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Cognition and activities of daily living in ageing and dementia

Anthony Martyr

Thesis submitted to the School of Psychology, Bangor University, in fulfilment of the requirements for the degree of Doctor of Philosophy

April 2013

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Summary

Background: Impairments in cognition and instrumental activities of daily living (iADL) increase the risk of developing dementia; therefore, it is vital to identify cognitive predictors of potential functional decline. It is unclear how aware older people and people with dementia (PwD) are of their iADL abilities, and there are concerns over the reliability of iADL ratings. This thesis will explore predictors of iADL and the accuracy of iADL ratings in healthy older people and PwD.

Method: A meta-analysis synthesised results of studies investigating the association between executive function and activities of daily living in PwD. Four empirical studies built on the meta-analysis by investigating predictors of iADL in healthy older people and PwD. Rating accuracy was investigated by comparing self-ratings with informant ratings and by comparing self-ratings and informant ratings with performance on an objective iADL measure.

Results: The Trail Making Test 4 predicted iADL in healthy older people whereas everyday memory predicted iADL in PwD. The Addenbrooke's Cognitive Examination-Revised (ACE-R) predicted iADL in both healthy older people and PwD. Healthy older people underestimated their functional ability whereas their informants were more accurate. PwD were able to accurately rate their iADL ability whereas informant ratings underestimated the functional ability of PwD.

Conclusions: The ACE-R may potentially help to identify older people at risk of developing functional dependence and to predict functional decline in PwD. Caution should be used when interpreting iADL ratings made by healthy older people as they may underestimate their ability. The finding that PwD were more able to accurately rate their iADL ability compared with their informants has important implications for the use of self-ratings and informant ratings of iADL in the dementia diagnostic process. The findings of the thesis have profound implications for the reliability of ratings of iADL made by healthy older people and PwD.

Chapter 1

Introduction

1.1 Introduction

Functional independence is an integral part of healthy ageing. The ability to safely and effectively perform complex activities of daily living, referred to as instrumental activities of daily living (iADL), becomes increasingly more difficult as people age (Béland & Zunzunegui, 1999; Hayase et al., 2004). As the global population continues to age (United Nations, 2002) there will be an increase in the number of people with age-related functional and cognitive impairments. The loss of functional independence has devastating effects on the well-being and the quality of life of older people (Covinsky et al., 2003; Mack, Salmoni, Viverais-Dressler, Porter, & Garg, 1997). Indeed, impaired everyday function and loss of independence increases the risk of institutionalisation (Jette, Branch, Sleeper, Feldman, & Sullivan, 1992), places a high burden on individuals and health care systems (Bianchetti, Frisoni, Ghisia, & Trabucchi, 1998; Rochat et al., 2010; Wiener & Tilly, 2002) and increases the risk of mortality (Guralnik, LaCroix, Branch, Kasl, & Wallace, 1991; Klijs, Mackenbach, & Kunst, 2010). It is therefore important to investigate how changes in everyday functional abilities affect older people.

As the number of people showing an age-related decline in iADL increases, the need for accurate ways of assessing functional ability becomes ever more important. Older people want to remain living in their own home and to be independent for as long as possible (Boaz, Hayden, & Bernard, 1999). However, from a societal perspective, the health and social care services required by older people with impaired functional ability will be a growing burden and a major concern for the 21st century (Beck & Stuck, 1996; Wiener & Tilly, 2002); already in 2010 older people accounted for 43% of the annual National Health Service budget (Centre for Workforce Intelligence, 2011). It is therefore vital to reduce demands on these limited resources and to enable and empower people to manage independently for longer.

The early identification of those at risk of functional disability has implications for the effective implementation of interventions (Galasko et al., 1997; Guralnik, Branch, Cummings, & Curb, 1989; Saliba et al., 2001). One way of identifying people at risk of functional dependence is to determine the mechanisms that lead to disability in older people. The risk of functional dependence is high in people with impaired cognitive functioning (Gill, Richardson, & Tinetti, 1995). For example, people with Mini-Mental State Examination (MMSE: Folstein, Folstein, & McHugh, 1975) scores between 24 and 27 were found to be

more likely to display functional dependence compared with those with MMSE scores between 28 and 30 (Greiner, Snowdon, & Schmitt, 1996). Intact executive function is also thought to increase the chances of remaining functionally independent (Grigsby, Kaye, Baxter, Shetterly, & Hamman, 1998; Grigsby, Kaye, & Robbins, 1995). A decline in functional ability is one of the first signs of incipient dementia (Galasko et al., 2006; Pérès et al., 2008) and a decline in executive function is commonly reported in ageing (Dempster, 1992) and dementia (Grober et al., 2008). Therefore, understanding which aspects of everyday functional ability are impaired in older people may help identify those at risk of developing dementia.

Dementia represents the extreme of cognitive ageing (Deary et al., 2009) and is associated with both cognitive and functional declines. Indeed, impairments in activities of daily living (ADL)[1] are present in all stages of dementia and as cognitive decline increases people with dementia (PwD) show evidence of concomitant difficulty with everyday functional abilities (Eisdorfer et al., 1992; Stuck et al., 1999). The majority (63.5%) of PwD still live in their own homes (Alzheimer's Society, 2007) and the ability to remain living in their own home is a common concern for PwD (Fukushima, Nagahata, Ishibashi, Takahashi, & Moriyama, 2005). However, estimates suggest that PwD become dependent in one functional ability each year (Farias et al., 2009) and the decline in ADL associated with dementia has been found to be the most troubling aspect of the disease for both PwD and carers due to increased dependency and the increased need for care (Desai, Grossberg, & Sheth, 2004; C. R. Green, Mohs, Schmeidler, Aryan, & Davis, 1993). Therefore, investigating the association between cognition and iADL in people with dementia has important implications for the independence and well-being of PwD.

There has been an increase in research investigating the association between executive function and iADL in older people and PwD. However, there are certain limitations in the literature. There are different methods of assessing iADL and it is not known whether findings from one method of assessing iADL can be extrapolated to another assessment method. For example, ratings made by a key informant, typically the spouse or adult child of the person with dementia, are the most commonly-used method, but despite their widespread use there is limited understanding of how informant ratings relate to actual performance. In

[1] Throughout the thesis the abbreviation 'ADL' is used to indicate when basic activities of daily living and instrumental activities of daily living are combined.

addition, self-ratings of iADL made by PwD are rarely taken, and it is therefore unclear whether PwD are able to give accurate ratings of their own everyday functional ability. Researchers have tended to use a relatively restricted range of executive function tests to assess the association with everyday functional ability, and this restricted range of tests may partly account for the consistently-reported association. Assessments of iADL in older people tend to involve hospital inpatients or other 'at risk' groups rather than healthy older people, and there is therefore a need to assess healthy older people to gain an understanding of normal functional ability.

The aim of this thesis is to extend our understanding of the association between functional ability and cognition in healthy older people and people with early-stage dementia. This will be achieved by comparing self-ratings with informant ratings and by exploring how self-ratings and informant ratings of everyday functional ability relate to scores on an objectively-assessed test of iADL, and by examining the association between iADL and cognition, with a particular focus on executive function.

The following sections will introduce background information relevant for the studies presented in this thesis. First, a definition of dementia will be given and the prevalence of dementia will be briefly summarised. Then, a brief description of the various commonly-used tests that have been employed to assess executive function in older people and PwD will be given. The different methods of assessing iADL will be discussed. Finally, research that has investigated the link between executive function and iADL in both healthy older people and PwD will be discussed. The research questions and methodology for this thesis will then be introduced followed by a summary of the content.

1.2 Definition and prevalence of dementia

Dementia is a common neurodegenerative disease associated with global cognitive decline and decline in activities of daily living. There are many different types of disorders grouped under the term dementia. Two commonly-diagnosed dementias are Alzheimer's disease and vascular dementia. A third category is that of a mixed pathology that has features of both Alzheimer's disease and vascular dementia. There are a number of other dementias such as Lewy body dementia, fronto-temporal dementia and its variants, Korsakoff's syndrome and

Creutzfeldt-Jakob disease and a range of less commonly diagnosed dementias. However, the term dementia is used in this thesis to refer to Alzheimer's disease, vascular dementia and a mixture of Alzheimer's disease and vascular dementia only.

Dementia primarily affects people over the age of 65, with the risk of developing dementia doubling every five years once people reach the age of 65 (Jorm & Jolley, 1998). Developing dementia below the age of 65 is rare, with incidence rates estimated as 54 per 100,000 for people aged between 30 and 64 (Harvey, Skelton-Robinson, & Rossor, 2003). With people over 65 forming an increasingly large segment of society the likelihood of being diagnosed with a dementia at age 65 is one in 100 and by the time someone reaches 80 years of age this incidence rate has increased to one in six (Alzheimer's Society, 2012).

In previous guidelines the upper age at which it was possible to diagnose dementia was arbitrarily set at 90 (e.g. McKhann et al., 1984); however, in recently updated guidelines (McKhann et al., 2011; NICE, 2006), this requirement has been removed in the light of increasing evidence that the dementia pathology is similar in those over and under 90 (McKhann et al., 2011). Once people reach the age of 90 the likelihood of being diagnosed with a dementia increases exponentially, with an incidence rate of 18.2% per year, while the incidence rate for people over the age of 100 is 40.7% per year (Corrada, Brookmeyer, Paganini-Hill, Berlau, & Kawas, 2010).

The number of people aged 80 and above is increasing rapidly (United Nations Population Fund and HelpAge International, 2012). Therefore, as the population ages the number of PwD is predicted to increase dramatically. Indeed, current estimates suggest that there are 800,000 people living with a dementia in the UK and this number is expected to increase to one million by 2021 and to 1.7 million by 2051 (Alzheimer's Society, 2012). Globally the number of people currently living with a dementia is 35.6 million and this is estimated to increase to 115.4 million people by 2050, with the largest increase seen in developing countries (Prince & Jackson, 2009). Therefore, dementia presents an increasingly significant global concern.

In dementia there is a gradual decline of cognition and the ability to perform ADL over several years, with crucial differences evident according to the severity of dementia. Dementia is typically stratified into three categories: mild, moderate and severe (National

Institute on Aging, 2012). People in the mild stage of dementia show some decline in memory and cognition and begin to develop everyday functional impairments but they are generally able to remain living relatively independently, though with an increasing need for supervision. In the moderate stage of dementia people tend to have more marked memory and cognitive impairments. For example, they may mistakenly recognise their grandchildren as their own children. They may also have difficulty with more basic activities of daily living such as dressing. People in the severe stage of dementia are often unable to recognise family members and will eventually be unable to walk or talk. Caregivers attend to even basic needs such as washing. Due to the cognitive and behavioural factors associated with the more severe stage of dementia, the PwD included in this thesis fall into the mild to moderate stages. For the purposes of this thesis, PwD with MMSE scores of 18 or above are judged to be in the mild to moderate stages of dementia.

1.3 Dementia and cognition

Dementia is a degenerative brain disorder which results in multiple cognitive impairments. The primary clinical feature of dementia is an impairment in learning and retaining new information, with specific difficulties evident in immediate recall of both verbal and non-verbal material (R. S. Wilson, Bacon, Fox, & Kaszniak, 1983). The first cognitive function to decline in dementia is immediate recall, with a rapid decline occurring around seven years before a diagnosis of dementia (Grober et al., 2008). Immediate recall has good specificity with regard to distinguishing PwD from healthy older people (Carlesimo, Perri, & Caltagirone, 2011). Delayed recall is also a good marker for dementia as it discriminates between PwD and healthy older people and typically shows an early floor effect in dementia (Locascio, Growdon, & Corkin, 1995; Oksengard et al., 2010). However, impairments in delayed recall are not unique to dementia; for example, attentional impairments in depression in older people often mimic the symptoms of dementia (Dubois et al., 2007), and therefore for an accurate diagnosis of dementia impairments in delayed recall need to be differentiated from similar difficulties found in other conditions. Indeed, for many years diagnosing dementia was often a process of excluding alternative disorders (Dubois et al., 2007).

Other cognitive impairments such as impaired executive function, impaired visuospatial abilities, impaired language and changes in personality or behaviour are required for a

diagnosis of dementia to be made (American Psychiatric Association, 1994; Dubois et al., 2007; McKhann et al., 2011; World Health Organization, 1992). Executive function is an umbrella term for a number of distinct high-level cognitive processes that control everyday actions and thoughts, including working memory, attentional control, planning, inhibition, rule discovery, set-shifting, updating or monitoring information and concept generation (Elliott, 2003; Jurado & Rosselli, 2007; Miyake et al., 2000; Royall et al., 2002). There is a large and growing body of research indicating that executive impairments are present even in the earliest stages of dementia (e.g. Bhutani, Montaldi, Brooks, & McCulloch, 1992; Broks et al., 1996; Collette, Van der Linden, & Salmon, 1999; Lafleche & Albert, 1995; Nathan, Wilkinson, Stammers, & Low, 2001). Indeed, longitudinal studies have shown that, after memory, executive function is typically the next cognitive impairment to appear, with a rapid decline beginning between two and three years before diagnosis (Amieva et al., 2005; Grober et al., 2008).

A number of researchers have investigated the prevalence of executive dysfunction in PwD. Swanberg, Tractenberg, Mohs, Thal, and Cummings (2004), using a letter cancellation task and maze performance, found that 64% of people with early Alzheimer's disease showed evidence of an executive dysfunction, though others with executive dysfunction may have been missed due to the narrow range of tests used to investigate executive function. Some researchers have found evidence that there may be a subgroup of PwD with a specific dysexecutive pattern of impairment (Back-Madruga et al., 2002; Binetti et al., 1996; Mez et al., 2013; Sahakian et al., 1990; Woodward, Brodaty, et al., 2010; Woodward, Jacova, et al., 2010) while others have proposed that executive dysfunction may be the core underlying impairment associated with dementia (Balota & Faust, 2001; Voss & Bullock, 2004). Therefore, the available evidence suggests that a significant proportion of PwD have discernible executive impairments.

There is a debate in the literature about whether executive function should be regarded as a single domain or a set of related but separate functions (e.g. Balota & Faust, 2001; de Frias, Dixon, & Strauss, 2006; Friedman et al., 2008; Hull, Martin, Beier, Lane, & Hamilton, 2008). Some have suggested that a single, unifying factor such as working memory, processing speed or general intelligence underlies the core processes of executive function (de Frias et al., 2006; Duncan, Emslie, Williams, Johnson, & Freer, 1996; Salthouse, 2005), while others propose that executive function is fractionated into various distinct subprocesses (Busch,

McBride, Curtiss, & Vanderploeg, 2005; Goldman-Rakic, 1996; Stuss & Alexander, 2007). The debate continues; however, in a highly influential paper, Miyake et al. (2000) studied three often-postulated aspects of executive function, and reported that set-shifting, updating and inhibition were found to be separable but moderately correlated constructs. This suggests that both unitary and non-unitary components form part of the executive function system. Executive function therefore may be "a unified system with multiple functions or an agglomeration of independent though interacting control processes" (Baddeley, 1996, p. 5).

1.4 Tests of executive function

Due to the often broad and vague definitions of executive function (see Salthouse, 2005, for discussion), a number of tests have been used to investigate executive function in ageing and dementia. Commonly-used tests of set-shifting include the Trail Making Test and the Wisconsin Card Sorting Test (Rabin, Barr, & Burton, 2005). The Trail Making Test consists of two parts. Part A requires participants to draw lines to connect numbers in ascending order; this is often purported to be a test of processing speed as well as a test of visual search. Part B is the main executive component, and contains a series of numbers and letters where participants are required to connect both numbers and letters alternately in ascending order. The Trail Making Test has been frequently used with healthy older people (e.g. Ashendorf et al., 2008; Hamdan & Hamdan, 2009; McDougall Jr., Becker, & Arheart, 2006; Tombaugh, 2004) and PwD (e.g. Back-Madruga et al., 2002; Hall, Vo, Johnson, Barber, & O'Bryant, 2011; Marshall et al., 2011; Willis et al., 1998). However, some authors have suggested that Part B may be too demanding for PwD, as many PwD are unable to complete the test within the time limit (Ashendorf et al., 2008; Chen, Sultzer, Hinkin, Mahler, & Cummings, 1998; Tomaszewski, 2000), or take an excessively long time to complete the test where no time-limit is imposed (Burdick et al., 2005), thus potentially reducing the set-shifting element and instead taxing the ability to remember the demands of the task.

Frequently used tests of inhibition include the Stroop test and the verbal fluency task (Rabin et al., 2005). The well-established Stroop test (1935) requires participants to identify the colour in which a word is printed. In the first part of the test colour words are presented congruently; for example, the word 'red' is printed in red ink. However, during the second part of the test colour words are printed in incongruent coloured ink and participants have to

inhibit their natural inclination to read the word and instead have to identify the colour in which the word is printed; i.e. if the word 'green' is printed in red ink the correct response is to say 'red'. Older people tend to be slower than younger people to respond to incongruent colour words on the Stroop test (see MacLeod, 1991, for a review). Similarly, PwD are often significantly slower to respond to incongruent colour words compared with normal controls (Amieva et al., 2002; Belleville, Rouleau, & Van der Linden, 2006; Koss, Ober, Delis, & Friedland, 1984; Perry & Hodges, 1999), though the effect has not always been found (Razani, Casas, et al., 2007). The verbal fluency task requires participants to generate words based on specific criteria, typically words beginning with the same initial letter (Letter Fluency) or words from the same category such as animals or boys' names (Semantic Fluency), within a set time limit. Verbal fluency is thought to involve the executive sub-domains of inhibition and initiation/response generation, in addition to language and semantic memory components (Jurado & Rosselli, 2007). Verbal fluency is frequently employed in the study of ageing with older people tending to produce fewer words and make more errors than younger people (McDowd et al., 2011; Meinzer et al., 2009; Tombaugh, Kozak, & Rees, 1999). Verbal fluency has been investigated extensively in the early stages of Alzheimer's disease, with a meta-analysis finding considerable Letter and Semantic Fluency impairments (Henry, Crawford, & Phillips, 2004). Letter Fluency is also frequently used as part of a diagnostic assessment, and has been recommended as a screening tool for dementia and a possible indicator of dementia severity (Hart, Smith, & Swash, 1988; Kitabayashi et al., 2001). Ecologically-valid tests of inhibition have been developed; one example is the second part of the Hayling Test (Burgess & Shallice, 1997) where participants have to respond with a word that makes no sense in the context of the sentence, rapidly inhibiting the tendency to respond with a word that makes sense. Ageing effects have been found, with older people being significantly slower than younger people in the time needed to complete the second part of the test, although for the number of errors produced the difference between younger and older people was not significant (Belleville et al., 2006). PwD have been found to make more errors and respond more slowly on the second part of the Hayling Test than older controls; indeed, in one study the authors reported that all participants with dementia except one were impaired on the second part of the test (Belleville et al., 2006), suggesting that it may be a useful assessment of inhibition. However, the test has so far not been widely adopted in studies with older people or PwD.

The ability to plan is an important component of executive function. However, planning is a more complex construct than set-shifting or inhibition (Miyake et al., 2000), and involves different processes such as sustained attention, abstract thinking, temporal sequencing, and reasoning (Kramer, 2010). A frequently employed test of planning is the Tower Test (Rabin et al., 2005), which is related to a number of similar tests such as the Tower of Hanoi, the Tower of London, Stockings of Cambridge, etc. The Tower Test requires participants to build a series of progressively more complex towers based on a predetermined design within a specific timeframe and within a set of rules. The Tower Test has been used less frequently than the Trail Making Test or Letter Fluency with healthy older people (e.g. Rönnlund, Lövdén, & Nilsson, 2001) and PwD (e.g. Beaunieux et al., 2012; Coubard et al., 2011; Razani, Casas, et al., 2007). Older people tend to take longer and make more errors than younger people in the Tower Test (Rönnlund et al., 2001). PwD tend to be slower than older controls in completing the task (Beaunieux et al., 2012; Coubard et al., 2011) yet require a similar number of moves to complete each tower (Beaunieux et al., 2012). However, others have found that PwD make significantly more moves but produce a similar number of errors to older controls (Razani, Casas, et al., 2007). An example of an ecologically-valid test of planning is the Zoo Map Test from the Behavioural Assessment of the Dysexecutive Syndrome (B. A. Wilson, Alderman, Burgess, Emslie, & Evans, 1996) which has been used in ageing (Allain et al., 2005) and dementia studies (Amanzio et al., 2013; Coubard et al., 2011; Espinosa et al., 2009). In this test participants are required to plan the most efficient route to visit a series of eight designated animal enclosures on a map of a zoo. Planning ability is only examined in the first part of the test, with the second part of the test assessing how well participants can follow instructions when the most efficient route is indicated to them. The Zoo Map Test has been suggested to be a valid test of planning in a heterogeneous neurological and psychiatric patient sample (Oosterman, Wijers, & Kessels, 2013). In one of the few studies to investigate ageing effects on the Zoo Map Test, older people tended to take longer to plan and draw the route and made more errors than younger people (Allain et al., 2005). A significant difference between older controls and PwD in the ability to successfully plan the route around the zoo has been reported (Espinosa et al., 2009), although when both parts of the test are used in combination PwD still show evidence of impairment (Amanzio et al., 2013; Coubard et al., 2011; da Costa Armentano, Porto, Nitrini, & Dozzi Brucki, 2013; Espinosa et al., 2009).

Therefore, older people tend to perform more poorly and make more errors than younger people in both traditional and ecologically-valid tests of executive function. Additionally, there is clear evidence that PwD show impairments on a number of tests that measure executive function.

1.5 Activities of daily living in older people

Activities of daily living are typically divided into two categories: 'basic' and 'instrumental' (Royall et al., 2007). Basic activities of daily living are self-maintenance skills such as bathing, toileting, feeding and dressing, which tend to be associated with impairments in motor functioning (Boyle, Cohen, Paul, Moser, & Gordon, 2002). In contrast, iADL involve more complex activities such as handling finances, shopping, using the telephone, and managing medication and tend to be more vulnerable to cognitive impairments (Njegovan, Hing, Mitchell, & Molnar, 2001).

There are typically four methods of investigating everyday functional ability: objective assessment measures, informant ratings, self-ratings and clinician ratings. There are advantages and disadvantages with each method. Objectively-assessed measures of everyday functioning are often assumed to be more reliable as they have greater face validity compared with questionnaire ratings (Guralnik et al., 1989) and they assess simulated performance of specific ADL rather than relying on the accuracy of ratings (Goldstein, McCue, Rogers, & Nussbaum, 1992; Vaughan & Giovanello, 2010; Zanetti, Bianchetti, & Trabucchi, 1995). However, objective assessment measures also tend to be administered in very structured settings, with little scope for self-initiated behaviour or multi-tasking, aspects of everyday life that are essential for independent living. Additionally, they are generally designed to assess the ability of a participant to undertake functional tasks in optimal conditions rather than assessing abilities in more naturalistic settings (Glass, 1998). Finally, a major limitation of objectively-assessed measures of functional ability is that there is limited evidence that they accurately measure real world performance or are able to predict functional independence (Moore, Palmer, Patterson, & Jeste, 2007).

Informant ratings of ADL involve using questionnaires to obtain ratings from key informants, typically spouses or adult children or close friends of the participant. Informant ratings take a few minutes to complete and give an approximate of how a participant will perform a task. In healthy older people self-ratings are more frequently employed than informant ratings as researchers assume that older people are able to accurately rate their own everyday functional ability. However, overestimation in self-reports is common in older people (Kempen, Steverink, Ormel, & Deeg, 1996; Sager et al., 1992; Vaughan & Giovanello, 2010; Willis, 1996) though evidence for this is mixed as some researchers have found good agreement between self-ratings and informant ratings (Galasko et al., 2006; Magaziner, Zimmerman, Gruber-Baldini, Hebel, & Fox, 1997). When compared with objectively-assessed performance, self-ratings of basic activities of daily living may be more accurate than informant ratings (Dorevitch et al., 1992). A study that combined basic and instrumental activities of daily living found that objectively-assessed performance correlated more strongly with informant ratings than with self-ratings (Little, Hemsley, Volans, & Bergmann, 1986), although another study found that, when compared with objectively-assessed performance, self-rated telephone use and walking ability were more accurate than informant ratings whereas there was no difference in accuracy for eating and dressing (Elam et al., 1991).

Finally, ratings made by clinicians or health care professionals are infrequently used in research and typically offer a subjective view of the everyday functional ability of older people from information offered in clinical interviews. In one of the few studies that has compared clinician ratings with objectively-assessed performance, clinician ratings of walking, transferring and using a telephone were found to be significantly less accurate than self-ratings made by a sample of older patients in a rehabilitation unit (Elam et al., 1991).

Typically, studies have tended to compare self-ratings and informant ratings of hospital inpatients (Dorevitch et al., 1992; Elam et al., 1991) or people in care homes (Little et al., 1986). Recently, however, self-ratings from community-dwelling samples have been employed and these studies have found evidence that older people overestimate their level of functional ability compared with objectively-assessed performance (Mitchell & Miller, 2008a; Suchy, Kraybill, & Franchow, 2011). Interestingly, overestimating functional ability was associated with poorer crystallised intelligence, whereas under-estimating functional ability was found to be associated with better executive function (Suchy et al., 2011).

There are questions concerning the accuracy of ratings made by healthy older people. Galasko et al. (2006) found that self-ratings made by healthy older people tend to be associated with increased age, with older people rating themselves slightly worse at iADL than younger people. Typically, accuracy of self-ratings or informant ratings in relation to objectively-assessed performance is determined by correlating scores on standard iADL questionnaires with scores from objective assessments of functional ability. Myers, Holliday, Harvey, and Hutchinson (1993) found that when the wording of questionnaires matched objective assessments there was good correspondence between performance and self-reported ability, suggesting that the often-reported discrepancy between ratings and objectively-assessed performance may be partly due to the questionnaires and assessment methods used. In a recent study, questions from a standard ADL questionnaire that matched objectively-assessed tasks were used, and the results indicated that informant ratings of ADL were more strongly correlated with objectively-assessed performance than self-ratings (Mitchell et al., 2011). Indeed, self-ratings were found to significantly overestimate functioning, suggesting that the accuracy of informant ratings, but not self-ratings, may improve when questionnaires are worded more similarly to objective functional assessments. However, the sample consisted of centenarians, so the findings may not be generalizable to other populations of older people. Additionally, the mean MMSE score suggests that the sample may have included some individuals with cognitive impairment. Therefore, the variability of results between different methods of investigating iADL and the accuracy of perceived functioning when compared with objective assessments are important factors to consider when investigating everyday functional ability in older people.

1.6 The relationship between cognition and activities of daily living in healthy older people

As declines in activities of daily living is a key diagnostic criterion in dementia, it is important to investigate iADL ability in healthy older people, especially as difficulties with iADL in older people may be a sign of early dementia (Pérès et al., 2008). It is therefore important to disentangle the effects of ageing from the effects of early dementia on the ability of older people to perform iADL. There is typically a relationship between increasing age and increased difficulty with everyday activities, with people over the age of 80 being particularly at risk of losing their independence due to impaired ADL (Royall et al., 2007). Therefore, if

incipient iADL difficulty can be identified this may enable older people to remain living independent for longer, thus increasing the well-being of older people, reducing potential caregiver burden and reducing the financial and social costs of health care provision (Beck & Stuck, 1996; Bell-McGinty, Podell, Franzen, Baird, & Williams, 2002). It is therefore important to investigate how changes in functional abilities affect older people as this may have implications for their ability to remain living independently and for their quality of life.

The everyday functional ability of older people is influenced by cognition (McDougall Jr., Becker, Vaughan, Acee, & Delville, 2010; McGuire, Ford, & Ajani, 2006; Njegovan et al., 2001). A comprehensive review article that included both healthy older people and PwD found that iADL are more strongly related to executive function than to memory, on average explaining at least three times as much of the variance in iADL (Royall et al., 2007). The Wisconsin Card Sorting Test has been shown to significantly predict objectively-assessed performance (Bell-McGinty et al., 2002) whereas Letter Fluency was found to predict informant ratings (Cahn-Weiner, Boyle, & Malloy, 2002). However, in older people the Trail Making Test-Part B has consistently been shown to be a strong predictor of objectively-assessed functional ability (Bell-McGinty et al., 2002; Cahn-Weiner et al., 2002; Mitchell & Miller, 2008b) and informant ratings (Cahn-Weiner et al., 2002), suggesting that set-switching may be an important predictor of functional ability in older people.

