Taking a positive spin: Preserved initiative and performance of everyday activities across mild Alzheimer's, vascular, and mixed dementia

Clarissa M. Giebel^{1,*}, Alistair Burns², & David Challis³

¹ School of Health Sciences, University of East Anglia, Norwich, UK

² Institute of Brain, Behaviour and Mental Health, University of Manchester, Manchester, UK

³ Personal Social Services Research Unit, University of Manchester, Manchester, UK

**Correspondence should be addressed to:* Clarissa M. Giebel, PSSRU Manchester, 2nd Floor Crawford House, The University of Manchester, Booth Street East, Manchester, M13 9QS. Email: <u>clarissa.giebel@manchester.ac.uk</u>; Tel: +44 161 275 5652

Abstract

Objectives: The literature commonly evaluates those daily activities which are impaired in dementia. However, in the mild stages, people with dementia (PwD) are still able to initiate and perform many of those tasks. With a lack of research exploring variations between different dementia diagnoses, this study sought to investigate those daily activities with modest impairments in the mild stages, and how these compare between Alzheimer's disease (AD), vascular dementia (VaD) and mixed dementia.

Methods: Staff from memory assessment services from nine NHS Trusts across England identified and approached informal carers of people with mild dementia. Carers completed the newly revised Interview for Deteriorations in Daily Living Activities in Dementia 2 (R-IDDD2) assessing the PwD' initiative and performance of IADLs. Data were analysed using analysis of variance (ANOVA) and Chi-square tests to compare the maintenance of IADL functioning across AD, VaD, and mixed dementia.

Results: In total 160 carers returned the R-IDDD2, of which 109, 21, and 30 cared for someone with AD, VaD, and mixed dementia, respectively. There were significant variations across subtypes, with AD showing better preserved initiative, and performance, than VaD for several IADLs. Overall, PwD showed greater preservation of performance than initiative, with tasks such as preparing a hot drink and dressing being best maintained.

Conclusion: Findings can help classify dementia better into subtypes in order to receive bespoke support. It suggests that interventions should primarily address initiative to improve overall functioning.

Introduction

Alzheimer's disease is the most common form of dementia, and has a different symptomatology than other dementia subtypes, such as behavioural variant frontotemporal dementia (bvFTD) or vascular dementia (VaD). These profiles are better understood for some symptoms than others. However, improved knowledge of different symptom profiles can aid the diagnosis of dementia and classification into specific subtypes.

One symptom area with limited evidence available to differentiate for example AD from VaD is everyday functioning. Everyday functioning comprises complex instrumental activities of daily living (IADLs), such as telephoning and finance management, and more basic activities of daily living (ADLs), such as dressing and continence. From the early stages onwards, the ability to perform IADLs deteriorates to a greater extent than ADLs (Mioshi *et al.*, 2007; Pocnet *et al.*, 2013), whilst some ADLs deteriorate early on and some only in the later stages (Giebel *et al.*, 2015b). The extent to which individual activities deteriorate throughout the course of dementia has been largely neglected within research. Instead, the majority of studies tend to report on overall IADL or ADL impairment (Giebel *et al.*, 2015a; Nagaratnam *et al.*, 2013; Ryd *et al.*, 2015). Focusing on overall everyday functioning impairments only provides a limited picture of the needs and abilities of people with dementia (PwD) though.

Whilst there is limited evidence on individual activities across dementia, even fewer studies have compared the maintenance of individual IADLs and ADLs across dementia subtypes. Although AD is the most common form of dementia, many people receive a diagnosis of VaD. In some cases, people experience symptoms of

both subtypes, which is classed as mixed dementia (Langa *et al.*, 2004). Considering the inconsistent evidence as to variations in cognitive profiles of AD and VaD (Graham *et al.*, 2004; McGuinness *et al.*, 2010), with cognition being associated with everyday functioning performance (Brown *et al.*, 2011; Liu-Seiffert *et al.*, 2015), AD might have a different profile of IADL and ADL impairment than VaD. This is supported by recent research highlighting the differential decline of global IADL performance between VaD and AD pre-diagnosis (Verlinden *et al.*, 2015). However, there is also evidence to the contrary (i.e. Kim et al., 2003), as a recent review into everyday functioning found no significant variations in global IADL performance across AD, VaD and mixed dementia (Martyr & Clare, 2012). Thus, with limited evidence as to the IADL and ADL symptomatology of different dementia subtypes, despite a burgeoning area of research into how different subtypes affect carer wellbeing (i.e., D'Onofrio *et al.*, 2015), research needs to direct more attention to everyday functioning to aid the diagnostic process.

