe dementia compared to mild and moderate dementia ($F(2,552)=15.414$, $p<.001$).

[INSERT HERE TABLE 1]

Impairments in initiating daily activities

Table 2 shows the level of impairment in initiating everyday activities across mild, moderate, and severe dementia. In mild dementia, the proportion of PwD impaired in initiating an activity (thus either scoring 1, 2, 3, or 4) ranged between 47 percent (*dressing*) and 92 per cent (*using the computer*). U*sing the computer* and *handling finances* were impaired to the largest extent both in the mean ratings and in the proportion of PwD impaired at this stage. Throughout the cognitive stages of dementia, these two activities remained amongst the most impaired activities. The ADL of *dressing* was the best preserved activity in mild, moderate, and severe dementia. At least 74 per cent of people with moderate dementia and 86 per cent with severe dementia experienced difficulties initiating any activity.

ANOVA with Bonferroni correction showed a significant gradual decline from mild compared to moderate and severe dementia for all activities except for *finance management*, which only significantly varied between the mild and moderate stage. For over half of the activities, PwD were poorer at initiating *washing oneself, dressing, brushing hair/teeth, shopping, preparing a cold meal, cleaning house/repair work, following familiar routes,* and *following current affairs* in the severe compared to the moderate stage. Figure 1 shows those activities that varied significantly across all three stages of dementia.

Single linear regression using the total sample (N=581) showed that initiative deficits predicted between 12 and 60 percent of variance in performance deficits.

[INSERT HERE TABLE 2 AND FIGURE 1]

Impairments in performing daily activities

Table 3 shows the level of performance deficits across dementia severity. The proportion of people impaired in the mild stages ranged from 45 to 90 per cent, whilst at least 69 and 84 per cent struggled performing any activity in the moderate and severe stages, respectively. *Using the computer, managing finances*, and *driving* were impaired to the greatest extent from the mild stage onwards. A large number of activities were often impaired, such as *maintaining an active social life*, *preparing hot meals, using the telephone,* and *managing medication or finances.*

ANOVA with Bonferroni post-hoc correction showed that people with mild dementia were significantly better at performing all activities compared to those in the moderate and severe stages. People with severe dementia were significantly poorer at performing over half of the activities than people with moderate dementia, including *washing oneself, preparing a hot drink, dressing, brushing hair/teeth, shopping, preparing a cold meal, cleaning/ repair work, maintaining an active social life, following familiar routes, recognising familiar faces,* and *monitoring own day*. Figure 2 shows those activities that varied significantly across all three stages of dementia.

Differences in initiating and performing everyday activities

In both mild and moderate dementia, paired samples t-tests showed that PwD were significantly poorer initiating *preparing a cold meal* (t_{mild}=4.719, p<.001; $t_{moderate}$=2.028, p<.05), *preparing a hot meal* (t_{mild}=4.509, p<.001; $t_{moderate}$=3.057, p<.01), *cleaning and doing repair work* (t_{mild}=4.077, p<.001; $t_{moderate}$=3.976, p<.001) and *finance management* (t_{mild}=3.129, p<.01; $t_{moderate}$=2.672, p<.01) than performing, whilst being significantly poorer at performing *dressing* (t_{mild}=-5.660, p<.001; $t_{moderate}$=-4.914, p<.001), *maintaining an active social life* (t_{mild}=-2.685, p<.01; $t_{moderate}$=-2.123, p<.01), and *following current affairs* (t_{mild}=-4.224, p<.001; $t_{moderate}$=-3.787, p<.001).

In severe dementia, PwD had significantly greater difficulty in initiating *finance management* (t=2.980, p<.01) and *driving* (t=2.249, p<.05) than performing these activities. They also experienced significantly greater difficulty performing *preparing a hot drink* (t=-1.992, p<.05), *dressing* (t=-5.123, p<.001), *washing/brushing hair or teeth* (t=-2.339, p<.05), and *maintaining an active social life* (t=-2.632, p<.05) than initiating these.

[INSERT HERE TABLE 3 AND FIGURE 2]

Scale attributes

The R-IDDD2 showed high construct validity for the Initiative ADL (Cronbach α=.913) and Initiative IADL (Cronbach α=.875) subscale, and high construct validity for the Performance ADL (Cronbach α=.904) and Performance IADL (Cronbach α=.941) subscale.

Discussion

This study is the first to highlight a hierarchical decline in the initiative and performance of IADLs in dementia, with findings based on a large representative sample of community-dwelling PwD. Previous research has shown how different basic ADLs deteriorate throughout the stages[11,17,21], with *bathing, dressing*, and *continence* for example deteriorating early on. Although IADLs are known to deteriorate largely in the early stages of the disease[31], comprehensive knowledge on the components of IADLs (initiative and performance) and their decline has been very limited to date[19,20,32,33].