Royall et al. (2007) also found that when scores for cognitive screening tests, such as the MMSE or the Mattis Dementia Rating Scale (Jurica, Leitten, & Mattis, 2001; Mattis, 1988), were combined in the analysis this provided an even stronger correlate of iADL than executive function. A study by Baird, Podell, Lovell, and Bell-McGinty (2001) seemed to support this, as the Mattis Dementia Rating Scale predicted all but one of the subscales of an objectively-assessed performance measure whereas Letter Fluency and the Trail Making Test-Part B predicted only two of the subscales, and in both cases the Mattis Dementia Rating Scale accounted for a greater proportion of the variance in performance. This suggests that tests of cognitive screening may be better predictors of everyday functional ability than tests of executive function. However, there are some questions concerning the Baird et al. (2001) study as the sample was selected from people who had been assessed at a diagnostic clinic and hence may have included people with early-stage dementia, as suggested by the mean Mattis Dementia Rating Scale score which was below the cut-off for dementia by ten points. It therefore remains to be determined whether the relationship between cognitive screening

tests and everyday functional ability is stronger than the more frequently explored relationship between everyday functional ability and executive function in healthy older people.

1.7 Activities of daily living in people with dementia

As in healthy older people, there are four methods of assessing ADL in people with dementia. The majority of objective everyday functional assessments have been specifically designed to assess the functional ability of PwD (Moore et al., 2007), suggesting they are reliable in this population. However, they are often impractical in clinical settings due to the lengthy administration time (Moore et al., 2007) and the potential for participants to develop fatigue. Objective assessments are more frequently employed in research settings (see Cahn-Weiner, Ready, & Malloy, 2003; Farias, Harrell, Neumann, & Houtz, 2003; Loewenstein et al., 1992; Razani et al., 2011), although less frequently employed than ratings of iADL.

Informant ratings are the most frequently employed method of assessing ADL decline in dementia research and clinical settings (Sikkes, de Lange-de Klerk, Pijnenburg, Scheltens, & Uitdehaag, 2009), with the collection of informant ratings forming part of the dementia diagnostic process (McKhann et al., 2011). In both clinical and research settings informant ratings are nearly always treated as accurate (Smyth et al., 2002). There is, however, increasing evidence that informant ratings may be susceptible to biases; for example they may be influenced by the age and the cognitive status of the person with dementia (Teri, Borson, Kiyak, & Yamagishi, 1989), the perceived quality of the dyadic relationship (Quinn, Clare, & Woods, 2009), limited caregiving experiences (Richardson, Nadler, & Malloy, 1995), the self-rated depression of the carer (Argüelles, Loewenstein, Eisdorfer, & Argüelles, 2001), or the stress or burden of the person making the ratings (Mangone et al., 1993; Razani, Kakos, et al., 2007; Slachevsky et al., 2013; Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999). Even the level of education and executive function ability of an informant has been shown to influence his/her accuracy of rating the functional ability of a person with dementia (Dassel & Schmitt, 2008), similar to how in healthy older people overestimation and under-estimation of functional ability has been found to associate with poorer crystallised intelligence and better executive function, respectively (Suchy et al., 2011). There is also evidence that informant ratings are relatively unstable over a one-month period, and that this

is likely due to the context of caregiving, since older control participants did not show the same instability (Wadley, Harrell, & Marson, 2003). Consequently, despite their widespread use, informant ratings may not be accurate representations of functional ability, and this calls into question the appropriateness of relying on such ratings in clinical and research settings.

Self-ratings of everyday functional ability made by PwD are infrequently employed in research and clinical settings. They offer the same time-saving benefit as informant ratings while also drawing on the opinion and judgement of the person with dementia, a perspective that is commonly under-used. However, while it is important to elicit the self-rated perception of functioning from PwD, these ratings may also be subject to biases. Self-ratings made by PwD may be influenced by their level of awareness (Clare, Marková, Roth, & Morris, 2011), the disruption of their self-image due to increased feelings of dependency (Cotrell & Schulz, 1993), or cognitive impairment (Sager et al., 1992; Vasterling, Seltzer, Foss, & Vanderbrook, 1995). Self-ratings made by PwD often overestimate ability (Clare, Nelis, Martyr, Whitaker, et al., 2012; DeBettignies, Mahurin, & Pirozzolo, 1990; Kiyak, Teri, & Borson, 1994) and show relative instability over one-month periods (Wadley et al., 2003) which may explain their under-use in research and clinical settings. However, it should be noted that self-ratings are typically compared with informant ratings rather than actual performance, so that while PwD appear to overestimate their everyday functional ability compared with the parallel ratings made by informants, few studies have compared perceived ratings of functional ability with objectively-assessed performance.

Finally, ratings made by clinicians or health care professionals typically offer a subjective view of the everyday functional ability of a person with dementia. Some questionnaires have been designed for use by health care professionals wishing to observe ADL in care home or day care settings (Verhey et al., 2003), although these rating scales tend to be used in the assessment of people with more moderate or severe dementia. Similarly to self-ratings, clinician ratings are infrequently employed in research and often the ratings themselves are based on information offered in clinical interviews by both the person with dementia and the informant (Sabbagh et al., 2007; Willis et al., 1998). As the scores are elicited from the same information sources as self-ratings and informant ratings, and not based on observations of functioning, they are therefore open to the same kind of biases.

When self-ratings and informant ratings of functioning are compared, findings tend to show that informant ratings indicate the presence of significantly more functional impairments than self-ratings (Clare, Nelis, Martyr, Whitaker, et al., 2012; DeBettignies et al., 1990; Kiyak et al., 1994; Ott et al., 1996; Vasterling et al., 1995; Wadley et al., 2003). Most have taken this as evidence of a lack of awareness of functional difficulties in PwD (DeBettignies et al., 1990; Ott et al., 1996; Vasterling et al., 1995; Wadley et al., 2003), though two longitudinal studies have suggested that while self-ratings clearly indicated significantly fewer functional difficulties when compared with informant ratings, self-ratings also showed evidence of a decline in ADL, indicating that PwD were able to rate their functioning with reasonable accuracy (Clare, Nelis, Martyr, Whitaker, et al., 2012; Kiyak et al., 1994). Using frequency analysis, Smyth et al. (2002) reported good agreement between self-ratings and informant ratings for most ADL, with only balancing a chequebook showing disagreement; interestingly over half of the informants agreed that the PwD were not impaired for using a television, using a telephone book and making a telephone call. Howorth and Saper (2003) also found that two-thirds of their sample were rated as having good or only mildly impaired awareness of ADL ability. There is therefore equivocal evidence for a discrepancy between the ways in which PwD and their informants rate ADL, and where a discrepancy exists there is little evidence to clarify which rating is the most accurate.

The calculation of a discrepancy score is a frequently employed method of assessing awareness (DeBettignies et al., 1990). It has been suggested that this discrepancy score mitigates some of the biases associated with ratings of functioning. It has been widely used in assessing awareness in relation to neuropsychological function (Morris & Hannesdottir, 2004), but has been less extensively explored with ratings of everyday functioning. The discrepancy between self-ratings and informant ratings of everyday functioning increases as dementia severity increases (Dourado, Marinho, Soares, Engelhardt, & Laks, 2007; Sato et al., 2007; Starkstein, Jorge, Mizrahi, & Robinson, 2006), though it is not related to the age of the person with dementia (DeBettignies et al., 1990). Others have investigated the cognitive correlates of a functional ability discrepancy score. Ott et al. (1996) found that the Trail Making Test-Part A, the Mazes planning test and the memory discrepancy score, which is a score similar to the functional discrepancy score that is calculated by subtracting self-ratings of memory ability from informant ratings of memory ability, were significantly associated with the discrepancy between self-rated and informant-rated everyday functioning. A recent study reported that a discrepancy score for functional ability was correlated with memory

discrepancy, Letter Fluency, self-reported anxiety, informant-rated psychiatric symptoms and informant-rated psychiatric symptom severity (Clare, Nelis, Martyr, Roberts, et al., 2012), which suggests that an awareness of everyday functional ability may be related to an awareness of memory functioning. Therefore, self-ratings of functioning made by PwD may be a useful measure to gauge current function, and when used in combination with informant ratings can be used to calculate a discrepancy score.

Other methods of investigating awareness include performance monitoring, where participants make subjective evaluations of their performance before and after test completion, and error monitoring, where participants are assessed on their ability to detect and correct any errors that they make during task performance (Clare, Marková, et al., 2011). Compared with the use of informant ratings, both methods are less frequently employed when assessing the everyday functional ability of PwD, though memory performance monitoring has been used previously with PwD (Clare, Whitaker, & Nelis, 2010; Clare et al., 2013; Clare, Wilson, Carter, Roth, & Hodges, 2002). Error monitoring studies in PwD have found that Letter Fluency, naming ability and Clock Drawing Test scores are associated with awareness of everyday functional errors on an objective assessment (Bettcher, Giovannetti, Macmullen, & Libon, 2008; Giovannetti et al., 2008), suggesting that initiation and language ability may be useful for error monitoring. It remains, however, an unresolved issue as to whether performance monitoring is also linked to awareness of iADL ability. Studies have reported that self-ratings made before an everyday memory task show evidence of greater discrepancy compared with self-ratings made after performing an everyday memory task (Clare, Whitaker, et al., 2010) and both have been found to differ from actual everyday memory performance (Clare et al., 2013); indeed, carers of PwD were found to overestimate their own memory before task completion but were more accurate after task completion, suggesting that both controls and PwD overestimated their own memory ability but controls were able to more accurately modify their post-test ratings (Clare et al., 2013). It is unclear whether this dissociation may also extend to judgements of functional ability.

1.8 The relationship between cognition and activities of daily living in people with dementia

A growing number of studies have investigated the link between cognition and ADL in people with dementia. Clearly, impairments in areas such as memory, planning, organisation, and awareness of problems may have a negative impact on daily functioning. Studies investigating the association between memory and ADL have found that in people diagnosed with mild cognitive impairment, often considered to be a prodromal stage of dementia (Petersen, 2004), only a test of immediate memory correlated with informant-rated ADL (Jefferson et al., 2008), whereas in mixed samples of older patients, including some PwD, memory was found to correlate with both objectively-assessed functional performance (Goldstein et al., 1992; McCue, Rogers, & Goldstein, 1990) and informant-rated functioning (Richardson et al., 1995). In people with dementia Breen, Larson, Reifler, Vitaliano, and Lawrence (1984) found that memory was a strong correlate of informant-rated ADL, but when entered into a regression it was not statistically significant, which may have been partly due to the small sample size. Studies investigating the association between executive function and iADL have found that those with impaired executive function tend to display greater functional difficulties on an objectively-assessed measure of iADL (Pereira, Yassuda, Oliveira, & Forlenza, 2008; Razani et al., 2011) or on ratings of functional ability made by informants (Chen et al., 1998; Monaci & Morris, 2012). Therefore, memory and executive function show evidence of being good correlates of iADL in people with dementia.

Studies that have assessed different cognitive functions in combination have found similar findings. Executive function, visual perception and immediate memory have all been found to correlate with informant-rated iADL (Cahn-Weiner et al., 2003; Farias et al., 2003; Hall et al., 2011; Hill, Backman, & Fratiglioni, 1995; Razani, Casas, et al., 2007) and objectively-assessed iADL performance (Farias et al., 2003; Razani, Casas, et al., 2007). None of these studies found evidence for an association between test scores for delayed memory or attention and iADL. There was mixed evidence for an association between tests of language and informant-rated iADL as in one study iADL ratings were significantly correlated (Farias et al., 2003) whereas in others iADL ratings were not significantly correlated with language (Cahn-Weiner et al., 2003; Hall et al., 2011). A recent five-year longitudinal study found that composite scores for memory and executive function were independently associated with informant-rated iADL, with each appearing to affect different aspects of iADL (Farias et al.,

2009). It appears therefore that for PwD there is no evidence that delayed memory and attention predict ratings of functional ability, whereas scores on tests of executive function, immediate memory and possibly language may be important predictors of functional ability.

1.9 Aims of the thesis and research questions

The aim of the thesis is to explore the relationship between, and relative accuracy of, objective assessments of functional ability and ratings of perceived functioning, and to examine how both functional ability and ratings of perceived functioning associate with tests of executive function, memory and general cognition, in healthy older people and people with dementia.

The following research questions are addressed in this thesis:

1) What is the relationship between different tests of executive function and different methods of assessing activities of daily living in people with dementia?
2) Which cognitive screening tests or tests of executive function best predict ability to perform instrumental activities of daily living in healthy older people?
3) How accurate are ratings of instrumental activities of daily living made by healthy older people when compared with an objective assessment?
4) Which tests of cognition best predict ability to perform instrumental activities of daily living in people with dementia?
5) How accurate are ratings of instrumental activities of daily living made by people with dementia and their informants when compared with an objective assessment?

1.10 Research methodology

In this section, the design and methodology of the studies presented in this thesis will be briefly described and the procedures for recruiting study participants will be outlined. Firstly, the methods used to address each of the research questions posed in this thesis will be summarised.

Research question 1 is addressed by collating data from studies that investigated executive function and activities of daily living in people with dementia and conducting a meta-analysis.

Research questions 2 and 3 are addressed with newly-collected cross-sectional data from a sample of healthy older people. Research question 2 investigates the association between executive function and cognitive screening tests in healthy older people. Research question 3 investigates rating accuracy in healthy older people.

Research question 4 builds on the findings of the meta-analysis and is addressed using data from two cross-sectional studies. One source was cross-sectional data from the baseline dataset of a previously completed 3-year longitudinal research study, the Memory Impairment and Dementia Awareness Study (MIDAS), funded by the Economic and Social Research Council (RES-062-23-0371). I worked together with Research Officer Dr Sharon Nelis to collect the data for this project, assessing participating PwD and carers over a three-year period. The other source was data collected in a cross-sectional study designed for this thesis. This study involved collecting data from people with dementia and a key informant over a two-year period.

Research question 5 extends the findings from the meta-analysis and the findings from research question 3 by addressing the accuracy of different methods of assessing everyday functional ability in PwD. Both analysis of newly-collected data and secondary analysis of existing data, from the sources described above under research question 4, were used to address this research question.

1.10.1 Ethical approvals

For the studies addressing research questions 2 and 3, ethical approval was obtained from the Bangor University School of Psychology Ethics Committee, details of which are found in Appendix A. For research questions 4 and 5 ethical approval was obtained from the Bangor University and National Health Service ethics committees. For the new data collected for the studies of PwD conducted for this thesis, details of the Ethical approval are found in Appendix B. Ethical approval for MIDAS was obtained by Professor Linda Clare using the

same procedures. All participants provided written informed consent (see Participant Information Sheets and Consent Forms in Appendices C-I).

1.10.2 Participant recruitment

Data for the study of healthy older people (research questions 2 and 3) were collected partly by me and partly by a group of MSc students carrying out their master's research project; the study included a small number of additional measures not presented in this thesis. Fifty-nine healthy older people were recruited for the study from local AgeWell centres, church groups and social clubs, and through local contacts and word of mouth. Data were collected in a single visit. I devised the assessment battery for the master's project, managed the dataset and contributed to the overall supervision of the students. I also instructed the students in how to administer the assessments.

Potential participants with dementia were identified through eight memory clinics in North Wales. This process was the same for both MIDAS and the empirical data collection for the PhD study, unless stated otherwise. To be included, participants had to have a diagnosis of probable or possible Alzheimer's disease, multi-infarct or subcortical vascular dementia or mixed Alzheimer's disease and vascular dementia (ICD-10, World Health Organization, 1992), a score of 18 or above on the MMSE, the ability to communicate verbally in English and a contributing informant; informants were typically spouses or adult children, though friends also provided ratings in some cases. Occasionally, other family members provided informant data in MIDAS. Exclusion criteria were concurrent major depression, psychosis or neurological disorder and past history of neurological disorder or brain injury. Potential participants were approached by staff members at the memory clinics, directly by me (and/or by Dr Nelis for MIDAS) at three of the eight memory clinics, or by staff members of the National Institute for Social Care and Health Research Clinical Research Collaboration (NISCHR-CRC); these staff are specifically employed by the National Health Service to support identification and recruitment of research participants by both screening medical notes at memory clinics and conducting face-to-face recruitment interviews with PwD and their carers. In addition, some participants were recruited from the NEURODEM research register and some were invited to take part upon completion of their involvement in other research projects.

The MIDAS sample consisted of 101 people with dementia and their caregivers who met the inclusion criteria for the study and agreed to take part (research questions 4 and 5). They were recruited over an 18-month time period. The study was devised to assess awareness of dementia over time in PwD. Participants were seen over three time points. For the baseline data the assessments for the study typically took two or three visits to complete. For the two follow-up visits, approximately 11 months and 20 months after baseline, assessments typically took one or two visits. Only baseline data are included in this thesis.

Over the two-year recruitment period for the empirical research study (research questions 4 and 5), 37 people with dementia met the inclusion criteria for the study and agreed to take part. The assessments for the study typically took two or three visits to complete.

1.11 Structure of the thesis

Following this introductory chapter, one chapter will outline a meta-analysis, two chapters will report findings from secondary analysis of an existing dataset and two chapters will report findings from two separate empirical studies, one study with healthy older people and one study with PwD. In the final discussion chapter the findings from all the preceding chapters will be summarised and discussed. The meta-analysis and empirical chapters are presented in the format of journal articles. The meta-analysis (Chapter 2) and the first secondary analysis chapter (Chapter 4) have been published in peer-reviewed academic journals. The remaining secondary analysis chapter has been submitted for publication in a peer-reviewed academic journal. The main findings of the empirical studies with healthy older people and PwD were described in Chapters 3 and 6 respectively and will be prepared for publication subsequent to the submission of this thesis. See below for details of where the articles have been published.

As the chapters investigate the same research area, often using the same assessment measures, there will be some duplication in the introduction and method sections of the individual chapters. The following is a summary of the content of each chapter:

Chapter 2 - Executive function and activities of daily living in Alzheimer's disease: a correlational meta-analysis

Chapter 2 presents the results of a systematic meta-analysis of published research studies that have investigated the association between executive function and ADL in people diagnosed with Alzheimer's disease. Where studies included people diagnosed with other dementias these data were not excluded from the meta-analysis, though the majority of the studies and the majority of the participants included only people diagnosed with Alzheimer's disease. The meta-analysis provides a statistical overview of the estimated effect size for the association between different tests of executive function and ADL in people with Alzheimer's disease. The meta-analysis also examines each of the four different assessment methods employed to assess ADL and how they are associated with executive function. An estimated effect size was additionally calculated for the association between executive function and driving ability. The meta-analysis synthesises data from 21 commonly-used tests of executive function and working memory drawn from 49 studies, and reveals a consistent moderate association between executive function and ADL.

Chapter 3 - Predictors of objectively-assessed, self-rated and informant-rated ability in instrumental activities of daily living in community-dwelling older people: associations with executive function and cognitive screening measures

Chapter 3 presents findings from an evaluation of awareness of functional ability in 59 healthy older people. The majority of the participants were married couples, with each member of the couple both giving self-ratings and acting as an informant for the other. Participants completed an objective functional assessment and a battery of executive function and cognitive screening measures. The results suggest that healthy older people under-estimate their level of functional ability while informants show more accurate ratings when compared with an objective assessment of iADL. A test of executive function and a cognitive screening test were found to best predict objectively-assessed functional ability in healthy older people.

Chapter 4 - Verbal fluency and awareness of functional deficits in early-stage dementia

Chapter 4 examines whether Letter Fluency, the National Adult Reading Test-Revised, the MMSE score and the age of the PwD predict self-ratings of iADL, informant ratings of iADL, and the discrepancy between self-ratings and informant ratings. Ninety-six PwD and their carers participating in MIDAS completed the assessment. Letter Fluency was found to

be the only predictor of self-ratings of iADL, whereas the age and the MMSE score of the person with dementia were found to associate with the informant rating. Letter Fluency and age predicted the discrepancy score. There was also evidence that PwD who displayed poorer Letter Fluency ability were more aware of their functional impairments.

Chapter 5 - Predictors of perceived functional ability in early-stage dementia: self-ratings, informant ratings and discrepancy scores

Chapter 5 examines the relationship between a wide range of cognitive tests and iADL self-ratings, informant ratings and discrepancy scores. This chapter employs the same dataset as used in Chapter 4, but includes all 101 PwD and carers who completed assessments in MIDAS. This chapter focuses on predictors of individual items on the iADL questionnaire as well as including a wider range of cognitive and psychological variables, among them a test of everyday memory, a test of immediate recall, and a measure of carer stress, than were included in Chapter 4. Immediate memory and carer stress were found to predict self-rated and informant-rated iADL respectively. Letter Fluency was found to predict the discrepancy score. The findings suggest that PwD were able to rate their everyday functioning with reasonable accuracy.

Chapter 6 - Awareness of functional ability in people with dementia: cognitive correlates

Chapter 6 presents findings from an empirical study investigating awareness of functional ability in PwD. Thirty-seven PwD completed an objective functional assessment. They also provided self-ratings of functional ability and completed a battery of neuropsychological tests, with a particular focus on tests of executive function. All participants had a contributing informant who provided a rating of the everyday functional ability of the person with dementia, as well as rating their own feelings of burden. The results suggest that, when ratings are compared with scores on an objective assessment of functional ability, PwD are able to accurately rate their functional ability whereas informants tend to overestimate the level of impairment. A test of everyday memory and a cognitive screening test were found to best predict objective functional ability.

Chapter 7 - General discussion

The final chapter summarises the results from the systematic review and empirical studies and discusses the findings in the context of the existing literature.

1.12 Dissemination of findings

Chapters 2 and 4 have been accepted for publication and Chapter 5 has been submitted for publication in peer-reviewed academic journals.

Chapter 2 has been published in *Dementia and Geriatric Cognitive Disorders*.
Martyr, A., & Clare, L. (2012). Executive function and activities of daily living in Alzheimer's disease: a correlational meta-analysis. *Dementia and Geriatric Cognitive Disorders, 33*, 189-203. doi: 10.1159/000338233

Chapter 4 has been published in *The Clinical Neuropsychologist*.
Martyr, A., Clare, L., Nelis, S.M., Marková, I.S., Roth, I., Woods, R.T., Whitaker, C. J. & Morris, R.G. (2012). Verbal fluency and awareness of functional deficits in early-stage dementia. *The Clinical Neuropsychologist, 26*, 501-519. doi: 10.1080/13854046.2012.665482

Chapter 5 has been submitted for publication.
Martyr, A., Nelis, S.M., & Clare, L. (submitted). Predictors of perceived functional ability in early-stage dementia: self-ratings, informant ratings and discrepancy scores.

A number of conference presentations have been made to date based on findings from the data included in this thesis:

Martyr, A. & Clare, L. (2013, February). *Executive function and activities of daily living in Alzheimer's disease: a correlational meta-analysis*. Poster presented at the International Neuropsychological Society Annual Meeting, Hawaii.

Martyr, A. & Clare, L. (2013, February). *Executive function and activities of daily living in older people*. Poster presented at the International Neuropsychological Society Annual Meeting, Hawaii.

Martyr, A. & Clare, L. (2011, November). *Executive function and activities of daily living in Alzheimer's disease: a correlational meta-analysis*. Paper presented at The British Neuropsychological Society autumn conference, London.

Martyr, A. & Clare, L. (2011, November). *Executive function and activities of daily living in Alzheimer's disease: a correlational meta-analysis*. Poster presented at the Psychology Postgraduate Affairs Group conference, Bangor.

Martyr, A., Nelis, S.M., Clare, L., Marková, I.S., Morris, R., Roth, I., & Woods, R.T. (2010, February). *Verbal fluency and impaired functional ability in people with dementia.* Poster presented at the International Neuropsychological Society Annual Meeting, Acapulco, Mexico.

1.13 Conclusions

The ability of older people to live independently is dictated partly by how well they are able to perform everyday functional tasks. The thesis will therefore explore how healthy older people perform on an objective assessment of everyday functional ability and compare this performance with how they and their informants rate their functional ability. This has important implications for how older people with functional difficulties are cared for, as, despite ratings being used more frequently than objective functional assessments, the reliability of ratings of functional ability of healthy older people is not well understood. There is also a need to identify cognitive predictors of functional ability in healthy older people as tests of cognition may help identify people at risk of developing functional dependence. Therefore, the thesis will explore how tests of cognitive screening and executive function predict functional ability in healthy older people. The findings from this research may have profound implications for the continued health and well-being of community-dwelling older people.

Despite considerable evidence of declining everyday functional ability in PwD there are still concerns over the reliability and the accuracy of the different methods of assessing iADL. This has important implications for the dementia diagnostic process as there has been remarkably little research comparing self-ratings and informant ratings of iADL with everyday functional ability. Therefore one aim of this thesis is to assess objective everyday functional ability and investigate the accuracy of ratings made by PwD and their key informants. There appears to be a strong correlation between tests of cognition and iADL,

particularly executive function and immediate memory, and therefore as performance on certain tests may help predict increasing functional dependence in PwD an additional aim of the thesis will be to investigate the contribution that executive function, memory and cognitive screening measures has on the different methods of assessing iADL in people with dementia.

Chapter 2

Executive function and activities of daily living in Alzheimer's disease: a correlational meta-analysis

Martyr, A., & Clare, L. (2012). Executive function and activities of daily living in Alzheimer's disease: a correlational meta-analysis. *Dementia and Geriatric Cognitive Disorders*, *33*, 189-203. doi: 10.1159/000338233

2.1 Abstract

The assessment of executive function and activities of daily living (ADL) are important elements in the diagnosis of Alzheimer's disease. Following a comprehensive search in three databases, a random-effects meta-analysis was used to investigate the association between ADL ability and seventeen tests of executive function, three tests of attention and working memory and the Mini-Mental State Examination. The association between executive function and ADL ability was further investigated in relation to four different methods of assessing ADL and one specific ADL, driving. Forty-nine studies met the inclusion criteria and a total of 3,663 participants were included, the majority of whom were diagnosed with Alzheimer's disease. Most of the individual tests, including commonly used tests of executive function such as the Clock Drawing Test, Letter Fluency and the Trail Making Test-Part B, showed a significant moderate association with ADL. Associations between executive function and ADL ability were similar for all four methods of assessing ADL ability. Driving ability was also moderately associated with executive function. The meta-analysis suggests a consistent moderate association between ADL and executive function, supporting the growing evidence for a link between ADL and executive dysfunction in early dementia.

2.2 Introduction

Alzheimer's disease, at least in the early stages, is typically characterised primarily by impairments in memory; however, for a diagnosis of Alzheimer's disease to be made other deficits also have to be present (American Psychiatric Association, 1994; World Health Organization, 1992). One area of cognition that may be affected is executive function, an umbrella term for a number of distinct high-level cognitive processes that control everyday actions and thoughts, including working memory, attentional control, planning, inhibition, rule discovery and concept generation (Elliott, 2003; Royall, 1994; Royall et al., 2002). There is a large and growing body of research indicating that executive impairments are present even in the earliest stages of Alzheimer's disease (e.g. Bhutani et al., 1992; Collette et al., 1999; Lafleche & Albert, 1995; Nathan et al., 2001). Longitudinal studies investigating pre-diagnostic symptomatology and staging of Alzheimer's disease report that executive dysfunction is present before diagnosis, with declining executive function occurring between two and three years before diagnosis (Amieva et al., 2005; Grober et al., 2008). This evidence has even led some authors to suggest that executive function may be the core underlying dysfunction associated with Alzheimer's disease (Balota & Faust, 2001; Voss & Bullock, 2004), while others have proposed that there may be a subgroup of Alzheimer's disease patients with a specific dysexecutive pattern of impairment (Back-Madruga et al., 2002; Binetti et al., 1996; Woodward, Brodaty, et al., 2010; Woodward, Jacova, et al., 2010). Therefore, the available evidence suggests that there is a significant proportion of people with Alzheimer's disease who have discernible executive deficits.