In addition to exploring the maintenance of individual IADLs across different subtypes, a further important level of analysis concerns the breakdown of activities into their different stages. Apathy, or the lack of motivation to engage in activities, is not only associated with, but also found to be predictive of developing, dementia (Fitts *et al.*, 2015; Richard *et al.*, 2012). Therefore, investigating IADL functioning separately for the initiative to perform, and the actual performance, arguably adds valuable insights into everyday functioning abilities. Some PwD may lack the initiative to engage in, but are fully capable to execute, a task. In this case, interventions focused on improving the performance of an activity would not be effective. Other PwD may struggle to carry out the activity, so that such interventions would more likely be effective. The few studies into initiative and performance in

dementia available are inconclusive as to which area is mostly preserved in the mild stages, which may be due to the mix of dementia types in the samples under investigation (Giebel *et al.*, 2014; Teunisse *et al.*, 1991; Voigt-Radloff *et al.*, 2012). To the best of our knowledge, no research has compared the initiative and performance of IADLs by subtype, so that this study will offer novel insights which could aid differential diagnoses.

The primary objective of this study was to take a different approach to the existing literature, which generally explores the deficits experienced as part of the disease. Instead, this study focused on those activities which remained primarily preserved in mild AD, VaD and mixed dementia. The second objective was to explore both the initiative and performance of individual activities across the three different subtypes. With contradictory evidence as to the variations in everyday functioning between AD and VaD, no clear hypothesis was made. Policy guidelines on dementia (DH, 2015) outline the importance of maintaining independent and avoiding institutionalisation for as long as possible. This can be achieved through understanding which IADLs are best preserved, and ensuring that these remain preserved for longer. Furthermore, improved knowledge of the everyday functioning profile of different subtypes can support the classification process.

Methods

Participants and recruitment

Ethical approval was obtained by the NRES Committee North West - Preston prior to the study. Carers were recruited from nine NHS trusts across England. Staff at memory clinics, as well as members from the Division 4 Greater Manchester NIHR

Clinical Research Network, identified suitable carers of people with mild dementia and distributes the questionnaire to them. Alternatively, carers were sent the questionnaire by post. Carers received a free return envelope to post back the questionnaire to the research team. Mild dementia was classed as having a Mini-Mental State Examination (MMSE; Folstein *et al.*, 1975) score of 21 or above (Earnst et al., 2001); a Montreal Cognitive Assessment (MoCA, Nasreddine et al., 2005) score of 15 or above (Vermeersch et al., 2015) or an equivalent score on the third version of the Addenbrooke's Cognitive Examination (ACE-III; Hsieh et al., 2013). A score of 65 or above on the ACE-III was considered to classify mild dementia. There was no specification of the type of dementia as an inclusion criterion. Data were collected from April 2014 to October 2015. For this study, only data from people with AD, VaD and mixed dementia were included. Subtype diagnosis was provided by family carers with tick boxes provided, although a reasonable attempt was made also in confirming the diagnoses. Because several carers were recruited via the Join Dementia Research Network, it was not possible to confirm the diagnoses of those PwD.

Measures

Revised Interview for Deterioration in Daily Living Activities in Dementia 2 (R-IDDD2) The R-IDDD2 is based on the original Interview for Deterioration in Daily Activities in Dementia (IDDD) (Teunisse *et al.*, 1991) and a further adapted version, the R-IDDD (Giebel *et al.*, 2014). The R-IDDD2 comprises several demographic questions (Carer age; PwD age; carer gender; PwD gender; dementia type; PwD medication; period of symptom presentation; period of caregiving duties; PwD living situation; sole carer status); one sub-scale on the initiative to perform daily activities; one sub-scale on the performance of daily activities; and an open-ended question on the most distressing activity impairment.

There are 17 items on the initiative scale and 20 on the performance scale. On both sub-scales (initiative and performance), carers can rate an activity from '0' (never lacking motivation/ never any difficulties) to '4' (always lacking motivation/ always some difficulties). Each activity on the performance sub-scale contains three further sub-activities, unlike other scales on everyday functioning (Gelinas *et al.*, 1999; Sikkes *et al.*, 2012). These sub-activities were based on qualitative data obtained from informal carers via semi-structured interviews (Giebel *et al.*, 2014). Only completed activities are counted towards a scale's total score, which is calculated as the percentage of dependency ranging from 0 to 100 percent.

The original IDDD has been found to be a valid and reliable measure of everyday functioning which was lacking further activities (Voigt-Radloff *et al.,* 2012).

Data analysis

Demographic characteristics and responses on the initiative and performance scales of the R-IDDD 2 were analysed using frequency analysis. Analysis of Variance (ANOVA) with Bonferroni correction at significance level p<.05 were used to compare continuous demographic characteristics across subtypes, and the means on the initiative items across AD, VaD and mixed dementia, and on the performance items across the three types of dementia. Chi-square tests were employed to compare categorical demographic characteristics across the subtypes, and the number of cases not impaired on initiative and performance items across the three subtypes. Where carers stated 'not applicable' for an activity, the activity was taken

out of the analysis and considered missing. This is because it was unclear whether the PwD had never been able to perform or interested in performing the activity, or whether the PwD had completely ceased to engage in this activity due to the dementia. Where carers entered scores on one or all three sub-categories of an activity but no total score, the median of the sub-category scores was calculated to represent the overall activity score. SPSS Version 22 was used for all data analysis.