This IADL hierarchy is particularly notable for its initiative decline. Previous studies have shown that initiating activities is impaired in dementia, yet to what extent it declines had to date not been explored[16,17,19,20]. Particularly in the early stages, initiating certain activities (i.e. *preparing a hot or cold meal, finance management*) was found to be more strongly impaired than their performance, with significantly greater disparity between initiative and performance in the mild stage compared to the moderate and severe stage. Considering that people in the severe stage still appear to experience stronger initiative than performance deficits for some tasks (i.e. *finance management*), this suggests that assessing the initiative to perform tasks remains an important factor in the assessment of everyday functioning in dementia. The R-IDDD2 employed for this analysis corroborates previous

reports of its good psychometric properties[5], and is thus a suitable tool for the comprehensive investigation of individual IADLs. Whilst rarely included in the assessment process, this study clearly highlights how initiative should be a vital component of this process.

The decline of initiative ratings throughout the course of dementia also offers suggestions for possible non-pharmacological treatments. Because variations between initiative and performance are evident across all three severity stages, interventions need to target each separately. Previous evidence failed to compare how both types of the activity process vary[20]. This study now clearly suggests though that even in the more advanced stages of dementia, PwD might benefit from receiving either support for improving their initiative or targeted training to help perform an activity. Considering that all PwD in this study still lived in the community, including those in the severe stages, offering suitable interventions to alleviate any initiative and performance difficulties can be important in delaying admission to a long-term care facility[34].

Lacking initiative to perform an activity can have several reasons, which are linked to how initiative might be improved. These include memory and executive function difficulties and more exogenous factors. In some cases, such as driving, PwD may have had to give up their licence due to difficulties in performance, which can be linked to deficits in executive function and visual attention[35], thus, they no longer initiate the activity. In other instances, PwD may forget that they should perform certain activities, such as doing the laundry or keeping an appointment. Deficits in memory and other types of cognition, such as executive function, are some of the primary symptoms of dementia[36,37], and so far only performing IADLs has been shown to be related to memory and other types of cognition[38]. If this is the reason for lacking the initiative to perform a task, providing memory aids offering cues could alleviate these difficulties. Moreover, for some PwD, depression may also affect their lack of initiative. With depression being a common comorbid disorder of dementia[39], treatments to help improve everyday functioning might need to consider avenues such as psychosocial therapy also in order to address depression as one of the possible causes of poor initiative. Whilst everyday activities can be influenced by a variety of comorbidities and other external factors, including physical limitations and environmental limitations[40,41], this mail out study already contained other questionnaires on carer and PwD well-being and quality of life. Therefore, no further questionnaires were included so as to not overburden the carer and to maximise the return rate. Indeed, all these factors may need to be considered when designing interventions to improve initiative.

In this study, dementia severity was based on a comprehensive method of analysis involving a large European data set for devising rules for classification into mild, moderate, and severe dementia. However, data were not collected on the level of cognitive functioning of the PwD, as carers would also not have been able to provide this information. This is a limitation of the study. With the range of some variables (years since symptom onset and daily hours of ADL and IADL care and supervision) overlapping in values between mild and moderate, and moderate and severe dementia, in some cases it was difficult to rate the levels of impairment and clearly distinguish between them. Using solely a cognitive tool for severity staging however might be limited and impractical for carers to self-complete, whilst using four variables on the level of care needs in the present study allows a more comprehensive classification. Thus, whilst having a clear cognitive score for each PwD would

have allowed for a more methodological method of severity staging, the rules devised from the European data set were as methodologically sound and tested.

Conclusions

In summary, this study indicates the utility of the R-IDDD2 in assessing everyday functioning across dementia stages. This tool can be of direct use in clinical practice in aiding early recognition of subtle symptoms in the mild stages of the condition, as well in severity staging. This is because the R-IDDD2 not only offers a very comprehensive breakdown of individual activities in their performance, but also considers the ability to initiate them. Improved recognition of dementia and thus improved diagnosis rates are central to governmental policies and worldwide initiatives[42,43]. Future work should further explore how the R-IDDD2 can help in the differential diagnosis of dementia subtypes, in addition to distinguishing between Alzheimer's disease, vascular, and mixed dementia[33]. Considering that different subtypes deteriorate at different speeds[44], it would be valuable to assess whether the same is the case for the initiative of daily activities.

Conflict of interest

None.

Description of authors' roles

C.G. designed the study, collected and analysed the data, and drafted the article. C.G. and C.S. rated the dementia cases for severity. C.S. and D.C. commented on versions of the article.

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