A diagnosis of Alzheimer's disease also requires evidence of impairments in everyday functioning (American Psychiatric Association, 1994; World Health Organization, 1992). Activities of daily living (ADL) vary in complexity and difficulty and are typically divided into 'basic' and 'instrumental' (iADL) categories (Spector, Katz, Murphy, & Fulton, 1987). Basic ADL - such as bathing, toileting, feeding and dressing - tend to be preserved in early-stage Alzheimer's disease, with links to motor rather than cognitive difficulties (Boyle et al., 2002). In contrast, iADLs - such as handling finances, shopping, using the telephone, and managing medication - are vulnerable to the effects of early Alzheimer's disease, with evidence for a direct link with cognitive status (Njegovan et al., 2001; Vitaliano, Breen, Albert, Russo, & Prinz, 1984). A recent review of studies with older people found that executive function explains at least three times as much of the variance in iADL as memory

(Royall et al., 2007), while studies of people with Alzheimer's disease have also linked executive dysfunction with declining skills and abilities in ADL (Baudic et al., 2006; Swanberg et al., 2004), suggesting that executive dysfunction may contribute significantly to functional difficulties. A longitudinal study investigating functional impairment found that two years before a diagnosis of Alzheimer's disease there was a noticeable decline in iADL ability (Pérès et al., 2008). This decline occurred during the same approximate pre-diagnostic timeframe in which executive function begin to decline (Amieva et al., 2005; Grober et al., 2008) suggesting the possibility that these contemporaneous declines may involve related mechanisms.

Two previous reviews have briefly discussed the association between declining executive function and functional impairment in Alzheimer's disease (M. B. Patterson, Mack, Geldmacher, & Whitehouse, 1996; Perry & Hodges, 1999), though at the time of publication there was little empirical evidence available. The evidence for a relationship presented in these reviews was mostly based upon clinical observations, an assumed relationship between everyday tasks and underlying cognitive mechanisms and a growing literature in other conditions, such as schizophrenia (M. F. Green, Kern, Braff, & Mintz, 2000). Since these reviews were published a number of studies have investigated the relationship between ADL and executive function in Alzheimer's disease using various tests and measures, the present meta-analysis draws on these findings to investigate the nature and strength of the association between tests of executive function and everyday ability in people with Alzheimer's disease.

2.3 Method

2.3.1 Literature search strategy

To identify studies investigating the relationship between executive function and everyday functioning in Alzheimer's disease PubMed, Web of Knowledge and CINAHL were searched on the 28th July 2010. Date of publication was not limited and no specific limit was imposed on the search other than the language of publication had to be English. In total 33 searches were conducted in each of the three databases. Alzheimer* was included as the first term in all searches, and search terms focussed on three areas: ADL (activities of daily living, daily functioning, disability, driving, functional ability, functional status, telephon* and financ*), executive function (attention, dysexecutive, executive, monitoring, planning, response

inhibition, set shifting, self-regulation, purposive action, effective performance, flexibility, volition and working memory), and specific tests of executive function (Behavioural Assessment of the Dysexecutive Syndrome, BADS, Delis-Kaplan Executive Function System, D-KEFS, Stroop, The Hayling Test, Stockings of Cambridge, Tower of Hanoi, Tower of London, Tower of Toronto, Trail Making Test and Wisconsin Card Sorting Test). Reference sections of included articles were examined for any additional studies not identified by the original search. Authors researching the area were contacted for in press/pre-publication journal articles or additional correlational data, including non-significant findings that were not included in relevant articles. An identical, updated search was carried out in the same three databases on the 5th July 2011 for articles published since the first search.

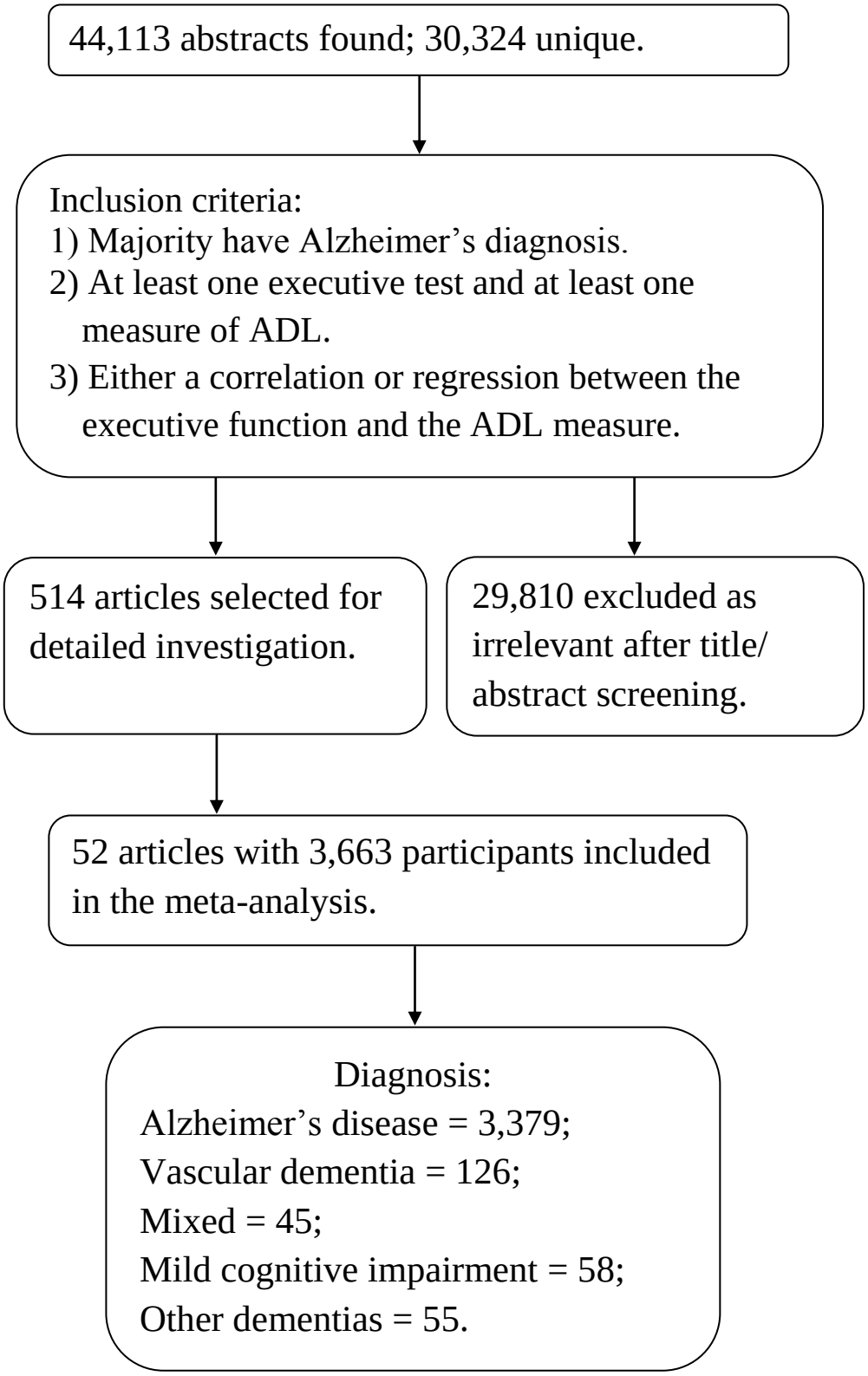
2.3.2 Inclusion criteria

Studies were included if a) they had recruited participants with a diagnosis of Alzheimer's disease or probable Alzheimer's disease only, or if at least half of the included participants had a diagnosis of Alzheimer's disease or probable Alzheimer's disease and the remainder had other dementia diagnoses; b) at least one executive function test and at least one measure of ADL were used; and c) analysis included either a correlation or regression, or data that could be converted to a correlation, that examined the association between the executive function and the ADL measures. Any studies not meeting these criteria, including studies that presented data for any participants without dementia, were excluded from the review.

2.3.3 Procedure

A summary of the process used to identify articles for inclusion is shown in Figure 2.1. After the search was conducted all unique abstracts were screened to identify those articles that matched the inclusion criteria. Full text articles were obtained for abstracts that appeared to meet criteria and to include the necessary statistical comparisons. Using these methods, 55 journal articles, one conference abstract and one PhD thesis were identified that contained the necessary correlations or regression coefficients to be included in the meta-analysis. The majority of studies included in the meta-analysis were cross-sectional; only baseline data was included if longitudinal articles were identified. One article, although it indicated possible significant associations between an ADL measure and both Category Fluency and the Stroop (Locascio et al., 1995), was excluded as it did not present data and details of correlations

Figure 2.1 Flow chart of procedure



could not be obtained. Four studies were excluded as the data presented included data from people without dementia (Burdick et al., 2005; Carr, LaBarge, Dunnigan, & Storandt, 1998; Duchek, Hunt, Ball, Buckles, & Morris, 1998; Hunt, Morris, Edwards, & Wilson, 1993). One study utilised a composite executive function score and individual test scores could not be obtained (Perry & Hodges, 2000); however, this article was included in secondary analysis that investigated different methods of assessing ADL. Another study that utilised a composite executive function score (Farias et al., 2003) was included in the main analysis as the necessary correlational data were available in the lead author's PhD thesis (Farias née Tomaszewski, 2000). Therefore, 52 articles were included in the meta-analysis.

2.3.4 Statistical analysis

The effect size *r* was used and the procedure outlined by Borenstein, Hedges, Higgins, and Rothstein (2009) was followed. A standardized correlation direction was used, and where necessary the direction was changed to facilitate cross-study comparisons. If a relevant study reported regression analyses, odds ratios, *t* or *F* statistics, these were converted to correlations. One study (Loewenstein, Rubert, Arguelles, & Duara, 1995) reported standardised betas, and these were converted to correlations using the formula $r = \beta + .05$ (Peterson & Brown, 2005) which it has been suggested accurately estimates correlations from beta coefficients. Two studies each contributed two independent samples to the meta-analysis; one study included an English speaking and a Spanish speaking sample (Loewenstein et al., 1995) while another included two separate samples of people with dementia (Ott et al., 2003). In four cases, pairs of studies reported the same samples and hence they were combined in the meta-analysis. The first pair investigated different aspects of driving ability (Uc, Rizzo, Anderson, Shi, & Dawson, 2004, 2005), though the later article included one further participant. The second pair investigated simulated driving ability (Rizzo, McGehee, Dawson, & Anderson, 2001; Rizzo, Reinach, McGehee, & Dawson, 1997), with the latter study amalgamating data from both studies. The third pair employed the Alzheimer's Disease Neuroimaging Initiative (ADNI) dataset and reported data for different tasks (Brown, Devanand, Liu, & Caccappolo, 2011; Marshall et al., 2011). The final pair reported data for different tasks from the Memory Impairment and Dementia Awareness Study (MIDAS) (Clare, Nelis, Martyr, Roberts, et al., 2012; Chapter 4).

Effect sizes were calculated using the random effects model since the included studies employed different methods of assessing ADL and executive function and included heterogeneous samples of people with Alzheimer's disease. The random effects model estimates and incorporates the magnitude of heterogeneity into the overall estimated effect (DerSimonian & Laird, 1986). Random effects meta-regression analyses were used to investigate moderator variables; these examined the effect of age and Mini-Mental State Examination (MMSE: Folstein et al., 1975) score on the estimated effect sizes. Between-study heterogeneity for each cognitive measure was assessed using an index of inconsistency (I^2). This calculates a percentage of heterogeneity resulting from study differences that is not due to chance; therefore larger values indicate greater heterogeneity (Higgins, Thompson, Deeks, & Altman, 2003). All computations were based on Fisher's *z* transformations and were conducted using the Comprehensive Meta-Analysis 2 (Borenstein, Hedges, Higgins, & Rothstein, 2005) software package which calculated average *z* scores and *p* values, weighted effect *r* values and 95% confidence intervals for the collective effect sizes. All but six of the included studies presented multiple correlations, typically between one measure of ADL and many executive tests, although 15 studies used more than one ADL measure. The software package was instructed to average the multiple within-study correlations to correct for violations of independence so that all available data could be included in the analysis. Forest Plot Viewer (Boyles, Harris, Rooney, & Thayer, 2011) was used to create the forest plot. Holm-Bonferroni correction for multiple comparisons at the 5% level was applied to all analyses.

To address the risk of possible publication bias, where studies of non-significant findings are less likely to be published than those with significant findings, 18 authors were contacted for additional information not included in relevant articles. Six responded, with five able to provide the necessary information; three of these provided details of statistically non-significant analyses.

Three analyses were conducted. The first analysis investigated the relationship between ADL and individual tests of executive function. Additionally, data from four tests which are not typically viewed as assessing executive function were included. Three tests of working memory or attention were included; Trail Making Test-Part A, Digit Span Forwards and Digit Span, a combined score for Digit Span Backwards and Digit Span Forwards that was reported in seven studies. Working memory and attention were specific search terms in the meta-

analysis and are viewed as related to or as important elements of executive function (Alvarez & Emory, 2006; Stuss & Alexander, 2007). The fourth test, the widely used MMSE, allowed for a comparison between cognitive status and ADL. Data from these four tests was only included in the first analysis. The second analysis investigated the effects of using different methods of assessing ADL by examining whether informant ratings, clinician ratings, objective assessment measures or self-reports of ADL differed in the strength of association with executive function; this analysis included data from one additional study (Perry & Hodges, 2000) which was excluded from the executive test analysis due to the use of a composite executive function score. The second analysis also included data from three tests of executive function that were each used in only one study: the D-KEFS Tower and Sorting tests (used in Razani, Casas, et al., 2007) and the Letter-Number Sequencing test (used in Earnst et al., 2001). A final analysis investigated the association between driving ability (see Dickerson, Reistetter, Davis, & Monahan, 2011, for discussion) and executive function and included informant-rating questionnaire studies and observational studies of practical driving ability.

2.4 Results

In the first search 40,790 references were found, with 27,704 of those being unique; in the second search a further 3,323 references were returned of which 2,620 were unique. Thus, there were 44,113 abstracts found in total, of which 30,324 were unique; 514 abstracts were investigated in more detail, and 49 studies reported in 52 articles met inclusion criteria. Table 2.1 describes the studies in more detail. Thirty-nine studies featured a sample consisting solely of people with Alzheimer's disease while a further 10 studies included people with a range of dementias, with Alzheimer's disease the most commonly reported. In total, data from 3,663 people with dementia were included in the meta-analysis; of those 3,379 were diagnosed with Alzheimer's disease, with 3,060 in Alzheimer's disease only studies. Those that remained had either vascular dementia (n = 126), mild cognitive impairment (n = 58), mixed dementia (n = 45), frontotemporal dementia (n = 8), Parkinson's disease (n = 1), Lewy body dementia (n = 3), or alcohol dementia (n = 6). Twenty-four were unspecified, and 13 had other dementias.

Table 2.1 Study details (summary of articles included in the meta-analysis)

Authors	Participants and demographics	Tests included	ADL measure
Alzheimer's disease only studies			
Alva et al. 2011	AD = 782 (mean age 73.6, mean MMSE = 16.5)	CDT, TMT-A	Informant: Alzheimer's Disease Assessment Scale-Activities of Daily Living
Back-Madruga et al. 2002	AD = 20 (Executive AD = 10 mean age 73.6 (9.6), mean MMSE = 22.2 (3.6); Typical AD = 10 mean age 79.9 (6.1), mean MMSE = 23.7 (3.1))	Letter Fluency[a], Similarities, Stroop[a], TMT-B[a]	Informant: IADL
Bassett, 1999	AD = 20 (mean age 75.3 (9.87), mean MMSE = 21.95 (4.14))	Digit Span, MMSE, Similarities, TMT-A, TMT-B	Self: 5 item Financial Competency Questionnaire devised for the study
Boyle et al. 2003	AD = 45 (mean age 76.7 (7.7), mean MMSE = 22 (3.2))	DRS Initiation	Informant: IADL, PSMS
Bracco et al. 1990	AD = 143 (mean age 60.8 (5.9), mean MMSE = 22 (3.2))	Digit Span Forwards, MMSE, Set Test (Category Fluency), Token Test	Informant: BDS

Breen et al. 1984	AD = 35 (AD = 21: mean age 75.14 (7.08), mean MMSE = 20.19 (4.42); AD with unipolar depression = 14: mean age 73.64 (8.67), mean MMSE = 17.50 (6.24))	Block Design, Digit Span, Digit Symbol, MMSE, Similarities	Informant: BDS
Brown et al. 2011	AD = 193 (mean age 75.33 (7.48), mean MMSE = 23.34 (2.06))	Brown et al: Digit Symbol (*n* = 189)[a], TMT-A (*n* = 191)[a], TMT-B (*n* = 183)[a]	Informant: FAQ
Marshall et al. 2011	AD = 178 (mean age 75.6 (7.4), mean MMSE = 23.4 (2.0))	Marshall et al: MMSE	
Cahn-Weiner et al 2003	AD = 24 (mean age 75.3 (7.1), mean MMSE = 24.2 (2.0))	Letter Fluency	Informant: combined modified IADL & PSMS
Čechová et al. 2009	AD = 34 (mean age 78.5 (7.3), mean MMSE = 22.5 (2.04))	Category fluency	Informant: combined Bristol Activities of Daily Living Scale, DAD, FAQ
Chen et al. 1998	AD = 31 (mean age 69.9, mean MMSE = 17.6)	Letter Fluency, DRS Conceptualisation, DRS Initiation, MMSE, WCST	Informant: BDS-Activities
Dawson et al. 2009	AD = 40 (mean age 75.1 (7.7), mean MMSE = 26.5 (2.9))	Letter Fluency, TMT-A, TMT-B	Objective: Driving errors
Earnst et al. 2001	AD = 20 (mean age 71.9 (7.2), mean MMSE = 20.5 (4.8))	Digit Span Backwards, Digit Span Forwards, Letter-Number Sequencing[b]	Objective: Financial Capacity Instrument total score

Farias et al. 2003 Tomaszewski, 2000	AD = 42 (mean age 71.67 (8.52), mean MMSE = 22.02 (5.11))	Farias et al. 2003: Digit Span Tomaszewski, 2000: Letter Fluency, MMSE, Similarities, TMT-A, TMT-B (*n* = 17)	Informant: IADL Objective: DAFS (plus Misplaced Objects & Spatial Orientation Tests included in total score)
Fox et al. 1997	AD = 19 (mean age 74.3 (6.4), mean MMSE = 21.3 (2.75))	Block Design, Digit Symbol, MMSE, TMT-A, TMT-B	Clinician: Driving predictions Objective: Driving test
Fukui & Lee, 2009	AD = 57 (mean age 78.0 (6.1), mean Hasegawa Dementia Scale-Revised = 16.0 (5.9))	CDT	Informant: modified IADL, modified PSMS
Giovannetti et al. 2008	AD = 70 (mean age 79.0 (6.7), mean MMSE = 20.08 (3.8))	Animal Naming-Association Index (Category Fluency; *n* = 54), CDT (*n* = 68), Letter Fluency (*n* = 60), Mental Control (*n* = 56), MMSE (*n* = 70)	Objective: NAT
Hall et al. 2011	AD = 202 (males = 91: mean age 74.36 (8.21), mean MMSE = 21.53 (4.59); females = 111: mean age 76.95 (7.74), mean MMSE = 20.95 (4.47))	CDT, Letter Fluency (*n* = 91), TMT-A, TMT-B (*n* = 91)	Informant: IADL, PSMS
Heinik et al. 2002	AD = 49 (mild: mean age 77.88 (7.16), mean MMSE = 20.53 (2.80); moderate: mean age 80.65 (6.13), mean MMSE = 13.21 (4.47))	CDT (two scoring methods)	Informant: IADL (*n* = 40), PSMS dressing subscale (*n* = 47)

Loewenstein et al. 1992	AD = 33 (mean age 77.1 (6.3), mean MMSE = 18.69 (4.74))	Block Design, Letter Fluency, MMSE, Similarities	Objective: Individual DAFS items
Loewenstein et al. 1995	AD = 183 (English (*n* = 127): mean age 77.29 (6.6), mean MMSE = 20.75 (3.9); Spanish (*n* = 56): mean age 73.00 (5.8), mean MMSE = 19.11 (4.7))	Block Design, Digit Span, Letter Fluency, MMSE	Objective: Individual DAFS items
Mahurin et al. 1991	AD = 18 (mean age 66.9 (5.4), mean MMSE = 19.4 (3.4))	Letter Fluency, MMSE, TMT-A, TMT-B	Objective: Structured Assessment of Independent Living Skills
Matsuda & Saito, 2005	AD = 73 (mean age 74.75 (8.94), mean MMSE = 18.42 (6.26))	Digit Span Forwards, Digit Symbol, Similarities	Informant: 27-item combined ADL/IADL questionnaire devised for the study
Monaci & Morris, 2012	AD = 34 (mean age 76.4 (7.4), mean MMSE = 19.6 (5.3))	CAMCOG-EFS, MMSE, Similarities	Informant: Katz index, IADL
Nussbaum et al. 1995	AD = 19 (mean age 75.47 (9.11), mean MMSE = 21.95 (2.04))	DRS Conceptualisation, DRS Initiation	Informant: Dementia Behaviour Rating Scale
Ott et al. 1996	AD = 26 (mean age 72.5 (7.5), mean MMSE = 21.1 (3.9))	CDT, Digit Span Backwards, Digit Span Forwards, Letter Fluency, Mazes, MMSE, TMT-A, TMT-B	Informant: 19-item combined ADL/IADL questionnaire devised for the study
Ott et al. 2000	AD = 79 (mean age 74.7 (7.9), mean MMSE = 19.6 (4.9))	CDT	Informant: 4-point informant-rated driving questionnaire

Ott et al. 2003	AD = 27 (mean age 74.9 (5.9), mean MMSE = 21.8 (2.9))	Porteus Maze, TMT-B	Informant: 4-point informant-rated driving questionnaire
Ott et al. 2008	AD = 88 (mean age 75.8 (6.9), mean MMSE = 24.0 (3.5))	5 Computer Mazes, MMSE, TMT-A, TMT-B	Objective: Driving test
Pereira et al. 2008	AD = 26 (mean age 73.8 (6.7), mean MMSE = 20.4 (6.0))	EXIT25	Objective: DAFS
Perry & Hodges, 2000[b]	AD = 24 (mean age 69.75 (7.6), mean MMSE = 21.0 (3.6))	Composite score (Dual performance test, TEA-Elevator counting with Distraction, TEA-Map Search, Stroop, WCST), MMSE	Informant: 25-item combined ADL/IADL questionnaire devised for the study
Razani et al. 2011	AD = 49 (mean age 74.41 (8.53), mean MMSE = 23.60 (5.24))	Category Fluency[a], Letter Fluency[a], WCST[a]	Objective: DAFS
Rebok et al. 1994	AD = 10 (mean age 75.4 (3.5), mean MMSE = 22.5 (2.4))	Category Fluency, MMSE	Objective: Driving Advisement System, Driver Performance Test
Rizzo et al. 1997	AD = 21 (mean age 71.5 (8.5)) no MMSE information provided	Block Design, Digit Span, Letter Fluency, TMT-B	Objective: Virtual driving test
Rizzo et al. 2001	AD = 18 (mean age 73.0 (7)) no MMSE information provided		
Senanarong et al. 2005	AD = 73 (mean age 70.28 (8.10), mean Thai MMSE = 18.42 (6.60))	Category Fluency, CDT, Letter Fluency, MMSE	Informant: FAQ, Thai ADL

Teri et al. 1989	AD = 56 (mean age 71.0 (6.3), mean MMSE = 23.0 (3.29))	DRS Conceptualisation, DRS Initiation	Informant: OARS-IADL, OARS-Self Care
Uc et al. 2004	AD = 32 (mean age 75.9 (6.2), mean MMSE = 26.3 (2.9))	Block Design, Letter Fluency, TMT-B	Objective: Driving test
Uc et al. 2005	AD = 33 (mean age 76.1 (5.9), mean MMSE = 26.1 (3.0))		Objective: Landmark test
Verhey, et al. 2003	AD = 283 (mean age 75.4 (6.3), mean MMSE = 19.4 (4.4))	CAMCOG-EFS	Clinician: Nurses' Observation Scale for Geriatric Patients-IADL subscale
Willis et al. 1998	AD = 65 (mean age 73.87 (8.63), mean MMSE = 19.83 (4.08))	Block Design, Digit Symbol, MMSE, TMT-A, TMT-B	Clinician: PSMS Informant: IADL Objective: Everyday Problem Test for Cognitively Challenged Elderly Self: IADL
Mixed dementia studies			
Bettcher et al. 2008	*N* = 53 (mean age 79.5 (5.4), mean MMSE = 20.9 (3.6)) AD = 29, VaD = 20, Mixed = 4	CDT (*n* = 50), Letter Fluency (*n* = 50), MMSE	Objective: NAT
Brennan et al. 2009	*N* = 44 (mean age 76.39 (9.42), mean MMSE = 22.64 (3.42)) AD = 22, VaD = 9, Mixed = 7, FTD = 4, PD/DLB = 2	CDT (*n* = 43), Letter Fluency (*n* = 38), Mental Control (*n* = 35), MMSE	Objective: NAT

Clare et al. 2012a Chapter 4	*N* = 96 (mean age 78.68 (7.84), mean MMSE = 24.22 (2.78)) AD = 50, VaD = 29, Mixed = 17	Clare et al: Category Fluency Chapter 4: Letter Fluency, MMSE	Informant: FAQ Self: FAQ
Hill et al. 1995	*N* = 81 (mean age 85.4 (5.58), mean MMSE = 17.9 (5.26)) AD = 45, VaD = 20, Mixed = 1, Alcohol dementia = 5, unspecified dementia = 10	Block Design, Digit Span Backwards, Digit Span Forwards, MMSE	Informant: Cambridge Mental Disorders of the Elderly Examination Family Interview Schedule, Katz index
Norton et al. 2001	*N* = 30 (mean age 73.1 (8.5), mean MMSE = 22.0 (4.0)) AD = 20, VaD = 3, DLB = 2, alcohol dementia = 1, dementia due to multiple aetiologies = 2, dementia of unknown aetiology = 2	DRS Initiation	Informant: IADL
Ott et al. 2003	*N* = 24 with mild or very mild dementia. Smaller sample excluding people with no dementia. No specific demographic information was provided.	10 Computer Mazes	Informant: 4-point informant-rated driving questionnaire
Razani et al. 2007a	*N* = 33 (mean age 73.82 (8.76), mean MMSE = 22.27 (5.13)) AD = 21, Mixed = 10, FTD = 2	Letter Fluency, MMSE, D-KEFS-Sorting[b], D-KEFS-Stroop, D-KEFS-TMT-B, D-KEFS-Tower[b], WCST	Informant: IADL Objective: DAFS

Sabbagh et al. 2007	AD/MCI = 124 (mean age 83.9 (7.6), mean MMSE = 21.1 (8.7)) AD = 66, MCI = 58	Category Fluency (*n* = 89), CDT (*n* = 85), Digit Span (*n* = 91), Letter Fluency (*n* = 90), Stroop (*n* = 74)	Clinician: Functional Assessment Staging
Stokholm et al. 2005	*N* = 33 (mean age 76.3 (6.2), mean MMSE = 24.2 (2.1)) AD = 22, VaD = 4, Mixed = 4, FTD = 2, other = 1	EXIT25[a] (*n* = 23), MMSE[a] (*n* = 23)	Informant: DAD
Vallotti et al. 2001	AD = 44 (mean age 79.0 (7.0), mean MMSE = 18.9 (5.2)) VaD = 41 (mean age 79.0 (6.0), mean MMSE = 18.7 (4.5))	Category Fluency, Letter Fluency, MMSE, Token Test	Informant: Barthel Index

[a] Not reported in paper but included in meta-analysis. [b] Articles or tests included in secondary analysis only.

ADL test abbreviations: Blessed Dementia Scale (BDS), Direct Assessment of Functional Ability (DAFS), Disability Assessment in Dementia (DAD), Functional Activities Questionnaire (FAQ), Instrumental Activities of Daily Living (IADL), Naturalistic Action Test (NAT), Older Americans Resource Scale (OARS), Physical Self-Maintenance Scale (PSMS).

Executive and cognitive test abbreviations: Cambridge Cognitive Examination-Executive Functioning Scale (CAMCOG-EFS), Clock Drawing Test (CDT), Delis-Kaplan Executive Function System (D-KEFS), Executive Interview (EXIT25), Mini-Mental State Examination (MMSE), Mattis Dementia Rating Scale (DRS), Test of Everyday Attention (TEA), Trail Making Test-Part A (TMT-A), Trail Making Test-Part B (TMT-B), Wisconsin Card Sorting Test (WCST).