Results

From a total sample of 183, data on 160 PwD were included for this analysis, of which 109 had AD, 21 VaD and 30 mixed dementia. Of the total sample, 23 were excluded for this analysis because of their different dementia subtypes, including Lewy Body and Parkinson's dementia. Table 1 shows the demographic characteristics of the carers and their PwD. In the final sample, carers were mostly female (74.2 percent), on average 66 (+/-11) years of age and primarily spouses. The majority of carers were the sole carers (81 percent) and 72.6 percent lived with the PwD. PwD were on average 77 (+/-9) years of age, and primarily male (45.0 percent). On average, carers reported that symptoms were present for 36.3 months (+/-27.6), whilst carers reported to have had to care for their relative for on average 25.7 months (+/-26.3). There were no significant variations in demographic characteristics across the subtypes. PwD age was significantly associated with Initiative_{Total} (r=.212, p=.007) and performance ratings for *cleaning/repair work* (r=.230, p=.005), maintaining active social life/engaging in hobbies (r=.216, p=.007), following familiar routes (r=.260, p=.001), and following current affairs (r=.208, p=.009) for the overall sample.

[insert here Table 1]

Initiating daily activities across dementia subtypes

Table 2 shows the level of ability and the number of PwD being able to initiate IADLs across AD, VaD and mixed dementia. In all three groups, the majority of PwD initiated *washing oneself, making a hot drink, dressing* and *brushing hair or teeth or shaving* with little to no difficulty, with more than half of the AD sample having preserved initiative. Initiating *using the computer* and *handling finances* were subject to the greatest levels of difficulty in AD, which was closely followed by lacking the initiative to *prepare a hot meal*. People with VaD were considered to lack initiative mostly with *driving, preparing a hot meal, handling finances,* and *cleaning or doing repair work*. People with mixed dementia were reported to mostly lack initiative to *handle finances, use the computer,* and *prepare a hot meal*.

When comparing all three dementia subtypes using ANOVA and Bonferroni post-hoc correction, people with AD were reported to express the least difficulties in initiating daily activities, which was statistically significant for *dressing* (p=.016); *brushing hair/teeth and shaving* (p=.034); *shopping* (p=.014); *preparing a cold meal* (p=.033); *following familiar routes* (p=.005); *following current affairs* (p=.004); and Initiative_{Total} (p=.007).

[insert here Table 2]

Performing daily activities across dementia subtypes

Table 3 shows the level of ability and the number of PwD being able to perform IADLs across AD, VaD and mixed dementia. Overall, PwD mostly performed *washing oneself, making a hot drink, dressing, brushing hair or teeth or shaving,* and

recognising familiar faces without or with little difficulty. People with AD and mixed dementia experienced most difficulties with using the computer and handling finances, with about 20 percent of PwD reported to have no problems. People with VaD were poorest on performing managing medication, engaging in social activities, and preparing a hot meal.

ANOVA with Bonferroni correction showed significant variations across AD, VaD, and mixed dementia in the performance of three activities. People with AD were significantly less impaired than people with VaD in *preparing a cold meal* (p=.005) and *following familiar routes* (p=.018). People with AD and mixed dementia were significantly less impaired than people with VaD in *recognising familiar faces* (p=.044). The Bonferroni correction was unable to distinguish the significant variations in performance between groups for *preparing a hot meal* (p=.062). All significant variations in the initiative and performance of activities across dementia subtypes are illustrated in Figure 1.

There were significant variations between initiative and performance of activities amongst dementia types. For AD, paired samples t-tests showed significantly better performance for *washing* [t(99)=2.149, p<.05]; *preparing a cold meal* [t(96)=2.970, p<.01]; *preparing a hot meal* [t(92)=4.688, p<.001]; *cleaning or doing housework* [t(98)=2.813, p<.01]; and *taking public transport* [t(79)=2.335, p<.05]; and significantly better initiative for *dressing* [t(102)=-3.312, p≤.001] and *following current affairs* [t(103)=-3.270, p≤.001]. For VaD and mixed dementia, paired samples t-tests showed significantly better performance for *cleaning or doing housework* [t_{VD}(19)=3.000, p<.01] [t_{mixedD}(27)=3.154, p<.01]. Overall, performance was better maintained than initiative.

[insert here Table 3 and Figure 1]

Discussion

This is the first study to have explored the initiation and performance of IADLs in people with mild AD, VaD and mixed dementia. With a lack of previous evidence on the preservation of initiative and performance of individual IADLs both in dementia, but specifically in AD, VaD, and mixed dementia, this study showed that AD shows a significantly better preserved functioning profile than VaD. In particular, it emerged that the majority of significant variations were noted between AD and VaD. This is perhaps understandable as mixed dementia contains elements of both AD and VaD, and is thus less likely to vary from either. The only exception was for the performance of *recognising familiar faces*, with both AD and mixed dementia being significantly more able than VaD.