Patient group abbreviations: Alzheimer's disease (AD), dementia of Lewy body (DLB), frontotemporal dementia (FTD), mild cognitive impairment (MCI), mixture of Alzheimer's disease and vascular dementia (Mixed), Parkinson's disease (PD), vascular dementia (VaD).

2.4.1 Analysis of associations between ADL ratings and scores on individual cognitive tests

The analysis examined the assessment between ADL ratings and scores on 21 different tests; see Table 2.2. Random effects meta-analysis found significant estimated effect sizes for all tests used in four studies or more, with the exception of Digit Span Forwards, a test of working memory. Block Design, Category Fluency, Digit Symbol, Similarities, Mazes and the Wisconsin Card Sorting Test showed the strongest associations with ADL. However, the estimated effect sizes for Mazes and the Wisconsin Card Sorting Test should be viewed as preliminary due to the small number of studies and the small sample sizes included in these analyses. Similarly, out of the seven tests that were used in three or fewer studies all but one showed non-significant effect sizes after Holm-Bonferroni correction. Of note, the large but non-significant estimated effect sizes for the Executive Interview (EXIT25: Royall, Mahurin, & Gray, 1992) and The Token Test were due to one study reporting a large correlation and the other study reporting a small correlation; which is indicated by the large confidence intervals in Figure 2.2. The findings from these seven tests should be viewed as preliminary since only with more studies will the eventual effect sizes for these less-commonly used tests be established. There was a moderate to large degree of between-study estimated heterogeneity, as indicated by the inconsistency indices (I^2) in Table 2.2 especially for Category Fluency, Digit Symbol, and most of the tests used in only a small number of studies, supporting the choice of a random effects model.

2.4.2 Moderator variables and heterogeneity

Moderator variables were investigated to see whether age or MMSE score influenced the estimated effect sizes. Age was found to be a significant moderator variable for three tests, Category Fluency (z = -2.172, p = .030), Trail Making Test-Part A (z = -2.073, p = .038) and MMSE (z = -1.986, p = .047), though after correcting for multiple comparisons these association were no longer significant. Meanwhile, MMSE score was not a significant moderator variable for any test. A further area of heterogeneity could arise from including multiple dementia diagnoses; consequently the meta-analyses were rerun excluding these 10 studies. In the original meta-analysis scores for Digit Symbol, the Cambridge Cognitive Examination-Executive Functioning Scale (Roth, Huppert, Mountjoy, & Tym, 1999), the Mattis Dementia Rating Scale (Jurica et al., 2001; Mattis, 1988) Conceptualization subscale,

Table 2.2 Effect sizes, confidence intervals and heterogeneity for individual tests

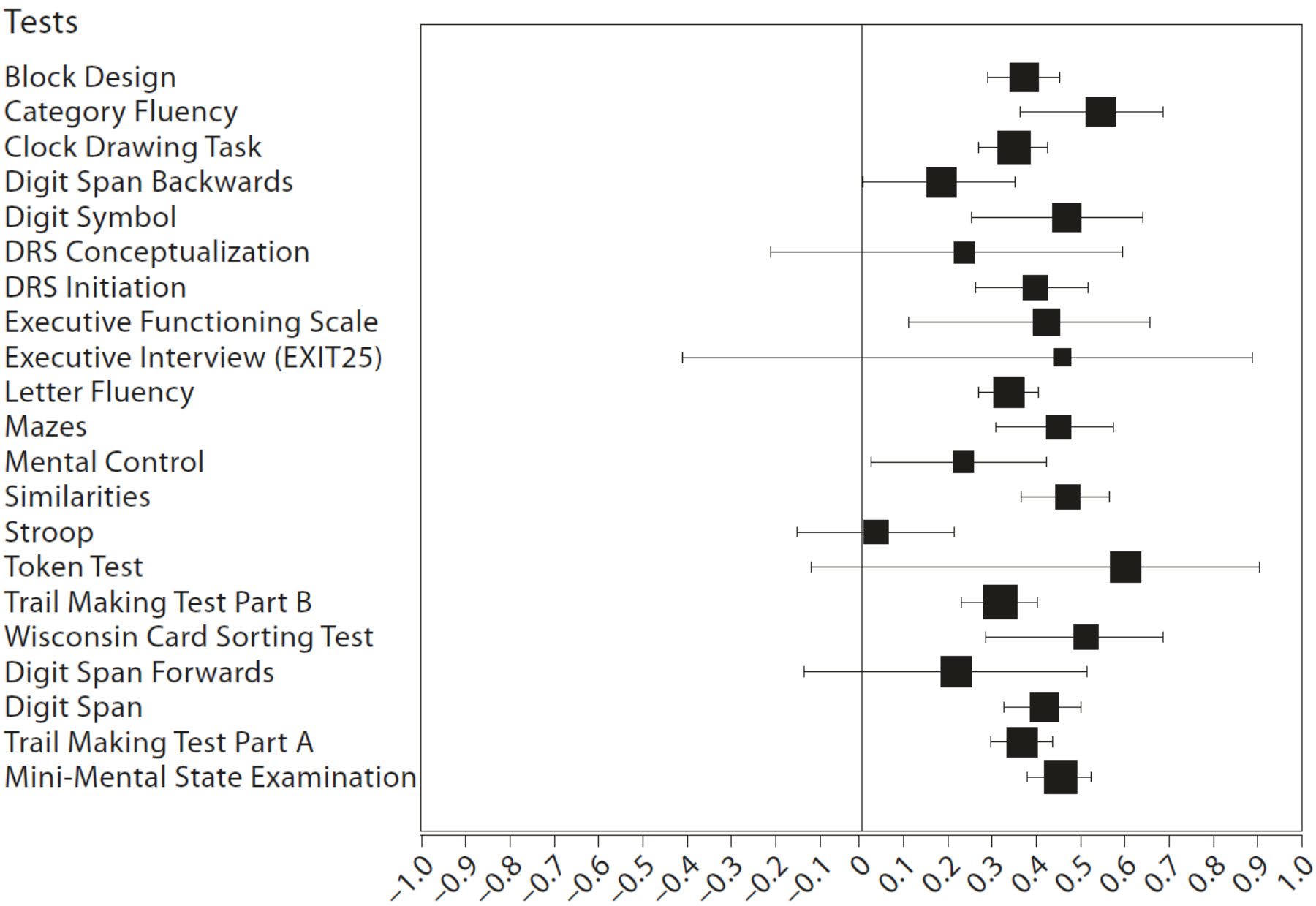
						Heterogeneity		
	n	k	Effect size	95% CI	*p*	Q	Q *p*	I^2
Executive test								
Block Design	464	9	.370	.286 - .448	**< .001**	6.267	.617	0.00
Category Fluency	630	9	.542	.360 - .684	**< .001**	59.89	< .001	86.64
Clock Drawing Test	1505	11	.347	.267 - .423	**< .001**	19.17	.038	47.83
Digit Span Backwards	127	3	.181	.003 - .348	.047	1.05	.593	0.00
Digit Symbol	381	5	.466	.250 - .638	**< .001**	18.48	.001	78.35
DRS Conceptualisation	106	3	.232	-.205 - .592	.298	8.72	.013	77.06
DRS Initiation	181	5	.395	.259 - .515	**< .001**	2.83	.587	0.00
Executive Functioning Scale	317	2	.419	.107 - .656	.009	3.52	.061	71.55
Executive Interview (EXIT25)	49	2	.455	-.408 - .889	.298	9.52	.002	89.50
Letter Fluency	1128	22	.335	.266 - .400	**< .001**	30.54	.082	31.24
Mazes	165	4	.448	.305 - .571	**< .001**	3.19	.364	5.88
Mental Control	89	2	.230	.022 - .419	.031	.00	.981	0.00
Similarities	257	7	.467	.361 - .561	**< .001**	1.84	.934	0.00
Stroop	127	3	.033	-.146 - .211	.716	.10	.950	0.00
Token Test	228	2	.599	-.114 - .904	.093	34.92	< .001	97.14
Trail Making Test-Part B	697	15	.315	.227 - .398	**< .001**	18.29	.194	23.44

Wisconsin Card Sorting Test	113	3	.509	.282 - .685	**< .001**	3.90	.142	48.68
Attention & working memory								
Digit Span Forwards	343	5	.214	-.131 - .512	.223	35.04	< .001	88.58[a]
Digit Span	386	7	.415	.323 - .499	**< .001**	2.21	.899	0.00
Trail Making Test-Part A	1398	11	.365	.292 - .434	**< .001**	14.20	.164	29.56
Cognitive status								
Mini-Mental State Examination	1397	25	.451	.376 - .520	**< .001**	59.91	< .001	59.94

[a] Removing Bracco et al. (1990) reduced I^2 to 0.00%, (n = 200, k = 4; effect size of .070; 95% CI; -.073 - .210, p = .335).

Note: bold indicates significant after Holm-Bonferroni correction for multiple comparisons.

Figure 2.2 Forest plot of executive and other cognitive tests



Similarities and Trail Making Test-Part A were available only for people with Alzheimer's disease so the analysis with regards to these tests was unchanged. For a further three tests (EXIT25, Mental Control and The Token Test) analysis could not be rerun as the data came from one study with Alzheimer's disease and one study with a mixed dementia sample in each case. Table 2.3, therefore, shows data for the remaining 13 tests. The estimated effect sizes and significance remained relatively unchanged after excluding studies with mixed samples of people with dementia, although the degree of inconsistency for many of the tests was greatly reduced; this was especially so for the Clock Drawing Test and Letter Fluency. The analysis was repeated with five tests where significant data from studies with mixed dementia samples could be included (Table 2.3). This shows that for all five tests the estimated effect sizes were slightly reduced, with the Clock Drawing Test no longer statistically significant. The inconsistency for three of the tests was higher than that seen in both the full analysis and the Alzheimer's disease only analysis, suggesting that there is generally more variability in the findings from studies conducted with mixed dementia samples, though it should be noted that the analysis with these studies had small sample sizes.

2.4.3 Associations between executive function scores and ratings based on different methods of assessing ADL ability

The next stage of the analysis investigated the association between executive function test scores and each of the four different methods of assessing ADL: objectively-assessed, clinician rating, informant rating or self-rating. Of the four methods, informant rating was the most commonly used, with objectively-assessed the next most commonly employed method. As Table 2.4 shows, similar estimated effect sizes were found for all four methods, and these did not differ statistically, suggesting there was little difference in results obtained for the four measurement approaches.

2.4.4 Moderator variables and heterogeneity

A moderate degree of within-test heterogeneity was found, especially for informant ratings. Age was found to be a moderating variable for informant ratings of ADL ($z = -2.579$, $p = .010$) and approached statistical significance as a moderator variable for objectively-assessed tests of ADL ($z = -1.910$, $p = .056$). MMSE score was not a significant moderator variable for any of the different methods of assessing ADL. Heterogeneity from the 10 studies with mixed

Table 2.3 Effect sizes, confidence intervals and heterogeneity for individual tasks for Alzheimer's disease only and mixed dementia samples

	Alzheimer's disease only samples					Mixed dementia samples				
	n	k	Effect size	*p*	I^2	*n*	k	Effect size	*p*	I^2
Executive test										
Block Design	383	8	.377	**< .001**	0.00					
Category Fluency	360	6	.585	**< .001**	87.26	270	3	.456	**< .001**	77.16
Clock Drawing Test	1328	8	.348	**< .001**	30.39	177	3	.305	.062	77.83
Digit Span Backwards	46	2	.188	.240	4.24					
Dementia Rating Scale Initiation	151	4	.386	**< .001**	0.00					
Letter Fluency	737	16	.365	**< .001**	0.00	391	6	.269	**.001**	59.14
Mazes	141	3	.406	**< .001**	0.00					
Stroop						107	2	.029	.768	0.00
Trail Making Test-Part B	664	14	.322	**< .001**	28.90					
Wisconsin Card Sorting Test	80	2	.564	**.003**	68.18					
Attention & working memory										
Digit Span Forwards	262	4	.234	.296	89.90					
Digit Span	295	6	.402	**< .001**	0.00					
Cognitive status										
Mini-Mental State Examination	982	18	.484	**< .001**	53.18	415	7	.364	**< .001**	70.51

Note: bold indicates significant after Holm-Bonferroni correction for multiple comparisons.

Table 2.4 Effect sizes, confidence intervals and heterogeneity for different methods of assessing everyday functioning

						Heterogeneity		
ADL method	*n*	k	Effect size	95% CI	*p*	Q	Q *p*	I^2
Clinician rating	452	4	.350	.217 - .471	**< .001**	5.08	.166	40.96
Informant rating	2415	30	.372	.312 - .430	**< .001**	58.88	.001	50.75
Objective	815	19	.390	.316 - .459	**< .001**	23.10	.187	22.19
Self-rating	181	3	.351	.214 - .475	**< .001**	1.14	.564	0.00
Alzheimer's disease only studies								
Clinician rating	367	3	.332	.148 - .494	**< .001**	8.89	.143	48.55
Informant rating	2043	23	.394	.324 - .459	**< .001**	48.42	.001	55.41[a]
Objective	694	16	.414	.334 - .488	**< .001**	19.46	.193	22.94[b]
Self-rating	85	2	.419	.222 - .583	**< .001**	.223	.637	0.00
Mixed dementia studies								
Informant rating	372	7	.294	.177 - .403	**< .001**	7.82	.252	23.24
Objective	121	3	.259	.079 - .422	**.005**	1.10	.577	0.00

[a] Removing Bracco et al. (1990) reduced I^2 to 38.74% (n = 1900, k = 22; effect size of .368; 95% CI; .303 - .428, $p < .001$).

[b] Removing Pereira et al. (2008) reduced I^2 to 0.00% (n = 668, k = 15; effect size of .387; 95% CI; .318 - .452, $p < .001$).

Note: bold indicates significant after Holm-Bonferroni correction for multiple comparisons.

dementia samples was also investigated. As Table 2.4 shows, the heterogeneity indices increased marginally when only people with Alzheimer's disease were included in the analysis, suggesting that the inclusion of participants with other dementias had little impact on heterogeneity. Interestingly, in the Alzheimer's disease only analysis, after the Bracco et al. (1990) study was removed from the informant rating analysis and after the Pereira et al. (2008) study was removed from the objective assessment analysis, the estimated effect sizes and the heterogeneity for both was reduced (see note in Table 2.4), suggesting that these two studies which found large effects were slightly inflating the estimated effect sizes.

2.4.5 Driving ability

A final analysis was conducted on the nine studies that investigated whether executive function was related to driving ability. This analysis included a combined sample size of 337 people and reported an effect size of .404 (95% CI; .266 - .526, $p < .001$, $I^2 = 39.84$) suggesting that executive function is moderately related to driving ability in people with Alzheimer's disease. The effect sizes after separating the studies into those using either objective assessment ($n = 207$, k = 6; effect size of .355; 95% CI; .224 - .473, $p < .001$, $I^2 = 0.00$) or informant/clinician ratings ($n = 149$, k = 4; effect size of .500; 95% CI; .216 - .706, $p = .001$, $I^2 = 68.22$) indicated that the two different methods of assessing driving ability were relatively comparable in their associations with executive function. There was a moderate degree of within-test heterogeneity, with the informant/clinician rated studies increasing the amount of between-study variance; however this was due to one study (Ott et al., 2000) and after this study was removed no inconsistency was found for informant/clinician ratings ($n = 70$, k = 3; effect size of .612; 95% CI; .431 - .746, $p = .001$, $I^2 = 0.00$). Neither age nor MMSE score was a significant moderating variable between driving ability and executive function. Due to the small number of studies, moderation analysis could not be conducted in relation to the different methodologies used to investigate driving.

2.5 Discussion

This random effects meta-analytic study investigated the relationship between executive function and activities of daily living in Alzheimer's disease. The first analysis found

significant associations between ADL and 13 out of 21 tests, including 10 out of 17 tests of executive function. The tests with the largest effect sizes also had relatively large confidence intervals and large indices of inconsistency, suggesting wide variability, though generally heterogeneity tended to be reduced once studies that included mixed dementia samples were excluded. For the seven tests where a significant relationship between executive function and ADL was not found, all tests were used in three or fewer studies involving smaller sample sizes, suggesting that reduced power may have contributed to the non-significant finding. The findings therefore support the conclusions of previous reviews that proposed a relationship between executive function and ADL (M. B. Patterson et al., 1996; Perry & Hodges, 1999), but demonstrate that the relationship is moderate in size; consequently, people with Alzheimer's disease who present at memory clinics with executive dysfunction are likely to have difficulties with everyday functioning. However, further research is needed to clarify the association between less frequently used tests of executive function and ADL in people with Alzheimer's disease.

Analyses investigating different methods of assessing ADL indicated that all four methods were moderately correlated with executive function, to a roughly similar degree. This indicates that if the primary question of interest is the relationship between executive function and ADL, then an ADL questionnaire may be just as informative as a more costly and time-consuming objective assessment measure of ADL. Finally, the nine studies that investigated the association between driving and executive function also found a moderate estimated effect size, as would be expected since driving is a complex, cognitively-demanding ability. The finding supports and partially updates a previous meta-analysis where neuropsychological test scores, including executive function, were related to driving ability in dementia (Reger et al., 2004). One difference however is that informant ratings of driving ability, albeit with only four studies, were largely comparable with objective assessments of driving ability, whereas previously objective assessments of driving ability have been seen as more strongly related to executive function (Reger et al., 2004). The association between driving ability and tests of executive function may indicate that people with early-stage Alzheimer's disease who present with discernible executive deficits may need a full driving assessment, especially those diagnosed at a younger age; tests of executive function may provide a preliminary screening.

Surprisingly, the random effects meta-analysis suggests a relatively consistent moderate association between executive function and ADL ability. An important caveat however is that few of the executive function tests included in the meta-analysis have established ecological validity and this may have important implications for the relationship between executive function and everyday functioning. It could be expected that due to increased face validity or acceptability to people with Alzheimer's disease, ecologically-valid tests of executive function would have stronger associations with ADL than more traditional neuropsychological tests of executive function such as those included in this meta-analysis. However, a review of six studies, none of which included people with Alzheimer's disease, suggests that the relationship between ecologically-valid tests of executive function and ADL may also be in the moderate range (Chaytor & Schmitter-Edgecombe, 2003). The strength of this relationship should be clarified through further research employing more ecologically-valid tests of executive function in Alzheimer's disease.

The current meta-analysis suggests that executive function plays an important role in influencing functional ability in Alzheimer's disease. However, the moderate effect size indicates that tests of executive function explain only some of the variance in ADL ability in people with Alzheimer's disease. Other cognitive functions such as memory or visual perception may also affect everyday functioning in people with Alzheimer's disease (Farias et al., 2009; Richardson et al., 1995). The moderate association between ADL and cognitive status (MMSE) indicates that cognitive status is also important for independent living, especially as the estimated effect size was relatively large; however, as a moderator variable MMSE had no impact on the association between executive function and ADL. Conversely, informant ratings of ADL were found to be significantly influenced by increasing age and a similar trend was seen for objective assessments of ADL, suggesting that functional ability reduces with age (Chapter 4; Teri et al., 1989); though interestingly, executive function was unaffected by age. However, the negative association between MMSE score and age may have implications for the clinical interpretation of cognitive test scores. Clinical assessments and research investigating Alzheimer's disease and ADL should therefore take age into account as this is likely to impact on both informant ratings and actual performance.

While it is important clinically to know that there is a consistent moderate association between ADL and executive function, it would also be important to know which specific ADL are more susceptible to executive dysfunction. However, studies that present data for

individual ADL are rare, so it is difficult to relate specific everyday functions to executive function or to determine which ADL are more strongly related to executive function. It is likely that more complex ADL place higher demands on executive function than simpler ADL, but this information is lost when presenting total scores. Future studies could investigate the association between specific ADL and executive function; to date few studies have investigated individual ADL (Farias et al., 2003; Loewenstein et al., 1992; Loewenstein et al., 1995; Razani et al., 2011; Razani, Casas, et al., 2007). These authors, coincidentally, used the same objective assessment measure of ADL; perhaps the nature of objective assessment measures of ADL encourages presentation of data from individual ADL, although recently studies have begun to investigate the association between executive function and specific ADL using questionnaires (Hall et al., 2011; Chapter 4).

2.6 Conclusions

The meta-analysis supports the clinical observation that executive function is associated with everyday functional ability, including driving, in Alzheimer's disease though the association was found to be moderate. The findings also show that cognitive status, as indexed by MMSE score, is associated with functional ability in people with Alzheimer's disease, indicating that while executive function is an important component of everyday functioning in Alzheimer's disease, other elements including cognitive status also affect everyday activities and tasks. Older age was found to impair functional ability, though age had little impact on executive function test performance. Thus, a person with Alzheimer's disease who is older, has an impaired MMSE score and evidence of executive dysfunction is likely to have greater functional disability. It is recommended that clinicians should conduct a detailed functional assessment and consider rehabilitation techniques designed to improve executive function, as this is likely to assist in improving or maintaining functional ability, which in turn supports independence and contributes to an increased quality of life. Any intervention approach should be tailored to the age of people with Alzheimer's disease since it is likely that older people with Alzheimer's disease will have different rehabilitation needs from younger people with Alzheimer's disease.

Chapter 3

Predictors of objectively-assessed, self-rated and informant-rated ability in instrumental activities of daily living in community-dwelling older people: associations with executive function and cognitive screening measures

3.1 Abstract

With the association between cognition and instrumental activities of daily living (iADL) in dementia clearly established, there is a need to identify cognitive predictors of potential functional decline in healthy older people. This study investigated the extent to which tests of executive function and cognitive screening predict functional ability and ratings of perceived functioning in 59 community-dwelling healthy older people. To assess functional ability, an objective test of iADL, an informant-rated questionnaire and two self-rated questionnaires, one given before and one after the objective test was administered, were employed. Eight executive function test scores, four traditional tests taken from the Delis-Kaplan Executive Function System and four ecologically-valid tests, including the Zoo Map test from the Behavioural Assessment of the Dysexecutive Syndrome, were employed along with the Addenbrooke's Cognitive Examination-Revised (ACE-R) as a cognitive screening measure. Only Trail Making Test Part 4 (TMT4) and ACE-R correlated with self-rated or informant-rated functioning. Both traditional and ecologically-valid tests of executive function, and cognitive screening tests, were found to correlate with objective functional ability, though only TMT4 and ACE-R predicted objective functional ability. TMT4 may be a useful screening tool to monitor functional decline in older people. When compared with objective iADL performance, informant ratings were found to be more accurate whereas self-rated iADL were found to underestimate functional ability. It is recommended that objective assessment measures or informant ratings of functioning be used when making functional assessments of older people.

3.2 Introduction

The continued ability to live independently is a common concern for older people (Mack et al., 1997), and changes in everyday functioning are central to understanding the health and well-being of older people (Applegate, Blass, & Williams, 1990). Complex everyday functional tasks are critical for living independently, and include abilities such as using a telephone, managing finances, managing medication and driving, referred to as instrumental activities of daily living (iADL). These everyday functional abilities are influenced by the cognitive ability of older people (McGuire et al., 2006; Vaughan & Giovanello, 2010). Older people with iADL disability are at an increased risk of developing dementia, especially with concomitant cognitive and memory problems (Sikkes et al., 2011), and it is therefore important to investigate how changes in functional abilities affect older people, and how performance of everyday activities relates to cognitive status.

One area of cognition which may be especially important is executive function. Executive function can be defined as a number of distinct high-level cognitive processes that control everyday actions and thoughts, such as planning, organisation, decision-making and self-control (Chan, Shum, Toulopoulou, & Chen, 2008; Goh, An, & Resnick, 2012; Henry, von Hippel, & Baynes, 2009). Indeed, it is to be expected that deficits in areas such as planning, self-control, organisation, and awareness of problems may negatively impact on daily functioning, since more complex cognitive abilities should be required to complete complex everyday activities. A number of studies have investigated the association between executive function and iADL in older people. Bell-McGinty et al. (2002) found that five tests of executive function explained 54% of the variance in objective functional ability, though only the Trail Making Test-Part B (TMT-B) and the Wisconsin Card Sorting Test were individually significant. Similarly, Cahn-Weiner et al. (2002) reported that TMT-B individually predicted 26% of the variance in objective iADL performance, while both TMT-B and Letter Fluency predicted 34% of the variance in informant ratings. Mitchell and Miller (2008b) found that a composite executive function score predicted objective iADL performance but only the Trail Making Test 4 (TMT4) from the Delis-Kaplan Executive Function System (D-KEFS; Delis, Kaplan, & Kramer, 2001), which is analogous to the TMT-B, individually predicted objective iADL performance. TMT4 is commonly conceptualised as a test of set-switching, and a recent study found that executive function and particularly set-switching significantly predicted objective iADL performance (Vaughan &

Giovanello, 2010); therefore executive function, especially set-switching as measured by the TMT4, may be an especially important predictor of functional ability in older people.

Cognitive screening measures, such as the Mini-Mental State Examination (MMSE: Folstein et al., 1975) or the Addenbrooke's Cognitive Examination-Revised (ACE-R: Mioshi, Dawson, Mitchell, Arnold, & Hodges, 2006), are also significant predictors of functional ability in older people, with a recent review reporting that tests of executive function and cognitive screening measures explained significantly more variance in functional ability in older people than memory, attention or verbal measures (Royall et al., 2007). A study that combined tests of executive function and cognitive screening measures found that the cognitive screening measure predicted all but one of the subscales of an objective performance measure whereas Letter Fluency and TMT-B predicted only two of the subscales, and in both cases the cognitive screening measure accounted for a greater proportion of the variance in performance (Baird et al., 2001). It remains to be determined whether the relationship between cognitive screening tests and functional ability is stronger than the more frequently explored relationship between functional ability and executive function.

Not only is there a lack of clarity surrounding the relationship between functional ability and tests of executive function and cognition, but there is also uncertainty about how best to measure everyday functional ability. Different methods of assessing iADL often lead to different conclusions, with overestimation in self-reports a common finding not just in people with dementia (Clare, Nelis, Martyr, Whitaker, et al., 2012; Kiyak et al., 1994; Ott et al., 1996) but also in older people without dementia (Kempen et al., 1996; Sager et al., 1992; Vaughan & Giovanello, 2010; Willis, 1996). When compared with objective performance, self-ratings of performance of basic activities, like bathing, eating and dressing, may be more accurate than informant ratings (Dorevitch et al., 1992), though evidence for this is mixed (Elam et al., 1991), and a study that combined basic and instrumental activities of daily living found that objective performance correlated more strongly with informant ratings than self-ratings (Little et al., 1986). More recently, Mitchell and Miller (2008a) found that objective functional performance was relatively normally distributed whereas self-ratings of functioning were heavily skewed towards the more negative end of the range, this ceiling effect indicating that self-ratings of iADL in older people may not accurately reflect their current functional ability. Suchy et al. (2011) compared objective performance with self-

ratings and found that the under-estimation of functional ability was associated with better executive function while the overestimation of functional ability was associated with poorer crystallised intelligence. The accuracy of self-rated functional ability is therefore unclear. Myers et al. (1993) found good correspondence between performance and self-reported ability when the wording of questionnaires matched objective tasks, suggesting that accuracy of ratings could be increased by altering the content of questionnaires. However, a recent study found that, despite questions being selected to match objective tasks, self-ratings made by a sample of centenarians overestimated functional ability compared with both informant ratings and objective performance, and objective performance was significantly less strongly correlated with self-ratings than informant ratings (Mitchell et al., 2011). Therefore the accuracy of perceived functioning when compared with objective performance, and the variability of results among different methods of investigating iADL, are important factors to consider when investigating everyday functional ability in older people.

Accuracy of appraisal of functional ability is a relatively understudied area despite many researchers and clinicians relying on self-reports or informant reports, in both people with dementia and healthy older people, to evaluate current functioning. Questionnaires where items map onto an objective assessment of functional ability have been employed previously (Mitchell et al., 2011; Myers et al., 1993) but no study to our knowledge has employed a metacognitive approach. Therefore to assess rating accuracy an informant rating and two self-ratings of perceived functional ability will be obtained. A self-rated prediction will be obtained before participants perform the task and a self-rated postdiction will be obtained immediately after participants perform the task. In summary, the current study will (1) explore the intercorrelations between self-rated predictions, self-rated postdictions, informant ratings of functional ability and objective assessment of functional ability; (2) examine the accuracy of self-ratings of performance made before and after the objective task is administered, and the accuracy of informant ratings of ability, by comparing these with scores on an objective assessment of functional ability; and (3) examine in more detail how tests of executive function and cognitive screening measures relate to functional ability and perceived functional ability.

3.3 Method

3.3.1 Design

This paper presents data from a study investigating the association between executive function and iADL in a sample of community-dwelling older people. Ethical approval was granted by the Bangor University School of Psychology Ethics Committee (see Appendix A). To be included participants had to live independently in their own homes, have an MMSE score of 26 or above and be able to communicate verbally in English. They also had to have someone who could provide informant ratings; informants were typically spouses, though adult children, friends and other family members also provided ratings in some cases.

3.3.2 Measures

3.3.2.1 Functional ability

iADL performance: modified Direct Assessment of Functional Status (DAFS)
The DAFS is a performance-based test of activities of daily living. The version used in the current study was an amalgamation of the original DAFS (Loewenstein et al., 1989) designed to investigate activities of daily living in people with dementia and a recent revision designed to investigate iADL in healthy older people (McDougall Jr. et al., 2010). The original DAFS consisted of seven subscales: time orientation, communication abilities, financial skills, shopping, driving, dressing/grooming skill and eating. The dressing/grooming skill and eating subscales were excluded from the current study as unsuitable for healthy, community-dwelling older people. The recent revision consisted of four subscales: communication, financial, shopping and medications. The communication, financial and shopping subscales were identical to or slightly modified from the original scale whereas the medication subscale was entirely new. The test used in the current study included six subscales, time orientation, communication abilities, financial skills, shopping, driving and medications (see Appendix J) and had a maximum possible score of 122, with a higher score indicating better functional ability.

iADL questionnaires. Two self-rated questionnaires, one for completion prior to the objective assessment (prediction; Appendix J) and one for completion following the objective assessment (postdiction; Appendix J), and one informant-rated questionnaire (Appendix K) were devised for the purposes of the study. Individual questions directly addressed the ability or function assessed by the parallel DAFS items. Each questionnaire contained 19 questions and used a five-point Likert scale (0 = very poor, 1 = poor, 2 = alright, 3 = good, and 4 = very good). The self-rated prediction questionnaire formed part of the standardised instructions, and was completed immediately prior to the corresponding DAFS item; for example, 'I'm going to ask you to write a cheque to yourself for £400.00. Using these words, how do you think you will do on this test?' The self-rated postdiction questionnaire was completed immediately after the corresponding DAFS item; for example, 'You were asked to write a cheque to yourself for £400.00. Using these words, how do you think you did on this test?' The informant-rated questionnaire was administered before the participant undertook the DAFS; for example, 'Your relative/friend has to write a cheque to him/herself for £400.00. Circle the number which you think best describes how s/he would do'. All three questionnaires had a maximum possible score of 76, with a higher score indicating less perceived functional impairment. All three questionnaires had good internal consistency: self-rated prediction Cronbach's $\alpha = .92$, self-rated postdiction Cronbach's $\alpha = .90$, informant rating Cronbach's $\alpha = .89$.

Comparison of iADL methods. All functional assessment scores were converted into a percentage of the maximum possible score to enable direct comparison. The three questionnaire scores were created using the formula (questionnaire score/76)*100. However, since the DAFS has variable scoring systems within the assessment (i.e. the score for driving is between 0 and 13, while scores for other subtests range from 0-4 and 0-8), some additional conversion is required, otherwise the driving assessment would be given more weight in the total score. Therefore, each subtest total score was converted to a score of 100, i.e. for a subtest scored between 0 and 4, a score of 2 would be converted to 50, while for the driving ability subtest a score of 2 would achieve a score of 15.39. The scores out of 100 for the 19 subtests were then summed and converted to a percentage score using the formula: (DAFS converted score/1900)*100.

3.3.2.2 Executive function

3.3.2.2.1 Traditional neuropsychological tests

D-KEFS: Trail Making Test (Delis et al., 2001)
This is a series of five visual-motor tasks, though only the score for the fourth (TMT4) was used in this study. TMT4 is the main executive component of the test, and participants have to connect both numbers and letters in ascending order while switching between the two (i.e. 1-A-2-B-3-C and so on). TMT4 has a time limit of 240 seconds and once this was reached participants were instructed to stop. Time taken to complete the test was the score used in this study, with a higher score indicating poorer performance.

D-KEFS: verbal fluency (Delis et al., 2001)
This is a series of three tests of verbal executive function, and scores for all three were included in this study. Letter Fluency asks participants to produce as many words as they can in 60 seconds beginning with a certain letter; this was repeated three times with different letters (F, A & S) and the total score for the three conditions was used in the analysis. Category Fluency asks participants to name as many different animals and different boys' names as they can in 60 seconds; the total score for the two conditions was used in the analysis. Switching Accuracy asks participants to switch between naming as many different types of fruit and different items of furniture as they can in 60 seconds; total switching accuracy was used in the analysis, i.e. if a participant said Apple-Chair-Banana-Cherry, this would give a score of two switches despite all four words being from the desired categories. For all tests a higher number of correct responses indicates better performance.

3.3.2.2.2 Ecologically-valid neuropsychological tests

Behavioural Assessment of the Dysexecutive Syndrome: Zoo Map Test (B. A. Wilson et al., 1996)
In this test participants are required to plan the most efficient route to visit a series of eight designated animal enclosures on a map of a zoo. Planning ability is examined in the first part of the test, and this is followed by a second condition that assesses how well participants can follow instructions when the most efficient route is indicated to them. For both parts a higher score indicates better performance; one point is awarded for each of the specified locations

visited in the correct order, and one point is subtracted for any errors that were made, such as visiting non-specified locations. The score for the first part of the test was used in the current analysis.

The Hayling Test (Burgess & Shallice, 1997)
The Hayling Test consists of two sets of 15 sentences with the last word missing in each case. In the first part of the test participants have to produce a word that best fits each sentence. In the second part of the test participants have to complete sentences by inhibiting the word that best fits the sentence and replacing it with an unconnected word. Errors in part two can either be caused by giving a word that fits the sentence (Category A error) or by giving a word that is semantically related to a word that fits the sentence (Category B error). The number of Category A errors and Category B errors produced in the second part of the test were used in the analysis.

Test of Everyday Attention: Map Search (Robertson, Ward, Ridgeway, & Nimmo-Smith, 1994)
In this test participants have two minutes to find as many of the 80 designated symbols on a coloured A3-sized map (297mm X 420mm) as they can. A higher score indicates better performance.

3.3.2.3 Screening tests for cognition and mood

Addenbrooke's Cognitive Examination-Revised (Mioshi et al., 2006)
The ACE-R is a cognitive screening tool that assesses five cognitive domains: attention and orientation, memory, verbal fluency, language and visuospatial perception skills. It also provides the widely used MMSE score. The maximum total score is 100, with higher scores indicating better performance.

National Adult Reading Test-Revised (NART-R: Nelson & Willison, 1991)
The NART-R is a well-established tool to estimate intelligence. It consists of a list of 50 phonetically irregular words (such as chord, ache etc) that participants read aloud. The score is between 0 and 50 errors with fewer errors indicating a higher IQ. An estimated IQ score was used in the analysis to aid interpretation.

Geriatric Depression Scale-Short Form (GDS-15: Yesavage & Sheikh, 1986)
The GDS-15 is a 15-item measure of depression requiring yes/no responses, designed especially for an older population (Appendix L). The maximum score is 15, with higher scores indicating greater depressive symptoms. Scores between 0 and 4 suggest no evidence of depression, scores between 5 and 9 suggest mild depression whereas scores between 10 and 15 suggest moderate to severe depression (Alden, Austin, & Sturgeon, 1989).

Apathy Scale (Starkstein et al., 1992)
The Apathy Scale is a screening tool for apathy and consists of 14 questions with answers made on a four-point Likert scale (Appendix M). The maximum score is 42 and a score above 14 suggests a clinically significant level of apathy.

3.3.3 Planned analyses

To examine the first research question, Spearman's rho correlations were conducted to investigate the intercorrelations between self-rated predictions, self-rated postdictions, informant ratings and objectively-assessed iADL performance. To test for significant skew, the skew of the ratings and the objective performance score was converted to z scores. For the second research question, total scores for the DAFS and the three questionnaires were converted to percentages, and Wilcoxon signed rank tests were used to compare the functional ratings with objectively-assessed functional ability in order to evaluate their accuracy. For the third research question, Spearman's rho correlations were conducted to investigate the relationship between raw scores for each type of iADL assessment and neuropsychological test scores, depression, apathy, age and years of education. Significant correlations were entered into stepwise regressions using the default criterion probability of F-to-remove $\geq .10$ with SPSS v.20. The model that accounted for the greatest variance, as indicated by the adjusted R^2, was chosen as the best predictor of functional ability. To aid comparison, effect sizes were calculated for z scores and Wilcoxon signed rank tests using the formula; $r = Z\sqrt{N}$ (Rosenthal, 1991). Holm-Bonferroni correction for multiple comparisons was applied to all analyses.

3.4 Results

Fifty-nine older people (35 females) provided self-ratings and performance measures for the study; see Table 3.1 for participant characteristics. The participants included 23 married couples, where each member of the couple acted as both participant and informant. For the other 13 participants, informant ratings were provided by friends (*n* = 6), adult children (*n* = 3) or other family members (*n* = 3), and one person did not have informant ratings as the informant declined to take part. All participants completed all tests, except for the TMT4 where data were lost for one participant due to researcher error; see Table 3.1 for mean test scores.

Table 3.1 Demographic information and mean scores on all measures

	n	Mean (SD)	Range
Demographics			
Age	59	72.05 (6.24)	63 - 94
Years of education	59	14.03 (2.31)	10 - 18
Number of health conditions reported	59	1.56 (1.24)	0 - 6
Number of prescribed medications currently taken	59	2.56 (2.94)	0 - 14
Screening tests			
Mini-Mental State Examination	59	28.73 (0.98)	26 - 30
Addenbrooke's Cognitive Examination-Revised	59	92.29 (4.68)	74 - 99
National Adult Reading Test-Revised IQ score	59	112.25 (10.74)	79 - 128
Geriatric Depression Scale-15	59	1.88 (1.95)	0 - 8
Apathy Scale	59	10.39 (4.46)	3 - 20
Functional ability assessments raw scores			
Direct Assessment of Functional Status	59	112.02 (5.85)	96 - 122
Self-rated predictions of functional ability	59	59.80 (9.95)	36 - 75
Self-rated postdictions of functional ability	59	61.80 (9.56)	36 - 74
Informant ratings of functional ability	58	66.54 (8.11)	41 - 76
Functional ability assessments percent of maximum score			
Direct Assessment of Functional Status	59	92.04% (4.60)	80.44 - 100%
Self-rated predictions of functional ability	59	78.68% (13.10)	47.37 - 98.68%

Self-rated postdictions of functional ability	59	81.31% (12.59)	47.37 - 97.37%
Informant ratings of functional ability	58	87.55% (10.67)	53.95 - 100%
Traditional executive function tests			
Trail Making Test 4	58	120.19 (57.31)	42 - 240[a]
Letter Fluency	59	41.07 (14.42)	11 - 74
Category Fluency	59	38.00 (9.96)	21 - 65
Switching Accuracy	59	11.41 (3.17)	3 - 17
Ecologically-valid executive function tests			
Zoo Map	59	1.44 (4.53)	-10 - 8
Map Search	59	53.90 (12.47)	27 - 76
Hayling Category A errors	59	1.85 (2.44)	0 - 13
Hayling Category B errors	59	3.42 (2.39)	0 - 9

[a] Six people failed to complete Trail Making Test 4 within the time limit.
Note: standard deviations in parentheses.

As indicated by NART-R IQ scores and years of education, the sample were well-educated. There was no evidence of clinically-significant depression; 7 participants fell within the mild depression range, though only two scored higher than 5. There was slightly more evidence for apathy, with 15 participants scoring above the cut-off of 14. Those who displayed significant apathy performed more poorly on all tests, although *t* tests indicated no significant differences after Holm-Bonferroni correction. When asked to give a rating of subjective health in comparison with other people of equivalent age only six participants rated their health as below average, 14 rated their health as average, 26 rated their health as above average, and 13 rated their health as excellent. No one rated his/her health as poor. The number of health conditions reported correlated significantly with depression, $rs(57) = .39$, $p = .002$. After Holm-Bonferroni correction, no other test or measure was associated with the number of health conditions reported or the number of prescribed medications being taken. There were no sex differences for any measure. After correcting for multiple comparisons there were few significant correlations among the tests of executive function. Indeed, only Letter Fluency and Category Fluency were found to correlate significantly. There was a more consistent association between tests of executive function and both ACE-R and NART-R IQ. The intercorrelations between tests of executive function and cognitive screening measures are shown in Appendix N.

3.4.1 The relationship between self-ratings, informant ratings and objective functional ability

There was significant skew for informant ratings, z = -3.36, $p < .001$, $r = -.44$, though after Holm-Bonferroni correction self-rated postdictions, z = -2.21, $p = .027$, $r = -.29$, and objective performance (DAFS), z = -2.26, $p = .024$, $r = -.29$, were not significantly skewed. There was no significant skew for self-rated predictions, z = -1.76, $p = .079$, $r = -.23$. Few functional difficulties were present as indicated by the negative skew and the corresponding means in Table 3.1. The DAFS total score significantly correlated with self-rated predictions, $rs(57) = .38$, $p = .003$, self-rated postdictions, $rs(57) = .51$, $p < .001$, and informant-rated functioning, $rs(56) = .43$, $p < .001$. Informant-rated functioning correlated with self-rated predictions, $rs(56) = .31$, $p = .018$, and self-rated postdictions, $rs(56) = .29$, $p = .027$. Self-rated prediction ratings were highly correlated with self-rated postdiction ratings, $rs(57) = .84$, $p < .001$. The associations between all four functional assessment methods suggest that self-rated prediction, self-rated postdiction and informant ratings were similar to objective performance scores.

3.4.2 Accuracy of functional ratings compared with objective performance

To investigate the accuracy of functional ratings, a series of Wilcoxon signed rank tests were used to compare the percentage scores for DAFS with the percentage scores for the three questionnaires; see Table 3.1 for mean percentage scores. The DAFS score was significantly higher than the self-rated prediction score, Z = -6.04, $p < .001$, $r = -.79$, self-rated postdiction score, Z = -5.87, $p < .001$, $r = -.76$, and informant-rated score, Z = -2.72, $p = .010$, $r = -.36$. While informant-rated functional ability was significantly different from the objective performance score, the effect sizes for self-rated prediction and self-rated postdiction were considerably larger than the effect size for informant rating suggesting that informant-rated functional ability was more accurate than self-rated functioning when compared with objective performance. The informant-rated score was significantly higher than self-rated prediction scores, Z = -4.14, $p < .001$, $r = -.54$, and self-rated postdiction scores, Z = -3.22, $p = .001$, $r = -.42$. Finally, the self-rated postdiction score was significantly higher than the self-rated prediction score, Z = -2.58, $p = .010$, $r = -.34$. These findings indicate that the accuracy of self-ratings improved after performing the test, although this increase in accuracy was marginal when compared with both informant-rated functioning and objective

Table 3.2 Correlations between functional ability and neuropsychological test scores

	DAFS		Self-Ratings				Informant Ratings	
	Total score	*p*	Prediction total score	*p*	Postdiction total score	*p*	Total score	*p*
Demographics								
Age	-.375	**.003**	-.065	.623	-.134	.312	-.202	.128
Years of Education	.430	**.001**	.199	.131	.290	.026	.144	.281
Screening tests								
ACE-R	.604	**< .001**	.446	**< .001**	.447	**< .001**	.279	.034
NART-R	.433	**< .001**	.202	.124	.304	.019	.208	.117
GDS-15	-.287	.027	-.335	.010	-.131	.322	-.126	.345
Apathy Scale	-.133	.317	-.236	.072	-.252	.054	-.171	.200
Traditional tests of executive function								
TMT4	-.641	**< .001**	-.335	.010	-.477	**< .001**	-.412	**.001**
Letter Fluency	.370	**.004**	.126	.343	.299	.021	.092	.492
Category Fluency	.501	**< .001**	.255	.051	.357	.005	.245	.064
Switching Accuracy	.165	.211	.106	.423	.147	.267	.075	.577
Ecologically-valid tests of executive function								
Zoo Map	.365	**.004**	-.009	.945	.051	.704	.122	.363
Map Search	.478	**< .001**	.105	.428	.175	.184	.162	.225
Hayling Category A errors	-.227	.084	-.044	.740	-.131	.323	-.113	.400
Hayling Category B errors	-.125	.345	.005	.972	-.152	.251	-.186	.161

Note: bold indicates significance at the 5% level after Holm-Bonferroni correction.

Abbreviations: Direct Assessment of Functional Status (DAFS), Addenbrooke's Cognitive Examination-Revised (ACE-R), National Adult Reading Test-Revised (NART-R), Geriatric Depression Scale-15 (GDS-15), Trail Making Test 4 (TMT4).

performance scores. Therefore, self-ratings of functioning suggest that more functional difficulties were present than both informant-rated and objective performance; this was consistent even when ratings were made immediately after objective performance, suggesting that self-ratings of functional ability by healthy older people may tend to underestimate their iADL performance.

3.4.3 The relationship between functional ability and executive and cognitive screening tests

Objectively-assessed performance was significantly related to five of the eight executive function test scores, particularly TMT4; see Table 3.2. Objectively-assessed performance was also significantly related to years of education, age, NART-R IQ and ACE-R score. Only ACE-R was found to significantly correlate with self-rated predictions, with no significant relationship between any executive function test and self-rated predictions of perceived functioning. ACE-R and TMT4 correlated with self-rated postdictions of perceived functioning, and a stepwise regression showed that only TMT4, $\beta = -.44$, $p < .001$, predicted self-rated postdictions, $F(1, 56) = 13.05$, $R^2 = .18$, $p < .001$.

Only TMT4 correlated with informant-rated functioning. The results therefore confirm that executive function, as measured by TMT4, and cognitive screening measures are important correlates of objective iADL performance. There is less support for the association between tests of executive function and ratings of functioning, though where significant associations were found only TMT4 and ACE-R correlated with functional ratings.

3.4.4 Predictors of objective functional ability

The nine test scores and demographic variables that significantly correlated with objectively-assessed performance were entered into a stepwise regression; results are summarised in Table 3.3. Total score for the DAFS was significantly predicted by the model, $F(3, 54) = 26.91$, adjusted $R^2 = .58$, $p < .001$, with both TMT4 and ACE-R individually significant; NART-R estimated IQ was also included in the model though this was not significant after correcting for multiple comparisons. Therefore, TMT4 and ACE-R may be the best predictors of objectively-assessed iADL performance. An additional stepwise regression was conducted

to investigate how well the five ACE-R subscales predicted objectively-assessed functional ability. DAFS total score was significantly predicted by the model, $F(3, 55) = 13.59$, adjusted $R^2 = .39$, $p < .001$, with language ($\beta = .41$, $p < .001$), memory ($\beta = .29$, $p = .006$) and visuospatial perception ($\beta = .28$, $p = .014$) subscales individually significant, suggesting that language, memory and visuospatial ability may play a role in predicting functional ability.

Table 3.3 Predictors of objective functional ability

	Direct Assessment of Functional Status	
adjusted R^2	.577	
	ß	*p*
Trail Making Test 4	-.370	**< .001**
Addenbrooke's Cognitive Examination-Revised	.356	**.002**
National Adult Reading Test-Revised IQ score	.222	.032

Note: bold indicates significance at the 5% level after Holm-Bonferroni correction.

3.5 Discussion

This study investigated the extent to which scores on tests of executive function and cognitive screening predict self-ratings and informant ratings of functioning, and objectively-assessed performance of functional ability, in healthy older people. Consistent with previous research (Mitchell & Miller, 2008a), scores on tests of executive function were found to correlate more strongly with objectively-assessed iADL performance than with ratings of perceived functioning. Indeed, only the Switching Accuracy component of the D-KEFS verbal fluency test and the two Hayling Category error conditions did not significantly correlate with objectively-assessed iADL performance, whereas no test of executive function correlated with self-rated predictions of functioning and only TMT4 correlated with informant-rated functioning and self-rated postdiction ratings of functioning. This finding in healthy older people is different to the pattern found in people with Alzheimer's disease, since a recent meta-analysis showed that tests of executive function are moderately correlated with self-

rated and informant-rated perceived functioning and objective functional performance in Alzheimer's disease (see Chapter 2). Supporting the conclusions of Royall et al. (2007), there was a more consistent association between cognitive status and functioning with only informant-rated functioning failing to show an association with ACE-R. This suggests that general cognitive status, rather than specific cognitive abilities like executive function, may be related to self-ratings of functioning. Despite the strong correlational relationship found between objectively-assessed functional ability scores and both scores on tests of executive function and screening tests, the only significant predictors of objectively-assessed functional ability were TMT4 and ACE-R. This is generally consistent with previous research where either TMT4 (Bell-McGinty et al., 2002; Cahn-Weiner et al., 2002; Mitchell & Miller, 2008b) or cognitive screening tests (Baird et al., 2001) were shown to significantly predict everyday functional ability in older people. Interestingly, in contrast with Baird et al. (2001) who found that the Mattis Dementia Rating Scale (Jurica et al., 2001; Mattis, 1988) predicted more variance in objective iADL ability than tests of executive function, we found that TMT4 and ACE-R were equally effective in predicting objective iADL ability. Baird et al. (2001) may have included people with early dementia, since the mean Mattis Dementia Rating Scale score was 121 and the cut-off for dementia is 132 (Matteau et al., 2011), which may partly explain the disparity between the two studies. The findings, therefore, indicate that a cognitive screening measure (ACE-R) and a test of set-switching (TMT4) predict functional ability in healthy older people.

All four methods of assessing functional ability were intercorrelated, with similar correlation effect sizes. This consistent association may have been due to the use of questionnaires in which items were matched to the content of the objective functional assessment, since this has previously been shown to increase the concordance between functional ratings and performance on a functional assessment (Myers et al., 1993). In a recent study that also employed similarly worded questionnaires, Mitchell et al. (2011) found that there was a stronger association between objectively-assessed performance and informant ratings than self-ratings, suggesting that informant ratings were more accurate than self-ratings. Consistent with Mitchell et al. (2011), we found that informant ratings were more accurate than self-ratings, though it should be noted that informant ratings of functioning were still significantly different from objective iADL performance. However, whereas Mitchell et al. (2011) found that self-ratings reflected a perception of better functional ability, we found that self-ratings suggested a perception of poorer functional ability. We also found evidence that

self-rated postdictions were more accurate than self-rated predictions of performance, which was consistent with previous findings from investigations of memory performance (Clare, Whitaker, et al., 2010) and word recognition (Tullis & Benjamin, 2012), though informant-rated functioning was still more accurate than self-rated postdictions. Therefore, rewording questionnaires to match functional tasks may make it more likely that ratings made by older people involve an under-estimation of functional ability, whereas the same approach may make informant ratings more accurate. This has important clinical implications since functional assessments of older people are typically conducted with self-rated questionnaires, and the findings suggest that self-ratings of functional ability may not be accurate. When standard self-rated questionnaire methods of assessing functioning are used, older people typically *overestimate* perceived functional ability (Kempen et al., 1996; Sager et al., 1992; Vaughan & Giovanello, 2010; Willis, 1996), whereas we found that participants *under-estimate* perceived functional ability. This suggests that, to accurately assess functional ability in older people, objective assessment measures or informant ratings should be used in place of self-rated questionnaires.

Two common methodological issues that frequently occur in the literature are a failure to correct for multiple comparisons and the recruitment of potentially non-representative samples of older people. Correction for multiple comparisons is important as failure to do so may artificially inflate the number of tests associated with functional ability. For example, without applying Holm-Bonferroni correction both TMT4 and ACE-R were significantly correlated with self-rated and informant-rated functional ability. This finding is similar to that of Cahn-Weiner et al. (2002), but after we applied retroactive Holm-Bonferroni correction to their data, Letter Fluency was no longer significant and only TMT-B significantly predicted informant-rated functional ability and objective performance. Similarly, after we applied correction for multiple comparisons to the data from Bell-McGinty et al. (2002), the Wisconsin Card Sorting Test no longer predicted objectively-assessed functional ability and only TMT-B remained significant. Therefore, this frequent failure to correct for multiple comparisons may explain the relatively equivocal evidence for correlates of ratings of perceived functioning, though the set-switching component of the Trail Making Test appears to be a consistent significant predictor of everyday functional performance in older people. An additional methodological problem relates to recruiting from non-representative samples. As discussed previously, Baird et al. (2001) included people who had been referred for a dementia assessment and who may potentially have been in a pre-clinical stage of dementia.

This is an important consideration since there is evidence that functional ability (Pérès et al., 2008) and cognition (R. S. Wilson et al., 2012) begins to decline at least five years before a diagnosis of dementia. Bell-McGinty et al. (2002) also included 35 people who were referred for a dementia assessment, and a further nine who were resident in a nursing home, which likely influenced their functional ability as they no longer took care of themselves; in fact only six participants were healthy community-dwelling individuals similar to those included in the current study. Similarly, Cahn-Weiner et al. (2002) made no attempt to exclude people with a history of psychiatric or medical conditions, and consequently some of their 30 participants may have had dementia or some other condition that could influence both functional ability and cognitive tests scores, though this is difficult to determine since there was little demographic information provided. Additionally, earlier studies typically consisted of samples recruited from selective communities, such as hospital inpatients (Elam et al., 1991; Magaziner et al., 1997; Sager et al., 1992), care home residents (Little et al., 1986), those living in sheltered accommodation (Myers et al., 1993; Royall, Palmer, Chiodo, & Polk, 2004, 2005) or those at risk of developing dementia (Jefferson, Paul, Ozonoff, & Cohen, 2006). Only by excluding people with acute health problems and those living in care can we gain an understanding of the functional abilities and difficulties of healthy older people living in the community. A strength of the current study, in line with other recent studies (Mitchell & Miller, 2008a, 2008b; Mitchell et al., 2011; Suchy et al., 2011; Vaughan & Giovanello, 2010) has been the focus on older people who still live in their own homes and who are still active in the community.

The study has some limitations. Demographic variables may limit the generalisability of the study. Age has been shown to influence everyday problem solving (Allaire & Marsiske, 1999; Blanchard-Fields, Chen, & Norris, 1997; Diehl, Willis, & Schaie, 1995) with 70 being suggested as the age where functional ability begins to rapidly decline (Willis, 1996) and from which performance on tests of executive function and working memory show steep declines (Hultsch, Hertzog, Small, McDonald-Miszczak, & Dixon, 1992). Therefore, the inclusion of people under the age of 70 may have resulted in underestimation of the association between iADL and executive function. The sample was also well-educated, and while the education level in our sample was consistent with previous studies that have investigated objective functional ability in older people (Bell-McGinty et al., 2002; Cahn-Weiner et al., 2002; McDougall Jr. et al., 2010; Mitchell & Miller, 2008a, 2008b; Vaughan & Giovanello, 2010), this reduces the ability to generalise the findings to people with lower

levels of education. There is a paucity of research into the effect that low levels of education has on everyday functional ability in older people; this is especially important as we and others (Herzog, Franks, Markus, & Holmberg, 1998; Mitchell & Miller, 2008b) have found that education influences functional ability. The inclusion of a wider range of cognitive assessments rather than focussing on tests of executive function would have potentially benefitted the study. The ability to remember objectives and goals has been shown to benefit successful completion of everyday tasks (Infurna, Gerstorf, Ryan, & Smith, 2011) and consequently the inclusion of a memory test may have accounted for some of the remaining 32% of the variance between cognition and iADL. In fact the language, memory and visuospatial perception subscales of the ACE-R were found to significantly predict objective performance, suggesting that future studies of the functional ability of older people should include tests of memory, language and visuospatial ability, though a recent longitudinal study suggests that for healthy older people executive function is more important than memory for predicting functional ability (Farias et al., 2009). The study relied upon self-reported medical history rather than obtaining objective information from medical records; this may attenuate the assertion that the sample was healthy since some participants may not have wanted to share an accurate medical history with younger researchers. However, as all participants were able to live independently without the need for assistance and all but six of the participants when asked to describe their subjective health compared with others their age responded that their health was average or better, it seemed reasonable to assume that the sample generally consisted of healthy individuals. Finally, including the self-rated prediction questionnaire as part of the standardised instructions for the objective iADL performance test may have been a limitation since people who were performing better or worse may have adjusted their ratings in line with their test performance. If the prediction questionnaire was administered separately from the objective test, similar to the way in which the informant-rated questionnaire was administered, the associations between self-rated predictions and cognitive tests may have been different. However, since scores on the postdiction questionnaire were also significantly lower than those for both the objective assessment measure and the informant-rated questionnaire, this methodological concern may not have unduly influenced the accuracy of the self-rated prediction questionnaire. It should also be noted that, despite the significantly lower self-ratings of perceived functioning, we found relatively high means for all four methods of assessing functional ability.