One particular trend that emerged was that in all cases of significant variations, people with AD had higher preserved functioning. Little is known about the specific cognitive underpinnings of individual IADLs, as one contributor to everyday functioning besides physical limitations, depression, environmental limitations, visual perception, and severe hearing loss (den Ouden et al., 2012; Gitlin et al., 2005; Glosser et al., 2002; Gopinath et al., 2012; Knapskog et al., 2013), with a few exceptions (i.e. Brown *et al.*, 2011; Ramsden *et al.*, 2008). Hence, it is difficult to explore whether different levels of impaired cognition in AD and VaD are the result of these variations. The study did not collect any data on the precise levels of cognition, as this was a mail-out study and carers were referred if their relative scored in the mild dementia stage. PwD age also is unlikely to have contributed to these variations, as it was found to be associated with both initiative and

performance across the subtypes, thereby confirming previous evidence on factors potentially influencing informant ratings of everyday functioning (Martyr *et al.*, 2012). Despite the lack of comparable evidence, a recent study by Chiong *et al.* (2014) showed that people with AD were less impaired on finance management than people with bvFTD. This further supports the fact that people with AD appear to have better preserved functioning than other subtypes. Further research should explore these subtype variations on a larger scale and across all dementia subtypes.

Focusing less specifically on the diagnosis, findings of this study indicate greater preservation of the performance of activities than their initiative. This is the first study to show a clear trend in preservation, as previous evidence was inconclusive (Giebel *et al.*, 2014; Teunisse *et al.*, 1991; 1997; Voigt-Radloff *et al.*, 2012). Considering that all research and clinical evaluations of dementia (with a few exceptions) exclusively assess performance, it is unexpected to find another element of everyday functioning to be more impaired than the one under investigation. To accommodate these deficits and thus more strongly support the preserved abilities of PwD, it is critical to improve initiative in IADLs.

There were certain limitations to this study. First, the sample size of the VaD and mixed dementia groups were relatively small compared to the AD group. This was the result of opportunistic sampling, as the overall study addressed carers of people with any type of dementia, and the three types evaluated here were the most prevalent. Second, this study only takes into account proxy reports of IADL abilities. However, the majority of research into everyday functioning is based on proxy reports (e.g. Brown *et al.*,2011; Mioshi *et al.*,2007).Future research should investigate variations between self and proxy reports on this questionnaire. Regarding the questionnaire specifically, the newly designed R-IDDD2 requires

further reliability and validity assessments and to judge how it addressed the limitations of the original IDDD(Voigt-Radloff *et al.*, 2012).However, its greater comprehensiveness is evident in sub-activities for each performance activity (three for each activity), as well as additional activities, such as *following familiar routes* and *recognising familiar faces*, and modern activities neglected in many IADL questionnaires, such as *driving* and *computer use*. This clearly distinguishes the R-IDDD2 from other IADL scales, such as the Amsterdam IADL scale (Sikkes *et al.*, 2012). As noted earlier, independent confirmation of diagnosis was only possible for some cases. Lastly, this study did not collect any data on global cognition. Although all carers supported a person in the mild stage of dementia based on cognition scores known to staff, the analysis of the data would have benefited from further evaluating how cognition impacted on everyday functioning, as established in a myriad of studies and reviews (Giebel *et al.*,2014; Martyr &Clare,2012).

Conclusions

In conclusion, this study is the first to show significant variations in the initiation and performance of IADLs between AD, VaD, and mixed dementia. These findings can be useful in clinical practice, and help to better define the dementia subtype by taking into account specific IADL abilities and deficits. To date, a subtype diagnosis is primarily based on clinical history (such as strokes being linked to VaD (Leys *et al.,* 2005)) and brain imaging (O'Brien, 2014). The R-IDDD2 might therefore be a cost-effective measure to aid in this process. Future research ought to evaluate different subtypes such as bvFTD or Lewy Body dementia to develop a better symptom profile. Furthermore, future non-pharmacological interventions and occupational

therapy sessions to maintain everyday functioning could focus also on the initiative of activities, not only their performance. The better IADL and ADL abilities are maintained, the longer can the admission into a long-term care facility be avoided (Risco *et al.*, 2015).

Disclosure Statement

No potential conflict of interest was reported by the authors.

Funding

This article presents independent research supported by the National Institute for Health Research (NIHR), under its Programme Grants for Applied Research programme (Grant Reference Number: DTC-RP-PG-0311-12003), and forms part of the doctoral thesis of CG.

Acknowledgements

We wish to thank staff at the following NHS Trusts for their support in recruiting participants: Catherine Turton, Joanne Woodward at 5 Boroughs Partnership; Ritchard Ledgerd, Alexandra Feast, Charlotte Stoner, Dr Joanne Rodda at North East London; Paula Harman, Dr Farhad Huwez at Southend University Hospital; Joanne Tomkins, Laura Lord, Dr Tarik Qassem at Black Country Partnership; Olga Balazikova, Sarah Hamilton, Ramin Nilforooshan at Surrey and Borders Partnership; Lisa Wilkinson-Guy, Prof George Tadros at Heart of England; and Kim Thompson,

Leigh Franks, Dr Rashi Negi at South Staffordshire and Shropshire Healthcare. We also wish to thank Division 4 Greater Manchester NIHR Clinical Research Network for recruiting participants to this study through Manchester Mental Health and Social Care and Greater Manchester West NHS Trusts. Our thanks also extend to the *JoinDementiaResearch* Network for allowing us to recruit carers through their network.

Key Points

- Alzheimer's disease and vascular dementia have a different profile of everyday activity impairments
- Performing activities in Alzheimer's disease is better preserved than initiating activities
- Preparing a hot drink, dressing, and washing oneself are amongst the best preserved activities across mild Alzheimer's disease, vascular and mixed dementia

References

- Brown PJ, Devanand DP, Liu X, Caccappolo E. 2011. Functional impairment in elderly patients with mild cognitive impairment and mild Alzheimer disease. *Arch General Psychiatr* **86**(6):617-626.
- Chiong W, Hsu M, Wudka D, *et al.* 2014. Financial errors in dementia: Testing a neuroeconomic conceptual framework. *Neurocase* **20**(4):389-396.
- den Ouden MEM, Schuurmans MJ, Arts IEMA, van der Schouw YT. 2012. Association between physical performance characteristics and independence in activities of daily living in middle-aged and elderly men. *Geriatr Gerontol Int* **13**(2): 274-280.
- D'Onofrio G, Sancarlo D, Addante F, *et al.* 2015. Caregiver burden characterization in patients with Alzheimer's disease or vascular dementia. *Int J Geriatr Psychiatry* **30**(9):891-899.
- Fitts W, Weintraub D, Massimo L, *et al.* 2015. Caregiver report of apathy predicts dementia in Parkinson's disease. *Parkinsonism Related Disord* **21**(8):992-995.
- Gelinas I, Gauthier L, McIntyre M, Gauthier S. 1999. Development of a Functional Measure for Persons With Alzheimer's Disease: The Disability Assessment for Dementia. *Am J Occ Therapy* **53**: 471-481.
- Giebel CM, Challis D, Montaldi D. 2014. A revised Interview for Deterioration of Daily Activities in Dementia (R-IDDD) reveals the relationship between social activities and wellbeing. *Dementia doi:10.1177/1471301214553614*
- Giebel CM, Challis D, Montaldi D. 2015a. Understanding the Cognitive Underpinnings of Functional Impairments in Early Dementia: A Review. *Aging Ment Health* **19**(10): 859-875.
- Giebel CM, Sutcliffe C, Challis D. 2015b. Activities of Daily Living and Quality of Life across different Stages of Dementia: A UK Study. *Aging Ment Health* **19**(1):63-71.
- Gitlin LN, Hauck WW, Dennis MP, Winter L. 2005. Maintenance of Effects of the Home Environmental Skill-Building Program for Family Caregivers and Individuals With Alzheimer's Disease and Related Disorders. *J Gerontol Scie A: Biol Scie Med Scie* **60**(3): 368-374.
- Glosser G, Gallo J, Duda N, De Vries JJ, Clark CM, Grossman M. 2002. Visual perceptual functions predict instrumental activities of daily living in patients with dementia. *Neuropsychiatr Neuropsychol Behav Neurol* **15**(3): 198-206.
- Gopinath B, Schneider J, McMahon CM, Teber E, Leeder SR, Mitchell P. 2012. Severity of age-related hearing loss is associated with impaired activities of daily living. *Age Ageing* **41**(2): 195-200.
- Graham NL, Emery T, Hodges JR. 2004. Distinctive cognitive profiles in Alzheimer's disease and subcortical vascular dementia. *J Neurol Neurosurg Psychiatr* 75:61-71.
- Hsieh S, Schubert S, Hoon C, Mioshi E, Hodges JR. 2013. Validation of the Addenbrooke's Cognitive Examination III in Frontotemporal Dementia and Alzheimer's Disease. *Dement Geriatr Cogn Disord* **36**:242-250.
- Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. 1963. Studies of illness in the aged: The index of ADL: a standardized measure of biological and psychosocial function. *JAMA* **185**(12):914-919.
- Knapskog AB, Barca ML, Engedal K. 2013. Prevalence of depression among memory clinic patients as measured by the cornell scale of depression in Dementia. *Aging Ment Health* **18:** 579–587.