3.6 Conclusions

There were few associations between ratings of functional ability and neuropsychological test scores, suggesting that an objective functional assessment may be more beneficial than relying on questionnaires, especially as self-rated functioning was generally less accurate when compared with objectively-assessed performance. Cognitive screening measures and tests of executive function were found to be significant predictors of objective iADL performance: people with higher scores on tests of executive function displayed better observed functional ability. After correcting for multiple comparisons the findings support the conclusions of previous research that set-switching (TMT4) may be an important predictor of functional ability in healthy older people. However, an additional test of set-switching, the D-KEFS Switching Accuracy verbal fluency subtest, was unrelated to both functional ability and the TMT4, suggesting that there may be something unique about the task demands of the TMT4 that makes it particularly suitable for predicting everyday functional ability. Older people with iADL disability and cognitive and memory problems may be at an increased risk of developing dementia (Sikkes et al., 2011) and therefore TMT4 could be a useful screening tool to monitor functional ability and, potentially, monitor clinically significant decline in people at risk of developing dementia.

Chapter 4

Verbal fluency and awareness of functional deficits in early-stage dementia

Martyr, A., Clare, L., Nelis, S.M., Marková, I.S., Roth, I., Woods, R.T., . . . Morris, R.G. (2012). Verbal fluency and awareness of functional deficits in early-stage dementia. *The Clinical Neuropsychologist, 26*, 501-519. doi: 10.1080/13854046.2012.665482

4.1 Abstract

Assessment of activities of daily living is an important element in the diagnosis of dementia, with research suggesting a link between functional ability and cognition. We investigated the relationship between self-ratings and informant ratings of instrumental activities of daily living (iADL) and verbal executive function in early-stage dementia. Ninety-six people with early-stage Alzheimer's disease, vascular or mixed dementia and their carers completed the Functional Activities Questionnaire; people with dementia also completed a test of Letter Fluency. Letter Fluency was associated with self-ratings of iADL, while informant ratings of iADL were associated with the age and Mini-Mental State Examination score of the person with dementia. Self-ratings of perceived functioning suggested significantly less impairment than informant ratings. Those with impaired Letter Fluency rated themselves as having greater difficulties in iADL than those who performed better. People with early-stage dementia vary in their subjective level of awareness of their iADL functioning, and difficulties with language production may contribute to better awareness of iADL impairments.

4.2 Introduction

There is a large body of research supporting the clinical observation that even in the early stages of their condition, people with dementia (PwD) show decline in their activities of daily living (ADL); indeed ADL decline is embedded in the diagnostic criteria for Alzheimer's disease, vascular dementia and mixed Alzheimer's disease and vascular dementia (American Psychiatric Association, 1994; World Health Organization, 1992). An hierarchical sequence of decline in ADL has been established (Spector et al., 1987). Instrumental activities of daily living (iADL), such as handling finances, shopping, using the telephone, and managing medication, are more vulnerable to the effects of early dementia (C. R. Green et al., 1993; Njegovan et al., 2001), with evidence for a direct link with cognitive function (Njegovan et al., 2001; Vitaliano et al., 1984). In contrast, basic activities of daily living such as bathing, toileting, feeding and dressing tend to be preserved for much longer and are linked with motor rather than cognitive difficulties (Boyle et al., 2002). Indeed, the relevance of iADL as an early diagnostic indicator is suggested by one large longitudinal study of prodromal Alzheimer's disease, exploring differences between those who do and those who do not later develop dementia ten years before diagnosis (Pérès et al., 2008). Those who went on to develop dementia had more difficulty with handling finances, transportation, using the telephone and managing medication and their performance declined more rapidly than that of those who did not go on to develop dementia. Pérès and colleagues also noted that the biggest decline in iADL performance was in the two years immediately preceding diagnosis.

A growing number of studies link reduced performance on Letter Fluency with declining iADL skills and abilities. Letter Fluency is a commonly used test of executive function. Executive function can be defined as a number of distinct high-level cognitive processes that control everyday actions and thoughts, and that enable us to perform complex, goal-directed behaviours (Elliott, 2003; Royall et al., 2002). Specifically, fluency processes are thought to involve the executive sub-domains of inhibition and initiation/response generation, though it is equally the case that Letter Fluency performance has language and semantic memory components (Jurado & Rosselli, 2007), and therefore it is likely that Letter Fluency utilises both executive and language processes. Letter Fluency has been investigated extensively in the early stages of Alzheimer's disease, with a meta-analysis finding considerable Letter and Semantic Fluency deficits (Henry et al., 2004). An example of the association between Letter Fluency and iADL is the finding by Giovannetti et al. (2008) that performance on Letter Fluency, the Clock Drawing Test and the

Mental Control subtest from the Boston Revision of the Wechsler Memory Scale (Cloud et al., 1995) correlated with errors made in everyday tasks, such as pouring too much cream into coffee so it overflows or buttering toast with a spoon or on both sides of the bread. Chen et al. (1998) found significant correlations between scores on an informant-rated iADL questionnaire and scores for Letter Fluency, the Wisconsin Card Sorting Test, and the Conceptualisation and Initiation subscales of the Mattis Dementia Rating Scale (Jurica et al., 2001; Mattis, 1988), again suggesting that fluency and additional tests of executive function have implications for iADL performance, though these associations were reduced after controlling for Mini-Mental State Examination score (MMSE: Folstein et al., 1975). Furthermore, a comprehensive study that investigated the relationship between iADL and cognition, including a number of executive tests (Wisconsin Card Sorting Test, Letter Fluency and the Trail Making Test, Sorting Test, Colour-Word and Tower Test subtests from the Delis-Kaplan Executive Function System; D-KEFS: Delis et al., 2001), found that in PwD scores for Letter Fluency, Wisconsin Card Sorting Test and the MMSE strongly correlated with functional status (Razani, Casas, et al., 2007). These studies suggest that Letter Fluency may be an important test when investigating the link between cognition and everyday functioning in PwD.

An additional issue, considered in this paper, is the possible link between verbal fluency, everyday functioning and awareness of functioning. The extent of awareness shown by a person with dementia regarding his/her everyday functioning is an important aspect for clinicians since increased awareness may facilitate rehabilitation training and promote safe, independent living for longer (Clare, Linden, et al., 2010), whereas poor awareness may result in unsafe or risky behaviour in everyday situations (Cotrell & Wild, 1999). Loss of awareness may be caused by or be mediated by other cognitive or functional decline, such that awareness and levels of neuropsychological function have been explored extensively (Morris & Hannesdottir, 2004) but there has been less emphasis on considering awareness in relation to measures of everyday functioning. Investigations of awareness in the sense of evaluative judgements about functioning in particular domains in PwD (Clare, Marková, et al., 2011), including everyday functioning, use the discrepancy between self-ratings and informant ratings as an index of awareness (DeBettignies et al., 1990). Studies that have investigated the relationship between evaluative judgements of everyday functioning and performance on neuropsychological tests have reported mixed associations with executive function in general with some indications of associations specifically with verbal fluency. For example, awareness of functional ability was found to be associated with the attention subscale of the Mattis Dementia Rating Scale, though not the

initiation subscale, which predominantly investigates verbal fluency (Kiyak et al., 1994). Ott et al. (1996) found an ADL discrepancy score was significantly associated with scores on the Trail Making Test-Part A and the Mazes planning test but not with other tests of executive function, although the association with Letter Fluency approached significance. Other methods of investigating awareness include performance monitoring, where participants make subjective evaluations of their performance before and after test completion, and error monitoring, where participants are assessed on their ability to detect and correct any errors that they make. A recent error monitoring study (Bettcher et al., 2008), found Letter Fluency was associated with awareness of everyday functional errors on a performance-based test of ADL. It remains, however, an unresolved issue as to whether Letter Fluency performance is linked to awareness of iADL ability; this may perhaps be dependent on the different methodologies employed since evaluative judgements have been shown to differ from performance monitoring judgements in a memory task (Clare, Whitaker, et al., 2010) and this may extend to judgements of functional ability.

The aim of the present study is to investigate the relationship between Letter Fluency performance and functional ability in people with dementia, taking into account both informant perceptions and self-ratings. As indicated above (Bettcher et al., 2008; Razani, Casas, et al., 2007), Letter Fluency performance could be an indicator of everyday functional ability and may be related to both informant ratings and self-ratings of functional ability. The study will also investigate whether informant ratings are affected by MMSE score (Chen et al., 1998) and whether type of dementia influences perceptions of iADL as these issues need to be considered when investigating the links between Letter Fluency and iADL. In summary, the current study (1) examines in more detail how Letter Fluency relates to self-ratings and informant ratings of perceived functional ability, with the prediction that self-ratings will show less perceived iADL impairment than informant ratings; (2) investigates ratings of individual iADL skills and how these relate to performance on the Letter Fluency task; and (3) explores how Letter Fluency performance varies across different subtypes of dementia diagnostic groups, and according to gender and level of perceived functional ability.

4.3 Method

4.3.1 Design

This paper presents data from the initial assessments conducted for the Memory Impairment and Dementia Awareness Study (MIDAS), a 3-year longitudinal study of dementia. Participants were recruited through six National Health Service memory clinics in North Wales. To be included, PwD had to have a diagnosis of probable or possible Alzheimer's disease, either multi-infarct or subcortical vascular dementia or mixed Alzheimer's disease and vascular dementia (ICD-10, World Health Organization, 1992), a score of 18 or above on the MMSE, a contributing informant and the ability to communicate verbally in English. Exclusion criteria were concurrent major depression, psychosis or neurological disorder and past history of neurological disorder or brain injury. Ethical approval was granted by the relevant University and National Health Service Ethics Committees.

4.3.2 Measures

Verbal executive function: D-KEFS Letter Fluency subtest (Delis et al., 2001). Participants have one minute in which to produce as many words as they can that begin with a specified letter; three letters are tested, F, A & S. The total score for correct responses to the three letters was used in the analysis, with more words indicating better Letter Fluency performance. Additionally, the D-KEFS allows age scaled scores to be calculated. These indicate how far above or below the mean a score is based on normative data; D-KEFS scaled scores have a mean of 10 and a standard deviation of 3. Using this delineation, the performance of those with a scaled score of 5 and below (below the fifth percentile) was classed as impaired and the performance of those with a scaled score of 15 and above (above the ninety-fifth percentile) was classed as superior. Those who remained were split into one of three groups; scaled scores between 6 and 8 were categorised as below average performance, between 9 and 11 as average performance, and between 12 and 14 as above average performance.

iADL: Functional Activities Questionnaire (FAQ: Pfeffer, Kurosaki, Harrah, Chance, & Filos, 1982). This is an 11-item questionnaire, modified from the original 10 items to include a question concerning telephone use: "Able to use telephone appropriately (e.g. finding and dialling correct numbers)". Possible scores range from 0-3 on each item, with a higher score

indicating greater perceived functional impairment (range 0-33). A score of 5 or more reflects perceived impairment in the original 10-item questionnaire (Pfeffer et al., 1982) and this cut-off was also used in the analysis. For this study a PwD self-rated (FAQ-S, Appendix O) and an informant-rated (FAQ-I, Appendix P) version was used. The two measures allowed for calculation of a discrepancy score that could serve as an index of awareness of functional ability in the PwD. The difference between FAQ-S and FAQ-I was divided by the mean of the two sets of ratings (FAQ-I – FAQ-S)/((FAQ-S + FAQ-I)/2) to calculate a corrected discrepancy score (FAD: Clare, Whitaker, et al., 2010). Using this calculation, scores closest to zero indicate good agreement; a positive score indicates that informant-rated functional ability is rated as more impaired than self-rated ability, and vice versa. The FAQ has been described as more sensitive than other measures to iADL dysfunction in early dementia (Karagiozis, Gray, Sacco, Shapiro, & Kawas, 1998).

Mood: The Hospital Anxiety and Depression Scale (HADS: Snaith & Zigmond, 1994) is a widely used 14-item self-report questionnaire investigating levels of anxiety (HADS-A) and depression (HADS-D), with seven questions relating to each aspect. Possible scores for each item range from 0-3; a higher score indicates more self-rated symptoms of depression (range 0-21) or anxiety (range 0-21). Scores of 10 and below indicate normal levels of anxiety or depression (Crawford, Henry, Crombie, & Taylor, 2001). Evidence suggests that self-report depression measures are accurate when administered with early-stage dementia populations (Gottlieb, Gur, & Gur, 1988), and the HADS has been used in previous dementia studies (Bradshaw, Saling, Hopwood, Anderson, & Brodtmann, 2004; Wands et al., 1990).

IQ: The National Adult Reading Test-Revised (NART-R: Nelson & Willison, 1991) consists of 50 phonetically-irregular words (such as chord, ache, etc) and gives an indication of pre-morbid intelligence. Participants read each word aloud and scoring is based on the number of errors (range 0-50), with fewer errors indicating a higher IQ. Error scores were converted to estimated IQ scores and these converted scores were used in the analysis to aid interpretation. Evidence suggests that the NART-R is a valid measure of premorbid IQ and is relatively unaffected by early dementia (Crawford, Parker, & Besson, 1988; Maddrey, Cullum, Weiner, & Filley, 1996; K. E. Patterson, Graham, & Hodges, 1994).

4.3.3 Procedure

The majority of participants were visited at home by two researchers; three chose to be assessed at the University. All PwD and informants were interviewed separately. The measures described here were typically administered during the first visit. Informed consent was obtained from both the person with dementia and informant.

4.3.4 Planned analysis

To examine the first hypothesis regression analyses were conducted to investigate which variables predicted FAQ-S, FAQ-I and FAD scores, with Letter Fluency, MMSE, age, and NART-R estimated IQ scores added into the model. Paired samples *t* tests were used to investigate whether there were differences between self-ratings and informant ratings of perceived functional ability. One-way analyses of variance (ANOVA) were used to compare differences between groups based on Letter Fluency scaled scores and FAQ, MMSE, age and NART-R estimated IQ scores. A regression analysis was conducted to investigate which variables predicted Letter Fluency, with MMSE, age, and NART-R estimated IQ scores added into the model. For the second hypothesis Spearman's rho correlation coefficients investigated associations between individual FAQ-S items and Letter Fluency. Paired samples *t* tests were used to compare self-ratings and informant ratings of individual functional abilities. For the final hypothesis two-way ANOVAs investigated whether there were any diagnostic or gender differences in Letter Fluency, NART-R estimated IQ and FAQ-S scores. As the sample consisted of a mixture of monolingual English speakers and bilingual Welsh and English speakers, a one-way ANOVA was used to compare differences between bilinguals and monolinguals on Letter Fluency, FAQ-S ratings and NART-R estimated IQ scores. Since type of relationship and cohabitation status could influence informant FAQ-I ratings a Kruskal-Wallis analysis was used to investigate whether there was a difference between informant ratings made by spouses, by adult children who lived with the person with dementia, and by adult children who did not live with the person with dementia; Kruskal-Wallis analyses was also used to investigate whether the age and the MMSE score of the person with dementia influenced the ratings made by these three groups of informants. Holm-Bonferroni correction for multiple comparisons was applied to all analyses.

4.4 Results

4.4.1 Participants

A total of 101 PwD participated in the MIDAS initial assessment. Participants without scores on either the FAQ (*n* = 3) or Letter Fluency (*n* = 2) were excluded from the analysis, leaving 96 who were included in the present analyses. Test non-completion was due to participant self-withdrawal (*n* = 4) or difficulty understanding the Letter Fluency task instructions (*n* = 1). The person who had difficulty understanding the task demands had a diagnosis of mixed dementia, a MMSE score of 18, an estimated NART-R IQ score of 80 and a self-reported FAQ score of 16, indicating that this person was reporting a significant level of functional limitation. Sample characteristics are summarised in Table 4.1. All participants were of white European extraction, which reflects the demographic characteristics of the study area.

Table 4.1 Demographic information and test mean scores

PwD (*n* = 96)		*n*
Gender	Female	51
	Male	45
Diagnosis according to ICD-10 criteria (World Health Organization, 1992)	Alzheimer's	50
	Vascular	29
	Mixed	17
	Mean (SD)	Range
Age	78.68 (7.84)	51 - 91
Years of education	11.76 (2.65)	8 - 19
Mini-Mental State Examination	24.22 (2.78)	18 - 30
National Adult Reading Test-Revised IQ (*n* = 94)	107.44 (11.63)	75 - 129
Letter Fluency	28.98 (13.24)	5 - 62
Functional Activities Questionnaire self-rating	6.14 (5.43)	0 - 19
Functional Activities Questionnaire informant rating	16.44 (8.29)	0 - 31
Functional Activities Discrepancy score	0.91 (0.80)	-2 - 2
Hospital Anxiety and Depression Scale - Anxiety	5.54 (4.00)	0 - 18
Hospital Anxiety and Depression Scale - Depression	4.26 (3.35)	0 - 17

Informants (*n* = 96)		*n*
Gender	Female	61
	Male	35
Live with the person with dementia	Yes	71
	No	25
Relationship to the person with dementia	Spouse	63
	Child	25
	Niece/Nephew	3
	Friend	3
	Sibling	2
	Mean (SD)	Range
Age	68.35 (14.13)	33 - 89

Note: standard deviations in parentheses.

4.4.2 Demographic analysis

Two-way ANOVAs found no significant between-group differences or significant interactions with regard to gender and diagnosis in respect of Letter Fluency, FAQ-S scores or NART-R estimated IQ, see Table 4.2. Twenty-six people identified themselves as Welsh speakers. One-way ANOVAs found that speaking Welsh had no influence on the number of words produced in Letter Fluency, FAQ-S ratings or NART-R estimated IQ. Therefore in the following analyses the data were collapsed according to gender, diagnosis and language. A Kruskal-Wallis test was conducted to investigate whether there was a difference in ratings between spouses (n = 68) and adult children who did (n = 7) or who did not (n = 18) live with the person with dementia; due to the small numbers in the categories nieces/nephews, friends and siblings (n = 8) they were excluded. This analysis showed no difference between the FAQ-I ratings made by spouses (mean 15.73, sd 8.66) and adult children who did (mean 22.86, sd 3.48) or did not (mean 16.11, sd 6.74) live with the PwD ($\chi^2(2, N = 88) = 4.81$, $p = .090$). Therefore informant ratings of functional ability were not influenced by the type of relationship or whether the person with dementia and informants lived together. However, the ratings made by the seven adult children who lived with the person with dementia were clearly higher than those made by the other two

Table 4.2 Means and standard deviations of gender, diagnostic and Welsh language score for Letter Fluency, functional ability and estimated IQ

	n	Letter Fluency Mean (SD)	*F*	*p*	FAQ-S Mean (SD)	*F*	*p*	NART-R IQ[a] Mean (SD)	*F*	*p*
Gender										
Female	51	28.80 (12.38)	$F(1, 90) = 0.34$	.560	5.78 (5.35)	$F(1, 90) = 0.74$	.392	105.55 (11.44)	$F(1, 88) = 2.74$	.101
Male	45	29.18 (14.29)			6.53 (5.56)			109.67 (11.58)		
Diagnosis										
Alzheimer's	50	30.12 (14.08)			6.34 (5.54)			105.70 (11.80)		
Vascular	29	25.24 (11.44)	$F(2, 90) = 1.79$	.172	6.35 (5.36)	$F(2, 90) = 0.34$	.711	109.96 (10.16)	$F(2, 88) = 0.94$	.393
Mixed	17	32.00 (12.87)			5.18 (5.48)			108.44 (13.22)		
Interaction			$F(2, 90) = .23$	.794		$F(2, 90) = 0.13$	.878		$F(2, 88) = 0.54$	.586
Welsh-speaking										
Yes	26	29.19 (13.91)	$F(1, 94) = 0.01$	.924	5.90 (5.32)	$F(1, 94) = 0.48$	.489	106.08 (11.52)	$F(1, 92) = 0.49$	.486
No	70	28.90 (13.09)			6.77 (5.79)			107.96 (11.71)		

[a] $n = 94$ (males = 43, vascular = 28, mixed = 16, non-Welsh speakers = 68).

Note: standard deviations in parentheses.

Abbreviations: National Adult Reading Test-Revised (NART-R), Functional Activities Questionnaire self-report (FAQ-S).

groups. Further analysis found that these functional ratings were unrelated to the MMSE scores of the PwD ($\chi^2(2, N = 88) = 1.82$, $p = .403$). In contrast the mean ages of the PwD (for PwD with spouse informants: mean 77.05, sd 8.59; for PwD with non-co-resident adult child informants: mean 80.39, sd 5.29; for PwD with co-resident adult child informants: mean 83.00, sd 2.89) suggest that the observed increase in ratings made by adult children who lived with the PwD may have been influenced by the age of the PwD, though a Kruskal-Wallis test found the difference only approached significance ($\chi^2(2, N = 88) = 4.88$, $p = .087$).

Table 4.1 summarises the mean scores on all measures. Mean MMSE scores show that the sample were in the early stages of dementia, while mean NART-R IQ scores show that the sample were generally slightly above average with regard to IQ. The mean HADS scores show that both anxiety and depression were predominantly in the normal range (89% were in the normal range for anxiety and 95% were in the normal range for depression) and these variables were consequently not included in the analysis. For the FAQ, informants rated the PwD as being more impaired than the PwD rated themselves, and the difference was significant, ($t(95) = -10.91$, $p < .001$). Frequency analysis showed that 49% ($n = 47$) of the PwD rated themselves as having normal everyday functioning (≤ 4) whereas only 9.4% ($n = 9$) of informants rated the person with dementia as showing normal everyday functioning; seven dyads were found to be in agreement that the PwD showed normal everyday functioning. These percentages were identical when the extra telephone item was excluded from the total score, indicating that this increase in items did not influence the number of people exceeding the cut-off score of five.

4.4.3 Predictors of self-, informant and discrepancy ratings of everyday functioning

Multiple linear regression analyses were used to investigate the measures that predict FAQ scores, with Letter Fluency, MMSE, age and NART-R estimated IQ scores added into the model; results are summarised in Table 4.3. Self-rated functional ability was significantly predicted by the model ($F(4, 89) = 3.99$, $R^2 = .15$, $p = .005$), with Letter Fluency individually significant, suggesting that PwD who rated themselves as more functionally impaired produced fewer words on the fluency task. Informant-rated functional ability was also significantly predicted by the model ($F(4, 89) = 8.32$, $R^2 = .27$, $p < .001$) with MMSE and age individually significant, suggesting that the informants tended to rate functional impairment as greater in the case of increased PwD age and lower MMSE scores. Finally, the discrepancy between self-rated and informant-rated functional ability was significantly predicted by the model ($F(4, 89) = 5.92$, $R^2 = .21$, $p < .001$). The significant betas for Letter Fluency and age were positive suggesting

that greater discrepancy (indicating lower awareness) was associated with better performance on Letter Fluency and greater age.

Table 4.3 Regression analyses, beta and significance values for functional ability

	Functional Activities Questionnaire					
	Self-rating		Informant rating		Discrepancy	
R^2 for model	.152		.272		.210	
	ß	*p*	ß	*p*	ß	*p*
Letter Fluency	-.294	**.007**	.057	.564	.307	**.004**
MMSE	-.220	.048	-.346	**<.001**	.082	.440
Age	-.044	.684	.294	**.004**	.340	**.002**
NART-R IQ[a]	-.009	.935	.040	.710	-.020	.855

[a] *n* = 94. Note: bold indicates significant at the 5% level after Holm-Bonferroni correction. Abbreviations: Mini-Mental State Examination (MMSE), National Adult Reading Test-Revised (NART-R).

4.4.4 Verbal fluency and perceived functional ability

D-KEFS scaled scores for Letter Fluency were used to separate the sample into impaired, below average, average, above average and superior groups. Table 4.4 shows the mean scores for Letter Fluency and other variables, and indicates that 20 PwD (20.8%) were classed as having verbal executive dysfunction on this measure. PwD in the impaired Letter Fluency group rated themselves lower on the FAQ-S than the remaining groups. The remaining four groups rated themselves below or close to the normal range for this measure, suggesting that those with the least impaired Letter Fluency generally do not think they are impaired in iADL. However, there was no significant difference in the FAQ-I for the five Letter Fluency groupings, suggesting that informants universally rated PwD as functionally impaired irrespective of Letter Fluency performance. For the FAD there was an overall significant finding, with post hoc analysis showing that those in the impaired group were less discrepant than those in the average and the superior groups; this analysis may also explain the significant positive beta between FAD and Letter Fluency in Table 4.3, since those in the impaired group were less discrepant from their informants. There were no significant differences in MMSE score or age between the five

Table 4.4 Mean scores on all measures for the five Letter Fluency scaled score groups and between-group comparisons

	Impaired (n = 20)	Below average (n = 30)	Average (n = 22)	Above average (n = 14)	Superior (n = 10)	F	p	Post hoc[c]
Letter Fluency	12.55 (4.29)	22.70 (3.54)	33.00 (3.82)	42.21 (3.38)	53.30 (4.50)	$F(4, 91) = 257.96$	<.001	I<BA<A<AA<S
FAQ-S[a]	10.25 (6.35)	5.50 (4.84)	4.91 (4.80)	5.86 (4.79)	2.90 (3.14)	$F(4, 91) = 4.81$	.001	I>BA>A>S
FAQ-I[a]	16.70 (9.59)	14.37 (8.11)	18.41 (7.13)	16.64 (7.70)	17.50 (9.48)	$F(4, 91) = 0.82$	.515	
FAD	0.41 (1.02)	0.84 (0.75)	1.19 (0.59)	0.98 (0.59)	1.39 (0.63)	$F(4, 91) = 4.05$	.005	I>A>S
Age	76.30 (9.35)	78.77 (7.82)	78.96 (8.35)	79.71 (6.99)	81.10 (3.54)	$F(4, 91) = 0.76$	.554	
MMSE	23.35 (3.12)	24.97 (2.36)	23.45 (3.08)	24.64 (2.59)	24.80 (2.39)	$F(4, 91) = 1.68$	.160	
NART-R IQ	97.40 (10.42)	108.80 (10.30)	108.00 (11.06)[b]	110.07 (11.00)	118.60 (3.44)	$F(4, 89) = 8.32$	<.001	I<BA<A<AA<S

[a] higher score indicates poorer perceived functioning. [b] n = 20. [c] indicates significant comparisons at the 5% level after Holm-Bonferroni correction.

Note: standard deviations in parentheses.

Abbreviations: Functional Activities Questionnaire self-report (FAQ-S), informant-report (FAQ-I) and discrepancy score (FAD), Mini-Mental State Examination (MMSE), National Adult Reading Test-Revised (NART-R).

groups, though there was a significant difference in NART-R IQ. Those in the impaired group were found to have a lower average estimated IQ than those in the remaining groups. A regression analysis with age, MMSE score and NART-R IQ entered as predictor variables into the model found Letter Fluency score was significantly predicted by this model ($F(3, 90) = 5.99$, $R^2 = .17$, $p < .001$) with only NART-R IQ individually significant ($\beta = .41$, $p < .001$; age: $\beta = -.02$, $p = .838$; MMSE: $\beta = .02$, $p = .873$) suggesting, as the means in Table 4.4 indicate, an association between Letter Fluency and NART-R IQ.

Table 4.5 Mean scores for individual self-ratings and informant ratings of functional items and Spearman's rho correlation coefficients between individual functional items and Letter Fluency

	FAQ-S Mean	FAQ-I Mean	Letter Fluency	
	(n = 96)	(n = 96)	r_s	p
Write cheques or pay bills	0.58 (0.95)	1.84 (1.11)	-.362	**<.001**
Tax or insurance documents	1.04 (1.07)	2.07 (1.07)	-.257	.011
Shopping alone	0.73 (0.95)	1.75 (1.21)	-.199	.052
Hobbies or games of skill	0.32 (0.61)	1.16 (1.17)	-.284	**.005**
Make tea or coffee	0.15 (0.54)	0.59 (0.88)	-.169	.100
Prepare balanced meal	0.56 (0.94)	1.66 (1.23)	-.172	.093
Keep track of current events	0.42 (0.68)	1.33 (1.19)	-.149	.147
Discuss book or TV programme	0.34 (0.72)	1.24 (1.05)	-.026	.801
Remember appointments and to take medication	0.89 (1.00)	2.00 (1.01)	-.313	**.002**
Travel out of local area	0.85 (1.16)	1.91 (1.21)	-.087	.400
Use telephone appropriately	0.25 (0.58)	1.02 (1.05)	-.403	**<.001**

Note: standard deviations in parentheses. Bold indicates significant at the 5% level after Holm-Bonferroni correction. Range of scores 0-3, higher score indicates poorer perceived functioning. Abbreviations: Functional Activities Questionnaire self-report (FAQ-S), Functional Activities Questionnaire informant-report (FAQ-I).

4.4.5 Item analysis of functional impairment responses and associations with verbal fluency

The means for the individual FAQ items in Table 4.5 suggest relatively high self-reported impairment for completing insurance and tax documents, shopping alone, remembering appointments and medication and travelling out of the local area. PwD reported little impairment with using the telephone and making tea or coffee; making tea or coffee tended to be self-rated as unimpaired, with frequency analysis showing that all but seven PwD self-rated this ability as normal. Interestingly, informants also tended to rate making tea or coffee as the least impaired iADL, with this being the only informant-rated mean score below 1.0; 60 informants rated this ability as normal. Paired-sample *t* tests found that informants rated each individual FAQ item as more impaired than the corresponding self-ratings made by PwD; all comparisons were significant at the $p < .001$ level (see Appendix Q). Spearman's rho correlation coefficients investigated how these individual ratings were associated with Letter Fluency. Significant negative associations were found for self-reports regarding writing cheques, playing games of skill, remembering appointments and medication and using the telephone appropriately, indicating that those with impaired Letter Fluency rated themselves as having more difficulties with these specific iADL. No individual item ratings by informants were associated with Letter Fluency.

4.5 Discussion

This study investigated the relationship between Letter Fluency and self-ratings and informant reports of instrumental activities of daily living in dementia, as well as the resulting discrepancy scores. Impaired Letter Fluency was associated with self-reported everyday functional difficulties, particularly with activities involving planning, initiation and language skills such as remembering appointments and taking medication, using the telephone and writing cheques. Previous research has indicated that these activities, along with transportation, may be the first iADL to show impairment before a diagnosis of dementia (Pérès et al., 2008). We also found evidence that keeping up with hobbies and playing games of skill were rated as impaired in the early stages of dementia. In contrast to the findings of Razani, Casas, et al. (2007) and Chen et al. (1998) Letter Fluency was unrelated to informant reports of iADL. Informant ratings were instead influenced by the current cognitive status and age of the person with dementia, which is consistent with previous

findings where informants rated older PwD as more impaired on iADL than those who were younger (Teri et al., 1989). In this study general cognitive function was measured by the MMSE, a test that does not adequately assess executive function (Folstein & Folstein, 2010); a possible explanation for the lack of association between informant reports of iADL and Letter Fluency may be that informants base their judgements on the general cognitive function of the PwD rather than as a result of observing a more specific impairment in verbal executive function. The relationship between MMSE score and informant reports of iADL functioning may also explain the reduced strength of associations found in previous research on iADL and executive function (Chen et al., 1998). Therefore, future studies should control for MMSE when associations between informant ratings of everyday functioning and executive function are being explored.

The relationship between Letter Fluency ability and iADL differed depending on whether the perspective of the person with dementia or informant was considered. For PwD, the impaired Letter Fluency group rated themselves as having iADL impairments whereas the means for the other groups were below or close to the clinical cut-off score (Pfeffer et al., 1982). This contrasted with informant ratings, which indicated much greater iADL deficits than PwD self-ratings suggested across all five Letter Fluency performance groups. Therefore, as Letter Fluency deficits increase, PwD self-reports of iADL impairments increase. The discrepancy analysis also suggests that those with reduced awareness of iADL ability performed better at Letter Fluency, indicating that awareness of functional deficits may be influenced by Letter Fluency. This is consistent with Salmon et al. (2006), who found that people with Alzheimer's disease with poorer Letter and Semantic Fluency had greater awareness of their cognitive difficulties. A straightforward explanation for this finding is that the PwD who are worse on fluency are simply more aware of their impairments overall. However, this explanation does not fully encompass the finding that informant ratings of iADL are related to MMSE scores and age. An alternative explanation for an increased awareness of functional deficits in those with poorer Letter Fluency is that this is a specific case, in that there may be concomitant word finding and naming problems associated with Letter Fluency difficulties which would likely provide strong, immediate and frequent feedback about the presence of impairments (Clare, Nelis, Martyr, Roberts, et al., 2012). This also indicates why in the group showing impaired Letter Fluency scores there may be more deficits in specific iADL with a large language component (such as self-rated ability with remembering appointments and taking medication, using the telephone and writing cheques) than in those without a large language component (such as making tea or coffee and travelling out of the local area). Additional research is needed to clarify whether awareness of functional ability is uniquely related to Letter

Fluency or whether other tests of executive function or tests of language produce a similar relationship with awareness of functional ability in PwD.

Consistent with earlier studies, we found that PwD rated themselves as less functionally impaired than did their informants (DeBettignies et al., 1990; Kiyak et al., 1994; Ott et al., 1996). In particular the Ott et al. (1996) evaluative judgement study suggests that awareness of functional difficulties may be better preserved than awareness of memory difficulties in PwD. That study also found that there was a non-significant trend towards association between Letter Fluency and iADL discrepancy score. Perhaps PwD who perform poorly on Letter Fluency exhibit a different form of iADL impairment than those who do not perform poorly on this test. A recent study investigating everyday errors produced by PwD found that Letter Fluency, the Clock Drawing Test and the Wechsler Memory Scale-Mental Control test (plus MMSE score and a naming test) were related to omission errors, but only Mental Control and MMSE score were related to commission errors (Giovannetti et al., 2008). A further study also found that Letter Fluency associated with error detection whereas performance on the Clock Drawing Test was more associated with error correction (Bettcher et al., 2008). Thus PwD with impaired Letter Fluency may have specific iADL impairments particularly relating to omitting items or steps in an activity and recognising errors. This suggests difficulties with the error monitoring aspects of awareness.

The present study had a number of limitations. The inclusion of different subtypes of dementias may lack specificity, since different aetiologies may lead to different cognitive and functional symptomatology. However, no statistically significant differences were found between diagnostic groups in our sample on any measure, despite people with vascular dementia producing on average five fewer words than people with Alzheimer's disease. Early research investigating differences between dementia diagnoses suggested there were more deficits in Letter Fluency and executive function in vascular dementia than Alzheimer's disease patients (see Looi & Sachdev, 1999, for review). However, the current study, along with other recent research (McGuinness, Barrett, Craig, Lawson, & Passmore, 2010; Voss & Bullock, 2004), suggests relative homogeneity between the different dementia diagnoses in executive function, though there may be differences in other areas of cognition according to diagnosis (Hayden et al., 2005). This equivocal finding needs further research since the non-significant difference in mean scores may have been due to the relatively small sample size. However, a recent meta-analysis reports that while people with Alzheimer's disease perform better than people with vascular dementia on Letter Fluency the difference is not clinically significant (Mathias & Burke, 2009). It is likely that the various dementia diagnoses

included in this study share more similarities than differences. The potential interrelationship between Letter Fluency and NART-R estimated intelligence should also be considered, since only NART-R estimated IQ was found to significantly predict Letter Fluency scores, and since those producing fewer words in the Letter Fluency task also had significantly lower estimated intelligence. However, this is perhaps to be expected as fluency tasks were originally conceptualised within theories of intelligence (Miller, 1984). This relationship may necessitate a reduction in the strength of the conclusions since rather than depending on executive function, Letter Fluency performance may depend on an individual's premorbid lexicon, as indicated by NART-R estimated IQ score, or may be affected by the intellectual deterioration associated with dementia (Crawford, Moore, & Cameron, 1992; Miller, 1984; K. E. Patterson et al., 1994), although it should be remembered that NART-R estimated IQ score was unrelated to all three functional scores whereas Letter Fluency was significantly associated with self-ratings and discrepancy scores.

Additionally, a disadvantage of using questionnaires to gauge functional ability is that they may not reflect actual everyday performance and may be vulnerable to response biases. Informant ratings may not be accurate due to either limited caregiving experiences (Richardson et al., 1995) or feelings of burden (Razani, Kakos, et al., 2007; Zanetti et al., 1999). Some caregivers may underestimate the capabilities that PwD still retain or they may deny that the person with dementia has any cognitive difficulties (Willis et al., 1998). In the early stages of dementia these issues are more likely to be apparent as a gradual increase in dependency on the part of the person with dementia starts to emerge, resulting in initially subtle changes in family member roles. Furthermore, self-reports by PwD may be reliant on intact awareness of everyday functioning, and may also be influenced by a need on the part of the person with dementia to appear competent when questioned by a clinician or researcher and to present the self in a more positive light (Kihlstrom & Tobias, 1991). A discrepancy score was included in the current analysis to counteract some of these limitations. Studies with PwD-informant dyads have compared informant ratings with objective assessments of iADL to investigate the veracity of informant ratings of functional ability. Farias et al. (2003) found moderate correlations between informant reports and objective assessments of iADL, while Loewenstein et al. (2001) found that informants accurately rated the iADL functioning of PwD with less functional impairment while overestimating the iADL functioning of PwD with more functional impairment. Loewenstein et al. (2001) also found that adult children were less likely to be able to accurately rate PwD than spouses, which is in contrast to the present study where no difference according to relationship type or cohabitation status was found using an iADL

questionnaire. Future research could investigate whether self-reports are related to objective assessments of iADL ability; this may also elucidate whether age and the general cognitive function of the person with dementia are related to everyday functioning, as suggested by informant ratings.

4.6 Conclusions

We found Letter Fluency deficits in one-fifth of people in the early stages of dementia. Self-ratings of perceived everyday functional ability was related to Letter Fluency, with those who show the most Letter Fluency deficits also showing the greatest awareness of their functional difficulties. However, those with poorer Letter Fluency also showed evidence of a reduced lexicon, as indicated by lower NART-R estimated IQ, which may have moderated Letter Fluency performance. Informant reports were related to MMSE score and the age of the person with dementia, suggesting the possibility of a response bias. The findings suggest that people with dementia who present at memory clinics with impaired Letter Fluency may be relatively aware of their difficulties with iADL and hence likely to respond well to specialist care and rehabilitation. Further research is needed to clarify whether other tests of executive function and/or tests of language show a similar association with awareness of everyday functioning, especially as the identification of additional tests may help profile people with dementia who are likely to benefit from rehabilitation. The discrepancy score between self-ratings and informant-rated functional ability also suggests that those with lower awareness may be older but perform better on Letter Fluency. However, Letter Fluency was influenced by intelligence, suggesting that caution is needed when interpreting the relationship between Letter Fluency and functional ability. Further research is required to investigate the clinical implications in more detail.

Chapter 5

Predictors of perceived functional ability in early-stage dementia: self-ratings, informant ratings and discrepancy scores

Martyr, A., Nelis, S.M., & Clare, L. (submitted). Predictors of perceived functional ability in early-stage dementia: Self-ratings, informant ratings and discrepancy scores.

5.1 Abstract

Assessing functional ability is an important element in diagnosing and monitoring the progression of dementia, with research suggesting a link between functional ability and cognition. We investigated the predictors of ratings of functional ability made by people with dementia (PwD) and carers of PwD, and the resulting discrepancy scores, examining both individual scale items and total scale scores. People with early-stage Alzheimer's disease, vascular or mixed dementia (n = 101) and their carers completed the Functional Activities Questionnaire. PwD also completed tests of general cognition, memory, verbal executive function and language, and provided ratings of mood. Carers provided a rating of their own level of stress. PwD immediate memory scores predicted self-rated functioning, whereas carer stress predicted informant-rated functioning. PwD Letter Fluency scores predicted the discrepancy between self-rated and informant-rated functioning. Scores for immediate memory, Letter Fluency and mood predicted self-ratings of individual scale items, with the distribution suggesting that PwD were able to rate their functioning with reasonable accuracy. Informant ratings were predicted by carer stress and to a lesser extent by everyday memory in the PwD. The discrepancy scores were also predicted by carer stress and PwD everyday memory, together with PwD Letter Fluency scores. Self-ratings of functioning showed evidence of awareness, whereas informant ratings were significantly influenced by carer stress. These findings have implications for the use of ratings of functional ability in clinical and research settings and suggest that self-ratings by PwD should be employed more often in research and clinical settings.

5.2 Introduction

Current diagnostic criteria for dementia require the presence of impaired functional ability (American Psychiatric Association, 1994; World Health Organization, 1992). Indeed, functional decline in people with dementia (PwD) has been shown to begin at least ten years prior to a diagnosis of dementia, with the greatest decline occurring around two years immediately preceding diagnosis (Pérès et al., 2008). Basic activities of daily living, like bathing, eating and dressing, show little decline in early dementia, unless there is some concomitant physical disability (Boyle et al., 2002). Instrumental activities of daily living (iADL), such as using a telephone, managing finances, managing medication and driving, are more vulnerable to the effects of dementia (Njegovan et al., 2001) and show a noticeable decline in the relatively early stages of dementia (C. R. Green et al., 1993) with evidence suggesting a link between cognitive impairments and iADL ability (Chapter 2; Njegovan et al., 2001; Vitaliano et al., 1984).

Studies that have investigated the association between cognition and functional ability in PwD have examined a range of cognitive processes. Hill et al. (1995) found significant associations between informant-rated iADL and executive function, visual perception and immediate memory have been found, but there was no association for delayed memory and attention. Cahn-Weiner et al. (2003) reported that verbal executive function significantly correlated with informant-rated functional ability although, possibly due to the small sample size, the moderate correlation between language and informant-rated functional ability was not significant; delayed memory and visual perception showed no association with informant-rated functional ability. Meanwhile, Farias et al. (2003) found that objective performance and informant-rated functional ability correlated with scores on tests of executive function, language, praxis, visuospatial perception and immediate memory, but not with delayed memory or attention. More recently, Hall et al. (2011) found that immediate memory and executive function significantly predicted informant-rated iADL total score whereas delayed memory, language and attention showed no association with informant-rated iADL total score. It appears therefore that for PwD there is no evidence that delayed memory and attention predict ratings of functional ability, whereas scores on tests of executive function and immediate memory may be important predictors of functional ability.

While informant ratings of functional ability are frequently employed in research and are predominantly relied upon in clinical settings, self-ratings of functional ability are rarely used

in clinical settings and are infrequently employed in research (see Chapter 2). Possible explanations for this under-utilisation of self-reports may be an assumption that cognitive impairment (Sager et al., 1992; Vasterling et al., 1995) or lack of awareness (Clare, Marková, et al., 2011) may reduce the reliability of self-ratings of functioning made by PwD. When self-ratings and informant ratings are compared, PwD consistently report fewer impairments than informants (Chapter 4; DeBettignies et al., 1990; Kiyak et al., 1994; Wadley et al., 2003), which may suggest reduced awareness about functional ability. However, informant ratings, typically provided by the primary family caregiver, may also be subject to biases due to the influence of factors such as caregiver stress or burden (Mangone et al., 1993; Razani, Kakos, et al., 2007; Zanetti et al., 1999), the age and cognitive status of the person with dementia (Chapter 4; Teri et al., 1989), or the perceived quality of the dyadic relationship between the person with dementia and caregiver (Quinn et al., 2009).

One frequently employed method of assessing awareness that may mitigate some of the biases associated with ratings of functioning involves calculating the discrepancy between self-ratings and informant ratings (DeBettignies et al., 1990). This awareness discrepancy method has been widely used in relation to neuropsychological status (Morris & Hannesdottir, 2004), but has been less extensively explored in relation to ratings of everyday functioning. One study reported that the Trail Making Test-Part A and the Mazes planning test were significantly associated with the discrepancy between self-rated and informant-rated functioning, whereas there was no association for other tests of executive function, immediate memory, delayed memory, language, visuospatial perception or attention (Ott et al., 1996). A recent study that focussed on the association between verbal executive function and functional ability found that Letter Fluency and age significantly predicted the discrepancy between self-rated and informant-rated functioning (see Chapter 4).

To date few studies have included the perspective of the person with dementia or considered discrepancies in everyday functioning. The current study will investigate the role of a range of cognitive functions and psychological variables as possible predictors of perceived everyday functioning in early-stage dementia. We will investigate how demographic variables and tests of verbal executive function, memory, language and intelligence relate to self-rated and informant-rated functional ability in PwD. Previous studies using this method and employing scales assessing functional ability typically focus on total scale scores rather than investigating individual scale items (see Chapter 2), but in this study we will also explore predictors of ratings for individual items. In summary, we will (1) examine in more detail

how cognitive and psychological predictors relate to perceived everyday functioning in people with dementia, with the prediction that verbal executive function, immediate memory and language will be strong predictors of functioning; and (2) investigate predictors of individual scale items, addressing both self-rated and informant-rated scores and the resulting discrepancy scores.

5.3 Method

5.3.1 Design

The Memory Impairment and Dementia Awareness Study (MIDAS) was a 3-year longitudinal study of awareness in early-stage dementia. This paper presents data from the initial MIDAS assessments. Participants were recruited through six National Health Service memory clinics in North Wales. To be included, participants had to have a diagnosis of probable or possible Alzheimer's disease, multi-infarct or subcortical vascular dementia or mixed Alzheimer's disease and vascular dementia (ICD-10, World Health Organization, 1992), a score of 18 or above on the Mini-Mental State Examination (MMSE: Folstein et al., 1975) a contributing informant and the ability to communicate verbally in English. Exclusion criteria were concurrent major depression, psychosis or neurological disorder and past history of neurological disorder or brain injury. Ethical approval was granted by the relevant University and National Health Service Ethics Committees.

5.3.2 Measures

To measure functional ability we employed the Functional Activities Questionnaire (FAQ: Pfeffer et al., 1982). The FAQ is an 11-item questionnaire, modified from the original 10 items to include a question concerning telephone use. Each item was rated on a 0-3 scale, with a higher score indicating greater perceived functional impairment. A person with dementia self-rated (FAQ-S, Appendix O) and an informant-rated (FAQ-I, Appendix P) version were used, allowing for calculation of discrepancy scores that could serve as an index of awareness of functional ability in the person with dementia. The difference between FAQ-S and FAQ-I was divided by the mean of the two sets of ratings using the formula (FAQ-I – FAQ-S)/((FAQ-S + FAQ-I)/2) to calculate a corrected discrepancy score (Clare, Whitaker, et al.,

2010); this approach was also applied to each individual item on the FAQ to produce a corrected discrepancy score for each rating of a particular aspect of functional ability. Corrected discrepancy scores close to zero indicate good agreement; positive scores indicate that the informant-rated functioning as more impaired than did the person with dementia, and vice versa.

The following additional measures from the MIDAS dataset were used in this analysis. The Hospital Anxiety and Depression Scale (Snaith & Zigmond, 1994) was used to assess anxiety (HADS-A) and depression (HADS-D). The Relative Stress Scale (Relative Stress: Greene, Smith, Gardiner, & Timbury, 1982, Appendix R) measured the level of self-reported carer stress. For both questionnaires a higher score indicates more symptoms. Memory was assessed using the Wechsler Memory Scale Word List Learning subtest (Wechsler, 1997), taking scores for both Immediate Memory (total number of correctly recalled words in the first four trials) and Delayed Memory (the number of words correctly recalled after a delay of 25 minutes). The total raw score for the Rivermead Behavioural Memory Test-Second Edition (RBMT: B. A. Wilson, Cockburn, & Baddeley, 2003) was used to assess everyday memory. Verbal executive function was measured with the Letter Fluency, Category Fluency and Switching Accuracy subtests from the Delis-Kaplan Executive Function System (Delis et al., 2001). The Graded Naming Test (McKenna & Warrington, 1983) and the Pyramids & Palm Trees picture-picture matching condition (Howard & Patterson, 1992) were employed to investigate language ability. The National Adult Reading Test-Revised (NART-R: Nelson & Willison, 1991) gave an indication of pre-morbid intelligence. For all tests a higher score indicates better performance.

5.3.3 Procedure

The majority of participants were visited at home by two researchers; three chose to be assessed at the University. All PwD and informants were assessed separately. Informed consent was obtained from both the person with dementia and informant.

5.3.4 Planned analysis

In order to investigate which demographic variables, psychological questionnaires or neuropsychological tests predicted functional ability in PwD, stepwise regression analyses were conducted. For each analysis age, MMSE, NART-R estimated IQ, HADS-A, HADS-D,

Letter Fluency, Category Fluency, Switching Accuracy, Pyramids & Palm Trees, Relative Stress, Graded Naming Test, RBMT, Immediate Memory and Delayed Memory scores were entered into stepwise regression models to investigate which variables best predicted individual items and total scores on the FAQ-S and FAQ-I and corrected discrepancy scores. The stepwise regression analyses were performed in SPSS v.20 and used the default criterion probability of F-to-remove $\geq .10$. The model that accounted for the greatest variance, as indicated by the adjusted R^2, was chosen as the best predictor. To correct for the number of variables entered into each model and to correct for multiple comparisons, Holm-Bonferroni correction was applied to all analyses.

5.4 Results

The MIDAS sample consisted of 101 PwD together with an informant (family member or close friend providing regular support to the person with dementia) in each case; sample characteristics are summarised in Table 5.1. The sample has been described in detail elsewhere (Clare, Whitaker, et al., 2011; Chapter 4).

Table 5.1 Profile of the participants and informants, and mean scores (sds, ranges) on measures of functional ability, cognition, mood and carer stress

PwD			*n*
Gender	Female		54
	Male		47
Diagnosis according to ICD-10 criteria	Alzheimer's		51
(World Health Organization, 1992)	Vascular		30
	Mixed		20
	n	Mean (SD)	Range
Age	101	78.74 (7.72)	51 - 91
Years of education	101	11.68 (2.67)	8 - 19
Functional Activities Questionnaire			
Self-rating	99	6.18 (5.46)	0 - 19
Informant rating	99	16.36 (8.30)	0 - 31
Discrepancy score	98	0.90 (.80)	-2 - 2

Neuropsychology			
Mini-Mental State Examination	101	24.17 (2.82)	18 - 30
National Adult Reading Test-Revised IQ	97	107.04 (11.91)	75 - 129
Letter Fluency	99	28.92 (13.13)	5 - 62
Category Fluency	98	20.77 (8.24)	2 - 40
Switching Accuracy	98	7.14 (3.40)	0 - 18
Pyramids and Palm Trees	98	47.41 (4.75)	30 - 52
Graded Naming Test	96	12.96 (6.65)	0 - 27
Immediate Memory	89	15.38 (6.22)	3 - 35
Delayed Memory	89	0.84 (1.85)	0 - 9
Rivermead Behavioural Memory Test	95	36.40 (17.26)	3 - 77
Hospital Anxiety and Depression Scale			
Anxiety	99	5.55 (4.02)	0 - 18
Depression	99	4.33 (3.41)	1 - 17
Informants			*n*
Gender	Female		64
	Male		37
Live with	Yes		74
	No		27
Relationship	Spouse		66
	Child		26
	Niece/Nephew		3
	Friend		3
	Sibling		3
	n	Mean (SD)	Range
Age	101	68.39 (14.00)	33 - 89
Relative Stress Scale	94	19.90 (11.45)	2 - 55

Note: standard deviations in parentheses.

Abbreviations: Wechsler Memory Scale Word List trials 1-4 (Immediate Memory), Wechsler Memory Scale Word List trial 6 (Delayed Memory).

5.4.1 Predictors of self-rated functioning

The regression analyses yielded significant models for each of the FAQ-S items, as shown in Table 5.2. Immediate Memory and self-rated depression were the most common predictors of individual item scores on the FAQ-S, though after correcting for multiple comparisons only Immediate Memory significantly predicted more than one FAQ item. Switching Accuracy, RBMT, HADS-A, MMSE, Pyramids & Palm Trees, Relative Stress and Delayed Memory did not predict scores on any item. For the total FAQ-S score, Immediate Memory, Letter Fluency and HADS-D accounted for 25% of the variance but after correcting for multiple comparisons only Immediate Memory was individually significant. Self-rated FAQ scores appear to be influenced by Immediate Memory and to a lesser degree by self-rated depression and Letter Fluency ability.

5.4.2 Predictors of informant-rated functioning

After Holm-Bonferroni correction, the regression analyses yielded significant models for all individual FAQ-I items and for the total score, as shown in Table 5.3. Relative Stress predicted six items and the total score, suggesting that informant ratings may be strongly influenced by carer stress. The PwD RBMT memory score was a significant predictor of three FAQ-I items while PwD Immediate Memory predicted only one item. Pyramids and Palm Trees score and PwD age predicted one item each. ‘Assembling tax records’ was the item with the highest number of predictors, and after correcting for multiple comparisons this was the only item significantly predicted by MMSE, Letter Fluency, and Immediate Memory. HADS-D and NART-R did not predict any item. PwD age, Immediate Memory, RBMT, and Relative Stress, contributed to the total FAQ-I score, accounting for 45% of the variance; however, after correcting for multiple comparisons only PwD age and Relative Stress predicted overall FAQ-I score. To be consistent with previous studies we conducted a further regression analysis for the total FAQ-I score with carer stress and PwD age excluded, and the model remained significant, $F(2, 84) = 17.08$, adjusted $R^2 = .27$, $p < .001$, with only Immediate Memory ($\beta = .31$, $p = .004$) and RBMT score ($\beta = .31$, $p = .004$) individually significant. Informant-rated FAQ scores appear to be influenced by level of carer stress, and to a lesser degree by the memory ability of the person with dementia.

Table 5.2 Predictors of self-ratings by people with dementia on the Functional Activities Questionnaire

	Writing cheques	Assemble tax records	Shop alone	Work on a hobby	Heat water for tea/ coffee	Prepare a balanced meal	Keep track of events	Discuss a TV show	Remember to take medication	Travel out of the local area	Using a Phone	Total Score
Mean (SD)	.60 (.97)	1.07 (1.07)	.73 (.94)	.32 (.60)	.14 (.54)	.55 (.93)	.43 (.69)	.36 (.76)	.86 (1.00)	.88 (1.17)	.24 (.57)	6.18 (5.46)
R^2adj	.211	.078	.127	.270	.070	.055	.086	.082	.143	.091	.123	.245
F	8.58	8.19	13.40	11.49	7.39	5.96	5.01	8.63	8.08	5.26	12.92	10.19
p	**< .001**	**.005**	**< .001**	**< .001**	**.008**	**.017**	**.009**	**.004**	**< .001**	**.007**	**< .001**	**< .001**
Age								-.305**		.220*		
MMSE												
RBMT												
NART-R		-.298**		-.207*								
Letter Fluency	-.266**								-.217*		**-.365*****	-.216*
Category Fluency							.284*					
Switching Accuracy												
P&PT												
GNT					-.284**							

Immediate Memory	-.245*	**-.371***	-.263**		**-.434****	-.287**	**-.338*****
Delayed Memory							
HADS-A							
HADS-D	.231*		**.376*****	.257*		.284*	.223*
RSS							

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Note: bold indicates significant at the 5% level after Holm-Bonferroni correction.

Abbreviations: Mini-Mental State Examination (MMSE), Rivermead Behavioural Memory Test (RBMT), National Adult Reading Test-Revised (NART-R), Pyramids and Palm Trees (P&PT), Graded Naming Test (GNT), Wechsler Memory Scale Word List trials 1-4 (Immediate Memory), Wechsler Memory Scale Word List trial 6 (Delayed Memory), Hospital Anxiety and Depression Scale anxiety subscale (HADS-A) and depression subscale (HADS-D), Relative Stress Scale (RSS).