- Kim JM, Lyons D, Shin IS, Yoon JS. 2003. Differences in the behavioral and psychological symptoms between Alzheimer's disease and vascular dementia; are there different pharmacologic treatment strategies justifiable? *Human Psychopharmacol: Clin Exp* **18**(3): 215-220.
- Kipps CM, Mioshi E, Hodges JR. 2009. Emotion, social functioning and activities of daily living in frontotemporal dementia. *Neurocase* **15**(3):182-189.
- Langa KM, Foster NL, Larson EB. 2004. Mixed Dementia: Emerging Concepts and Therapeutic Implications. *JAMA* **292**(23):2901-2908.
- Lawton MP, Brody EM. 1969. Assessment of older people: Self-maintaining and instrumental activities of daily living. *Gerontologist* **9**(3):179-186.
- Leys D, He'non H, Mackowiak-Cordoliani MA, Pasquier F. 2005. Poststroke dementia. *Lancet Neurol* **4:** 752–759.
- Lima-Silva TB, Santoro Bahia V, Nitrini R, Sanches Yassuda M. 2013. Functional status in Behavioral Variant Frontotemporal Dementia: A Systematic Review. BioMed Research international, ID 837120, doi: 10.1155/2013/837120.
- Liu-Seiffert H, Siemers E, Sundell K, *et al.* 2015. Cognitive and Functional decline and Their Relationship in Patients with Mild Alzheimer's Dementia. *J Alz Dis* **43**:949-955.
- Martyr A, Clare L. 2012. Executive Function and Activities of Daily Living in Alzheimer's Disease: A Correlational Meta-Analysis. *Dement Geriatr Cogn Disord* **33**: 189-203.
- Martyr A, Clare L, Nelis SM, *et al.* 2012. Verbal Fluency and Awareness of Functional Deficits in Early-Stage Dementia. *Clin Neuropsychol* **26**(3): 501-519.
- McGuinness B, Barrett SL, Craig D, Lawson J, Passmore AP. 2010. Attention deficits in Alzheimer's disease and vascular dementia. *J Neurol Neurosurg Psychiatry* **81:** 157-159.
- Mioshi E, Kipps CM, Dawson K, Mitchell J, Graham, A, Hodges JR. 2007. Activities of daily living in frontotemporal dementia and Alzheimer disease. *Neurol* **68**(24):2077-2084.
- Nagaratnam N, Nagaratnam K, O'Mara D. 2013. Bayer activities of daily living scale in mild and moderate dementia of the Alzheimer type. *Am J Alz Dis Other Dem* **28:**784-789.
- O'Brien JT. 2014. Role of imaging in the diagnosis of dementia. *British J Radiol* **80**(special 2): doi:10.1259/bjr/33117326
- Pocnet C, Rossier J, Antonietti JP, von Gunten A. 2013. Personality features and and cognitive levels in patients at an early stage of Alzheimer's disease. *Personality Indiv Diff* **54**(2):174-179.
- Ramsden CM, Kinsella GJ, Ong B, Storey E. 2008. Performance of everyday actions in mild Alzheimer's disease. *Neuropsychol* **22**(1):17-26.
- Richard E, Schmand B, Eikelenboom P, *et al.* 2012. Symptoms of Apathy Are Associated with Progression from Mild Cognitive Impairment to Alzheimer's Disease in Non-Depressed Subjects. *Dement Geriatr Cogn Disord* **33**:204-209.
- Risco E, Cabrera E, Jolley D. *et al.* 2015. The association between physical dependency and the presence of neuropsychiatric symptoms, with the admission of people with dementia to a long-term care institution. *Int J Nursing Stud* **52**(5):980-987.
- Ryd C, Nygard L, Malinowsky C, et al. 2015. Associations between performance of activities of daily living and everyday technology use among older adults with

mild stage Alzheimer's disease or mild cognitive impairment. *Scandinavian J Occupational Therapy* **22**(1):33-42.

- Sikkes SAM, de Lange-de Klerk ESM, Pijnenburg YAL, *et al.* 2012. A new informantbased questionnaire for instrumental activities of daily living in dementia. *Alzheimer Dementia* **8**(6): 536-543.
- Sutcliffe CL, Giebel CM, Jolley D, Challis D. 2016. Experiences of burden in carers of people with dementia at the margins of long-term care. *Int J Geriatr Psychiatr* **31**(2): 101-108.
- Teunisse S, Derix MMA, van Crevel H. 1991. Assessing the severity of dementia. *Arch Neurol* **48**(3): 274-277.
- Verlinden VJA, van der Geesr JN, de Bruijn RFAG, *et al.* 2015. Trajectories of decline in cognition and daily functioning in preclinical dementia. *Alzheimers Dement,* doi: 10.1016/j.jalz.2015.08.001
- Vermeersch S, Gorus E, Cornelis E, De Vriendt P. 2015. An explorative study of the relationship between functional and cognitive decline in older persons with mild cognitive impairment and Alzheimer's disease. *Br J Occ Therapy* **78**(3):166-174.
- Voigt-Radloff S, Leonhart R, Schutzwohl M, et al. 2012. Interview for deterioration in daily living activities in dementia: Construct and concurrent validity in patients with mild to moderate dementia. Internat Psychogeriatr **24**:382–390.

	AD	VaD	Mixed	Total sample
	N=109	N=21	dementia	N= 160
			N=30	
Carer Age,	66.4 (11.0)	64.6 (9.3)	66.2 (12.8)	66.1 (11.1)
Mean (SD)				
PwD Age,	76.1 (8.8)	77.8 (12.8)	79.5 (7.6)	77.0 (9.2)
Mean (SD)				
Months of	34.6 (27.4)	40.1 (29.0)	39.4 (27.8)	36.3 (27.6)
symptoms,				
Mean (SD)				
Months of care,	24.0 (26.5)	33.1 (30.9)	26.6 (21.6)	25.7 (26.3)
Mean (SD)				
Carer Gender				
Female	80 (74.1)	15 (71.4)	23 (76.7)	118 (74.2)
PwD Gender				
Female	45 (41.3)	11 (52.4)	16 (53.3)	72 (45.0)
Relationship to				
PwD				
Spouse	78 (71.6)	13 (61.9)	18 (60.0)	109 (68.1)
Child	26 (23.9)	6 (28.6)	11 (36.7)	43 (26.9)
Other	5 (4.6)	2 (9.6)	1 (3.3)	8 (5.0)
Sole carer	87 (81.3)	16 (76.2)	25 (83.3)	128 (81.0)
PwD living				
situation				
At home	104 (97.2)	21 (100)	28 (93.3)	153 (96.8)
Living with PwD	79 (74.5)	16 (76.2)	19 (63.3)	114 (72.6)

Table 1. Demographic characteristics across dementia subtypes

AD=Alzheimer's disease; VaD=Vascular dementia; PwD=People with dementia

	AD		VaD		Mixed dementia		ANOVA
	Mean	N(%) not	Mean	N(%) not	Mean	N(%) not	F-Value (p)
	(SD)	impaired	(SD)	impaired	(SD)	impaired	
Washing oneself	1.0 (1.3)	59 (54.1)	1.6 (1.5)	6 (28.6)	1.0 (1.3)	6 (28.6)	2.131 (.122)
Making tea/coffee	1.1 (1.4)	8 (53.7)	1.9 (1.4)	4 (19.0)	1.3 (1.5)	4 919.0)	2.926 (.057)
Dressing	.8 (1.1)	62 (57.4)	1.6 (1.4)	6 (30.0)	1.0 (1.3)	6 (30.0)	4.091 (.019)
Brushing hair/teeth, shaving	.8 (1.1)	64 (58.7)	1.5 (1.5)	8 (38.1)	.9 (1.1)	8 (38.1)	3.314 (.039)
Shopping	1.9 (1.4)	25 (23.4)	2.9 (1.4)	2 (9.5)	2.0 (1.5)	2 (9.5)	4.184 (.017)
Using the telephone	2.0 (1.5)	27 (25.0)	2.6 (1.5)	3 (14.3)	2.0 (1.4)	3 (14.3)	1.451 (.237)
Using the computer	2.8 (1.6)	16 (19.3)	2.7 (1.7)	3 (25.0)	2.9 (1.4)	3 (25.0)	.089 (.915)
Preparing a cold meal	1.6 (1.5)	33 (31.4)	2.5 (1.4)	3 (15.0)	1.8 (1.4)	3 (15.0)	3.339 (.038)
Preparing a hot meal	2.4 (1.5)	17 (16.5)	3.3 (1.3)	2 (10.0)	2.6 (1.5)	2 (10.0)	2.856 (.061)
Cleaning house/ doing repair work	2.2 (1.5)	25 (23.4)	3.0 (1.3)	2 (9.5)	2.5 (1.5)	2 (9.5)	2.044 (.133)
Handling finances	2.7 (1.5)	17 (16.7)	3.1 (1.4)	2 (9.5)	3.1 (1.3)	2 (9.5)	1.066 (.347)
Medication management	2.1 (1.7)	34 (32.4)	2.9 (1.4)	2 (9.5)	2.4 (1.6)	2 (9.5)	2.397 (.094)
Driving	2.3 (1.8)	26 (30.6)	3.4 (1.3)	1 (9.1)	2.5 (1.8)	1 (9.1)	2.025 (.137)
Taking public transport	2.2 (1.7)	29 (31.5)	2.8 (1.6)	3 (18.8)	2.5 (1.7)	3 (18.80	1.069 (.347)
Maintaining active social life/ Engaging in hobbies	2.1 (1.4)	24 (22.4)	2.9 (1.5)	3 (14.3)	2.1 (1.4)	3 (14.3)	2.748 (.067)
Following familiar routes	1.6 (1.4)	33 (31.1)	2.7 (1.3)	2 (9.5)	1.8 (1.4)	2 (9.5)	5.165 (.007)
Following current affairs	1.8 (1.4)	28 (26.2)	2.8 (1.4)	1 (4.8)	1.9 (1.2)	1 (4.8)	5.398 (.005)
INITIATIVE Total	42.1 (24.8)		60.1 (24.8)		48.5 (22.5)		5.057 (.007)

Table 2. Initiative scores across dementia subtypes

AD=Alzheimer's disease; VaD= vascular dementia

There were several missing/non-applicable responses for *using the computer* (N=44), *driving* (N=49), *and taking public transport* (N=28). These were not counted.

	AD		VaD		Mixed dementia		ANOVA
	Mean	N(%) not	Mean	N(%) not	Mean	N(%) not	F-value (p)
	(SD)	impaired	(SD)	impaired	(SD)	impaired	u /
Washing oneself	.9 (1.2)	59 (59.0)	1.4 (1.5)	9 (42.9)	1.0 (1.3)	9 (42.9)	1.454 (.237)
Making tea/coffee	1.0 (1.3)	50 (50.0)	1.5 (1.5)	8 (40.0)	1.4 (.5)	8 (40.0)	1.270 (.284)
Dressing	1.1 (1.3)	50 (48.1)	1.3 (1.4)	8 (38.1)	1.2 (1.4)	8 (38.1)	.189 (.828)
Brushing hair/teeth, shaving	.8 (1.2)	63 (62.4)	1.1 (1.4)	11 (55.0)	.8 (1.1)	11 (55.0)	.476 (.622)
Shopping	1.9 (1.5)	28 (29.5)	2.4 (1.5)	3 (17.6)	2.2 (1.5)	3 (17.6)	1.106 (.334)
Using the telephone	1.9 (1.4)	25 (23.8)	2.3 (1.5)	4 (19.0)	2.2 (1.3)	4 (19.0)	.900 (.409)
Using the computer	2.6 (1.6)	15 (21.1)	2.0 (1.8)	4 (19.0)	3.1 (1.3)	4 (40.0)	1.505 (.227)
Preparing a cold meal	1.2 (1.3)	45 (45.0)	2.3 (1.6)	3 (15.8)	1.7 (1.5)	3 (15.8)	6.030 (.003)
Preparing a hot meal	1.8 (1.5)	28 (29.8)	2.8 (1.7)	3 (18.8)	2.2 (1.5)	3 (18.8)	3.256 (.042)
Cleaning house/ doing repair work	1.9 (1.5)	31 (30.7)	2.2 (1.7)	6 (30.0)	1.9 (1.6)	6 (30.0)	.231 (.794)
Handling finances	2.6 (1.6)	20 (19.6)	2.7 (1.6)	4 (21.1)	2.8 (1.3)	4 (21.1)	.302 (.740)
Medication management	2.2 (1.6)	25 (24.5)	3.0 (1.4)	2 (10.0)	2.3 (1.6)	2 (10.0)	2.083 (.128)
Driving	1.9 (1.8)	27 (38.0)	2.0 (1.8)	3 (30.0)	2.7 (1.6)	3 (30.0)	1.376 (.258)
Taking public transport	1.7 (1.7)	36 (42.9)	2.5 (1.8)	5 (29.4)	2.4 (1.7)	5 (29.4)	2.313 (.103)
Maintaining active social life/ Engaging in hobbies	2.2 (1.4)	20 (19.4)	2.9 (1.3)	2 (10.0)	2.3 (1.5)	2 (10.0)	2.367 (.097)
Following familiar routes	1.5 (1.4)	35 (34.3)	2.5 (1.5)	4 (19.0)	2.0 (1.6)	4 (19.0)	4.437 (.013)
Following current affairs	2.1 (1.4)	21 (20.0)	2.6 (1.3)	2 (9.5)	2.4 (1.4)	2 (9.5)	1.509 (.224)
Recognising familiar faces	1.0 (1.1)	49 (46.7)	1.7 (1.6)	6 (28.6)	.9 (1.1)	6 (28.6)	3.628 (.029)
Monitoring own day	2.0 (1.4)	22 (20.8)	2.7 91.4)	3 (14.3)	2.4 (1.3)	3 (14.3)	2.903 (.058)
Monitoring current activity	2.1 (1.3)	19 (17.9)	2.6 (1.4)	3 (14.3)	2.5 (1.2)	3 (14.3)	1.931 (.149)
PERFORMANCE Total	42.3 (26.0)		55.8 (29.3)		49.7 (25.0)		2.453 (.089)

Table 3. Performance scores across dementia subtypes

AD=Alzheimer's disease; VaD= vascular dementia

There were several missing/non-applicable responses for *using the computer* (N=60), *driving* (N=64), *and taking public transport* (N=37). These were not counted.

Figure 1. Key differences in initiative and performance across dementia subtypes





Bar charts indicate 1 standard deviation of error