Table 5.3 Predictors of informant ratings on the Functional Activities Questionnaire

	Writing cheques	Assemble tax records	Shop alone	Work on a hobby	Heat water for tea/ coffee	Prepare a balanced meal	Keep track of events	Discuss a TV show	Remember to take medication	Travel out of the local area	Using a Phone	Total Score
Mean (SD)	1.82 (1.11)	2.10 (1.06)	1.71 (1.21)	1.15 (1.16)	.58 (.87)	1.62 (1.24)	1.32 (1.18)	1.22 (1.05)	1.96 (1.03)	1.90 (1.21)	1.00 (1.04)	16.36 (8.30)
R^2adj	.165	.298	.346	.233	.189	.247	.292	.179	.339	.270	.188	.447
F	6.60	8.21	16.00	13.93	10.90	14.94	18.50	7.19	22.83	11.50	7.58	18.18
p	**< .001**	**< .001**	**< .001**	**< .001**	**< .001**	**< .001**	**< .001**	**< .001**	**< .001**	**< .001**	**< .001**	**< .001**
Age			**.379***							.257*		**.267****
MMSE		**.356****									-.256*	
RBMT			-.236*			**-.373*****	**-.455*****	-.173	**-.428*****			-.218*
NART-R												
Letter Fluency	.226	**.316****										
Category Fluency										-.212*		
Switching Accuracy	-.311**							-.234*				
P&PT		-.217*		**-.437*****	-.244*							
GNT	-.260*											

Immediate Memory	**-.526***									-.222*
Delayed Memory								-.263*		
HADS-A							-.272**		-.215*	
HADS-D										
RSS	**.275****	**.286****	.224*	**.373*****	**.316*****	**.273****		**.370*****	.267**	**.363*****

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Note: bold indicates significant at the 5% level after Holm-Bonferroni correction.

Abbreviations: Mini-Mental State Examination (MMSE), Rivermead Behavioural Memory Test (RBMT), National Adult Reading Test-Revised (NART-R), Pyramids and Palm Trees (P&PT), Graded Naming Test (GNT), Wechsler Memory Scale Word List trials 1-4 (Immediate Memory), Wechsler Memory Scale Word List trial 6 (Delayed Memory), Hospital Anxiety and Depression Scale anxiety subscale (HADS-A) and depression subscale (HADS-D), Relative Stress Scale (RSS).

Table 5.4 Predictors of corrected discrepancies between self-ratings and informant ratings on the Functional Activities Questionnaire

	Writing cheques	Assemble tax records	Shop alone	Work on a hobby	Heat water for tea/ coffee	Prepare a balanced meal	Keep track of events	Discuss a TV show	Remember to take medication	Travel out of the local area	Using a Phone	Discrepancy
Mean (SD)	.61 (.72)	.51 (.74)	.49 (.66)	.40 (.62)	.22 (.47)	.53 (.74)	.43 (.74)	.43 (.67)	.55 (.64)	.51 (.67)	.37 (59)	.90 (.80)
R^2adj	.136	.139	.164	.187	.064	.263	.213	.176	.308	.064	.179	.284
F	7.71	5.57	9.35	5.88	6.79	11.10	8.66	7.07	10.46	6.77	7.18	9.42
p	**.001**	**.002**	**< .001**	**< .001**	**.011**	**< .001**	**< .001**	**< .001**	**< .001**	**< .001**	**< .001**	**< .001**
Age			**.305****								.231*	.234*
MMSE												
RBMT						**-.365*****	**-.325*****	-.230*	-.250**	-.273*		
NART-R		.236*		.209*								
Letter Fluency	.267**	.230*				.248**	.194*		**.318*****			**.329*****
Category Fluency												
Switching Accuracy												
P&PT				**-.383*****								
GNT												

Immediate Memory		-.264*									
Delayed Memory											
HADS-A	-.271**							-.280**		-.212*	-.217*
HADS-D				-.216*					-.256**		
RSS			.293**	.267**	.273*	**.298****	**.300****	.208*	**.327*****	.281**	.272**

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Note: bold indicates significant at the 5% level after Holm-Bonferroni correction.

Abbreviations: Mini-Mental State Examination (MMSE), Rivermead Behavioural Memory Test (RBMT), National Adult Reading Test-Revised (NART-R), Pyramids and Palm Trees (P&PT), Graded Naming Test (GNT), Wechsler Memory Scale Word List trials 1-4 (Immediate Memory), Wechsler Memory Scale Word List trial 6 (Delayed Memory), Hospital Anxiety and Depression Scale anxiety subscale (HADS-A) and depression subscale (HADS-D), Relative Stress Scale (RSS).

5.4.3 Predictors of functional ability discrepancy scores

After Holm-Bonferroni correction, regression analyses yielded significant models for discrepancy scores for each individual item and for the total discrepancy score, as shown in Table 5.4. Relative Stress was the most frequent predictor, emerging as significant for three items, which suggests that the discrepancy score may be influenced by carer stress. PwD RBMT score significantly predicted two items whereas PwD age, Letter Fluency and Pyramids and Palm Trees scores predicted one item each. PwD age, Letter Fluency, HADS-A and Relative Stress scores contributed to prediction of the total discrepancy score, but only Letter Fluency was individually significant. PwD Category Fluency, Switching Accuracy, MMSE, GNT and Delayed Memory scores did not predict any item. The discrepancy between self-rated and informant-rated functional ability scores was predicted by the degree of carer stress and to a lesser degree by PwD Letter Fluency and RBMT memory scores, accounting for 28% of the variance.

5.5 Discussion

In this study we investigated the relationship between cognitive, psychological and demographic variables and self-rated and informant-rated everyday iADL function in dementia, as well as the resulting discrepancy score. To our knowledge this is the first study to investigate predictors of self-rated everyday functioning in PwD, and we found that the only significant predictor was Immediate Memory. Carer stress and PwD age predicted informant-rated functioning while Letter Fluency score predicted the discrepancy between the two FAQ questionnaires. We also considered predictors of individual aspects of functional ability, which have hitherto been under-explored in research (see Chapter 2). Immediate Memory was associated with most self-rated FAQ items whereas RBMT score was a stronger predictor than Immediate Memory for individual informant-rated FAQ items and the individual FAQ discrepancy score items. However, carer stress predicted or contributed to the majority of the individual informant-rated FAQ items and individual FAQ discrepancy score items.

The finding that Immediate Memory predicted self-rated iADL functioning was consistent with previous informant-rated studies that have investigated the cognitive profile of iADL in dementia (Farias et al., 2003; Hall et al., 2011). This suggests that self-ratings of iADL may share some similarities with informant ratings of iADL. For informant-rated iADL we found partial support for two previous studies (Farias et al., 2003; Hall et al., 2011) since Immediate Memory and RBMT score were the only significant predictors once carer stress and PwD age were excluded from the regressions and this model explained 27% of the variance in informant-rated iADL. However, with carer stress and PwD age included, we found that both PwD age and particularly carer stress were important predictors of informant-rated iADL functioning and these two variables explained an additional 18% of the variance in informant-rated iADL. This could be because carers are more stressed where the functioning of the PwD is more compromised (Mangone et al., 1993; Slachevsky et al., 2013; Zanetti et al., 1999), but it might also indicate that carers who are stressed for whatever reason tend to rate the functioning of the PwD more negatively (Razani, Kakos, et al., 2007). The latter explanation would call into question the reliability of informant ratings in this context. Therefore, carer stress and PwD age are important variables to consider in future studies that employ informant ratings of iADL ability. We previously reported that the functional discrepancy score was predicted by Letter Fluency (see Chapter 4), and this remains the case even with the addition of other variables, suggesting that verbal executive function may be an important variable influencing the discrepancy between self-rated and informant-rated function. This contrasts with a previous study which reported that a moderate correlation between verbal fluency and the functional iADL discrepancy score was not significant (Ott et al., 1996), although the small sample size in that study may have contributed to the lack of association. Therefore, it appears that carer stress is a key variable when investigating informant-rated functioning in PwD, with other significant contributions made by PwD memory and Letter Fluency ability and age.

The distribution and direction of individual FAQ item predictors suggests that self-ratings of functioning may be relatively accurate, suggesting good awareness of functional ability, since consistent with predictors of objective performance (Razani et al., 2011), Immediate Memory was a strong predictor of ‘keeping track of current events’ and ‘shopping’. Letter Fluency predicted ‘telephone use’, consistent with predictors of objective performance (Loewenstein et al., 1992; Razani, Kakos, et al., 2007), and self-rated depression predicted ‘working on a hobby’. It would be expected that better memory would be useful for shopping alone and keeping track of current events, that better word initiation ability would be useful for using the telephone and that fewer depressive symptoms would be beneficial for keeping up with hobbies and interests, and these

findings suggest that PwD were aware that their mood and cognitive ability affected their ability to successfully perform certain daily functions.

Generally there were more significant predictors for informant ratings of functioning and for the discrepancy score than for self-ratings of functioning. Similar to previous studies (Mangone et al., 1993; Razani, Kakos, et al., 2007; Slachevsky et al., 2013; Zanetti et al., 1999), carer stress significantly predicted five of the individual informant-rated functional items and was also the most frequent predictor of the discrepancy score (DeBettignies et al., 1990). The current study extends this by including a wider range of cognitive measures and psychological variables, and indicates that carer stress is a more consistent predictor of informant ratings of functioning than PwD executive function, immediate memory ability or language ability, which have all previously been found to significantly predict informant-rated functioning (Cahn-Weiner et al., 2003; Farias et al., 2003; Hall et al., 2011). Everyday memory tests may be better predictors of informant ratings of functioning than more traditional tests of memory, since Immediate Memory predicted only one of the informant-rated FAQ items whereas the RBMT significantly predicted three items and made a non-significant contribution to two additional items. This is supported by the findings for the discrepancy score, as the RBMT significantly predicted two items and made a non-significant contribution to three other items. Consistent with previous studies (Cahn-Weiner et al., 2003; Farias et al., 2003; Hall et al., 2011; Hill et al., 1995) there was a weak association between Delayed Memory and iADL functioning, with only a single item showing an association. Therefore, while our findings support previous research which has indicated that carer stress predicts informant ratings of functioning (Mangone et al., 1993; Razani, Kakos, et al., 2007; Slachevsky et al., 2013; Zanetti et al., 1999), by examining the individual scale items we have shown that carer stress accounts for a considerable proportion of the variance in informant ratings of functioning.

As carer stress predominantly influences informant ratings of iADL ability, the accuracy of informant ratings of functioning, which has significant implications for clinical practice and research, is an important factor that needs to be addressed. The association between scores on an informant-rated iADL questionnaire and carer stress supports a previous study where caregiver burden was found to be strongly associated with scores on an informant-rated questionnaire of iADL whereas the association between caregiver burden and scores on an objectively-assessed functional ability measure were small (Razani, Kakos, et al., 2007). This suggests that ratings made by caregivers may be less accurate than objective assessment measures of functioning, and part of this inaccuracy may be due to caregiver burden or stress. This calls into question the use of

informant ratings in clinical and research settings, and may partly explain why previous studies have found only a moderate association between objectively-assessed performance and informant ratings of functioning (Farias et al., 2003; Zanetti et al., 1995). More work is needed to understand the way in which carer stress impacts on the degree of objectivity which carers are able to employ when rating the everyday functional ability of PwD. Indeed, due to the influence that caregiver burden exerts on informant ratings of functional ability, objective assessment measures may offer a more accurate indication of the current level of functioning of PwD (Razani, Kakos, et al., 2007).

The study has some limitations which should be considered when interpreting the findings. The inclusion of different diagnostic sub-groups might be regarded as a limitation, but as we have reported previously there were no differences between the three groups on any test (Chapter 4; Clare, Nelis, Martyr, Roberts, et al., 2012), a finding consistent with a recent meta-analysis which reported few clinically-significant cognitive differences between Alzheimer's disease and vascular dementia (Mathias & Burke, 2009). MIDAS included only a limited range of executive function tests, but scores on tests of executive function are moderately correlated with iADL in Alzheimer's disease (see Chapter 2). Including a wider range of executive function tests may have provided greater explanatory value, although it has been suggested that in dementia memory has a stronger influence on functioning than executive function (Farias et al., 2009). The FAQ has been described as one of the more sensitive functional questionnaires for people with early-stage dementia (Karagiozis et al., 1998). However, the FAQ typically incorporates multiple functions into individual items (i.e. 'Can you write cheques, pay bills, and keep financial records?') and this may influence ratings, with respondents focussing on different elements of the same item (Davis, 2001). Finally, the use of questionnaires rather than an objectively-assessed measure of functional ability was a limitation, especially as others have only found a moderate correlation between informant ratings and objective assessments of iADL (Farias et al., 2003; Zanetti et al., 1995). Also, while the individual item analysis indicated that self-ratings of iADL functioning may be more accurate than informant ratings, more work is needed to verify the accuracy of self-rated iADL. The accuracy of self-ratings in relation to scores on objective assessments of iADL has rarely been explored (see Wadley et al., 2003) and this may have important implications for the use of self-ratings of iADL functioning made by PwD in clinical and research settings.

5.6 Conclusions

Immediate Memory predicted self-reported iADL function, and PwD appeared to demonstrate reasonably accurate awareness of their own functioning. Carer stress predicted informant-rated iADL and was also an important predictor of the discrepancy between self-ratings and informant ratings of functioning. Informant-rated iADL appear to be strongly influenced by the level of carer stress, which may call into question the reliability of informant ratings. Self-ratings of functioning made by people with early-stage dementia may therefore be as useful as informant ratings, and our findings suggest that self-ratings of iADL should be elicited more frequently in research and clinical settings. Used in combination with informant ratings, self-ratings of iADL may provide an efficient measure of functional awareness. However, more work is needed to establish the accuracy of ratings of everyday functioning made by both PwD and their informants in relation to objective assessments of iADL ability.

Chapter 6

Awareness of functional ability in people with dementia: cognitive correlates

6.1 Abstract

Awareness of functional ability in people with dementia (PwD) is an important area of study. Most researchers and clinicians rely on informant ratings rather than observing actual functional performance or employing self-ratings made by PwD. There has however been little research to verify whether informant ratings of functioning are accurate and there has been even less research investigating the accuracy of self-ratings of functional ability in PwD. Thirty-seven PwD completed a functional assessment and provided self-ratings both before and after an objective assessment. Informants provided ratings of functioning. PwD also completed a battery of executive function tests, the Rivermead Behavioural Memory Test (RBMT) and the Addenbrooke's Cognitive Examination-Revised (ACE-R). Findings suggest that self-ratings of functional ability may be more accurate than informant ratings, with informants significantly underestimating the functional ability of PwD. The RBMT and the ACE-R were good predictors of objective functional ability, though there were few significant correlations between ratings of functional ability and cognition. The ACE-R may therefore be a good test to monitor functional decline in PwD. The findings call into question the likelihood that informants will provide accurate ratings of functional ability and suggest that self-ratings may offer a more accurate estimate of functional ability in PwD.

6.2 Introduction

Dementia is characterised by multiple cognitive and behavioural impairments, including a decline in the ability to carry out activities of daily living (ADL) (American Psychiatric Association, 1994; World Health Organization, 1992). It has been established that there is a hierarchical decline in ADL (Njegovan et al., 2001; Spector et al., 1987). Basic activities of daily living such as bathing, toileting, feeding and dressing tend to be preserved in the early stages of dementia, unless there is comorbid physical disability (Boyle et al., 2002), whereas declines in more complex activities such as using a telephone, driving, shopping, and handling finances, referred to as instrumental activities of daily living (iADL), are more frequently associated with the early stages of dementia. Indeed, evidence from a longitudinal pre-diagnostic study shows that informant-rated deficits in iADL begin to appear around ten years before diagnosis with a more rapid decline around two years immediately before diagnosis (Pérès et al., 2008).

The ability to remember objectives and goals is important for successfully completing functional tasks (Infurna et al., 2011) and in mixed samples of older patients, including some with dementia, memory has been found to correlate with both objective functional performance (Goldstein et al., 1992; McCue et al., 1990) and informant-rated functioning (Breen et al., 1984; Richardson et al., 1995). A test of immediate memory has been shown to be the only significant correlate of informant-rated ADL in people diagnosed with mild cognitive impairment (Jefferson et al., 2008), often considered to be a prodromal stage of dementia (Petersen, 2004). Alongside memory, the ability to plan and initiate goals is also important for successfully completing functional tasks. Executive function is an umbrella term for a number of distinct high-level cognitive processes that regulate everyday behaviour, such as the ability to plan and initiate goal-directed actions (Elliott, 2003; Royall et al., 2002). A recent meta-analysis reported a strikingly consistent moderate association between executive function and ADL ability in Alzheimer's disease (see Chapter 2). The evidence therefore suggests that memory and executive function are associated with ADL ability in early-stage dementia.

A number of studies have examined both memory and executive function when investigating iADL functioning in people with dementia (PwD). Cahn-Weiner et al. (2003) found that only verbal executive function predicted informant-rated iADL functioning, with no association

between informant ratings and delayed memory. Farias et al. (2003) found that composite scores for immediate memory and executive function were associated with both informant-rated and objectively-assessed iADL performance, although only immediate memory predicted informant ratings. Cahn-Weiner et al. (2007) found that a composite score for memory correlated with informant-rated longitudinal functional decline; however, when a composite score for executive function was included, the latter was the only significant predictor of decline. A recent five-year longitudinal study found that memory and executive function composite scores were independently associated with informant-rated iADL, with each appearing to affect different aspects of iADL (Farias et al., 2009). Hall et al. (2011) found that both immediate memory and executive function predicted informant-rated iADL. We found evidence that immediate memory and everyday memory predicted self-rated and informant-rated iADL ability while verbal executive function predicted the discrepancy score between self-rated and informant-rated iADL (Chapter 5). These studies suggest that memory, particularly immediate memory, and executive function are important predictors of everyday functional ability in dementia.

Assessing functional ability in PwD frequently involves the use of either informant ratings or objective assessment measures, with self-ratings and clinician ratings less frequently employed (see Chapter 2). Objective assessment measures of functioning are assumed to be more reliable than self-ratings or informant ratings as they assess performance rather than relying on the accuracy of individual perceptions (Goldstein et al., 1992; Vaughan & Giovanello, 2010; Zanetti et al., 1995). However, due to the lengthy administration time (Moore et al., 2007), objective measures of functioning are often impractical in clinical settings, especially when a questionnaire can give an approximate idea of functioning in just a few minutes. Informant ratings of functioning are generally assumed to be accurate (Smyth et al., 2002), there is increasing evidence, however, that informant ratings may be biased by the age and the cognitive status of the person with dementia (Chapter 4; Teri et al., 1989), the perceived quality of the dyadic relationship (Quinn et al., 2009) or carer stress or carer burden (Chapter 5; Mangone et al., 1993; Razani, Kakos, et al., 2007; Slachevsky et al., 2013). Therefore, informant ratings may not be accurate representations of functional ability, and it may not be appropriate to rely on these in clinical and research settings (see Chapter 5).

Self-ratings of functioning made by PwD may be influenced by factors such as their level of awareness (Clare, Marková, et al., 2011), the disruption of their self-image due to increased feelings of dependency (Cotrell & Schulz, 1993) or cognitive impairment (Sager et al., 1992; Vasterling et al., 1995). Consequently, self-ratings of functioning may also lack accuracy, although there is limited empirical evidence available to allow us to establish the veracity of self-rated functioning, as self-ratings have rarely been elicited from PwD in research studies (See Chapter 2). Some studies have investigated the discrepancy between self-rated and informant-rated functioning, with findings tending to show that while self-ratings indicate significantly fewer functional difficulties when compared with informant ratings, self-ratings do reflect an awareness of decline in functioning (Chapter 4; DeBettignies et al., 1990; Kiyak et al., 1994; Ott et al., 1996; Vasterling et al., 1995) which suggests that self-ratings of iADL functioning made by PwD may be a useful means of gauging current function, and may potentially be just as useful as informant ratings (Chapter 5).

As indicated above, the accuracy of self-ratings or informant perceptions of ADL functioning is an under-studied area despite the reliance on informant ratings as a means of evaluating current functioning. To our knowledge the performance-monitoring metacognitive approach has not previously been applied to assessing awareness of everyday functional ability in people with early-stage dementia, though it has been employed in the memory domain (Clare et al., 2013; Clare et al., 2002). The present study aims to address this gap in two ways. Firstly, we will assess the accuracy of informant ratings of functional ability, and of self-ratings made by PwD both before and after undertaking an objective assessment of functional ability. Secondly, we will examine the cognitive correlates and predictors of self-rated and informant-rated and objectively-assessed functional ability, focusing on general cognition, executive function and everyday memory. Both traditional and ecologically-valid tests of executive function will be included. In summary, the current study will (1) explore the intercorrelations between self-rated predictions, self-rated postdictions, informant ratings of functional ability and objective assessment of functional ability; (2) compare the accuracy of informant-rated functional ability and the accuracy of self-ratings of performance made before and after an objective assessment was administered with scores on an objective assessment of functional ability; and (3) examine in more detail how a cognitive screening test, a test of everyday memory and tests of executive function relate to objectively-assessed and perceived functional ability in PwD.

6.3 Method

6.3.1 Design

This paper presents data from a study investigating awareness of functional ability and the association between executive function, everyday memory and tests of cognitive screening and iADL in people with early-stage dementia. Participants were recruited through eight National Health Service memory clinics in North Wales. To be included, participants had to have a diagnosis of probable or possible Alzheimer's disease, multi-infarct or subcortical vascular dementia or mixed Alzheimer's disease and vascular dementia (ICD-10, World Health Organization, 1992), a score of 18 or above on the Mini-Mental State Examination (MMSE: Folstein et al., 1975), the ability to communicate verbally in English and a contributing informant; informants were typically spouses or adult children, though friends also provided ratings in some cases. Exclusion criteria were concurrent major depression, psychosis or neurological disorder and past history of neurological disorder or brain injury. Ethical approval was granted by the relevant University and National Health Service Ethics Committees (see Appendix B).

6.3.2 Measures

6.3.2.1 Functional ability

iADL performance. Direct Assessment of Functional Status (DAFS)
The DAFS is an objective assessment of functional ability designed to investigate ADL in PwD (Loewenstein et al., 1989). The DAFS as used in the current study consists of six subscales: time orientation, communication abilities, financial skills, shopping, driving and managing medication (see Appendix J). The managing medication subscale was taken from McDougall Jr. et al. (2006). The time orientation subtest consists of two elements, telling time and orientation to date (16 points); the communication abilities subtest consists of three elements, using a telephone, dialling numbers and getting a letter ready for posting (13 points); the financial skills subtest consists of five elements, identifying currency, counting currency, writing a cheque, balancing a chequebook and counting change (28 points); the shopping subtest consists of three elements, remembering and recalling six items of shopping

and using a shopping list (20 points); the driving subtest consists of identifying 13 road signs and road markings (13 points); and the medications subtest consists of two elements, identifying and managing medication (10 points). The DAFS as used in the current study had a maximum possible score of 100, with a higher score indicating better functional ability.

iADL questionnaires. Two self-rated questionnaires, one for completion prior to the objective assessment with the DAFS (prediction, Appendix J) and one for completion following the DAFS objective assessment (postdiction, Appendix J), and one informant-rated questionnaire (Appendix K) were devised for the purposes of the study. Individual questions directly addressed the ability or function assessed by the parallel DAFS item. Each questionnaire contained 16 questions and used a five-point Likert scale (0 = very poor, 1 = poor, 2 = alright, 3 = good, and 4 = very good). The self-rated prediction questionnaire formed part of the standardised instructions for the objective assessment, and was completed immediately prior to the corresponding DAFS item. The self-rated postdiction questionnaire was completed immediately after the corresponding DAFS item. The informant-rated questionnaire asked the informant to consider how well the person with dementia would be likely to perform if asked to carry out the activity stipulated in the corresponding DAFS item. All three questionnaires had a maximum possible score of 64, with a higher score indicating less perceived functional impairment.

To permit direct comparison of the questionnaire scores with the DAFS score, the questionnaire scores were converted to a percentage of the total possible score using the formula: (questionnaire score/64)*100. However, since the DAFS has variable scoring systems within the assessment (i.e. the score for driving is between 0 and 13, while scores for other subtests range from 0-4 and 0-8), some conversion is required, otherwise the driving assessment would be given more weight in the total score. Therefore, each subtest total score was converted to a score of 100, i.e. for a subtest scored between 0 and 4, a score of 2 would be converted to 50, while for the driving ability subtest a score of 2 would achieve a score of 15.39. The scores out of 100 for the 16 subtests were then summed and converted to a percentage score using the formula: (DAFS converted score/1600)*100.

6.3.2.2 Traditional neuropsychological tests

D-KEFS: Trail Making Test (Delis et al., 2001)

This is a series of five visual-motor tasks, though only the score for the fourth (TMT4) was used in this study. TMT4 is the main executive component of the test, and participants have to connect both numbers and letters in ascending order while switching between the two (i.e. 1-A-2-B-3-C and so on). TMT4 has a time limit of 240 seconds and once this was reached participants were instructed to stop. Time taken to complete the test was the score used in this study.

D-KEFS: verbal fluency (Delis et al., 2001)

This is a series of three tests of verbal executive function, and scores for all three are included in this study. Letter Fluency asks participants to produce as many words beginning with a certain letter as they can in 60 seconds; this is repeated three times with different letters (F, A & S). The total score for the three conditions was used in the analysis. Category Fluency asks participants to name as many different animals and boys' names as they can in 60 seconds; the total score for the two conditions was used in the analysis. Switching Accuracy asks participants to switch between naming as many different types of fruit and different items of furniture as they can in 60 seconds; total switching accuracy was used in the analysis, i.e. if a participant said Apple-Chair-Banana-Cherry, this would give a score of two switches despite all four words being from the desired categories.

D-KEFS: Design Fluency (Delis et al., 2001)

This is a series of three tests designed to measure the ability to generate novel designs as quickly as possible by connecting a set of dots using only four straight lines; each test has a time limit of one minute. In the first test the participant has five filled dots in each square and participants have to draw as many different designs as they can. In the second test there are ten dots in each square, of which half are empty and half are filled, and the participant has to draw as many different designs as possible connecting only the empty dots. In the third part of the test, each square again shows ten dots, half empty and half filled, and the participant has to connect empty and filled dots in an alternating sequence. The combined score for all three parts was the score used in this study.

D-KEFS: Colour-Word Interference test (Stroop: Delis et al., 2001)
This test is analogous to the classic Stroop test where colour words are printed in incongruent coloured ink and the participant has to identify the colour in which the word is printed; i.e. if the word 'red' was printed in blue ink the correct response would be 'blue'. This test includes the words 'red', 'blue' and 'green' printed in five rows of ten words printed in incongruent coloured ink. The test has a time limit of three minutes, and the total time taken to complete this task was used in the analysis.

6.3.2.3 Ecologically-valid neuropsychological tests

Behavioural Assessment of the Dysexecutive Syndrome (BADS): Rule Shift (B. A. Wilson et al., 1996)
This test consists of two parts. In both parts participants have to respond 'yes' or 'no' depending on a specified rule. In the first part participants have to say 'yes' if a card is red and 'no' if a card is black. In the second part of the test participants have to say 'yes' if the card displayed is the same colour as the previous card, and otherwise say 'no'. In both parts of the test the same 20 cards are presented in the same order. Depending on the number of errors that are made in the second part a profile score of between -1 and 4 is scored; this profile score was used in the current study.

BADS: Key Search (B. A. Wilson et al., 1996)
In this test participants have to imagine that a square presented to them on an A4 piece of paper is a large field in which they have lost their keys. They have to draw a line to indicate the route they would take to make sure they would find their keys. Depending on the route that they draw they can achieve a profile score of between -1 and 4. This profile score was used in the current study.

BADS: Zoo Map Test (B. A. Wilson et al., 1996)
This test consists of two parts. In the first part participants are required to plan the most efficient route to visit a series of eight designated locations on a map of a zoo while in the second part participants are given the most efficient route and are required to follow the route as quickly as they can. For both parts a higher score indicates better performance; one point is awarded for each of the specified locations visited in the correct order, and one point is subtracted for any errors that are made, such as visiting non-specified locations. As the

profile score for this test is a combination of both parts 1 and 2, the total correct raw score for part 1 was used in this study as this was the score that assessed planning.

Test of Everyday Attention: Map Search (Robertson et al., 1994)
In this test participants have two minutes to find and circle as many of the 80 designated symbols on a laminated coloured A3-sized map (297mm X 420mm) as they can.

The Rivermead Behavioural Memory Test-Second Edition (RBMT: B. A. Wilson et al., 2003)
This is a test of everyday memory. It includes 12 subtests such as remembering a name, remembering faces, remembering an appointment etc. The total raw score achieved on the 12 subtests was included in the analysis, with possible scores ranging from 0-105.

For all the neuropsychological tests except TMT4 and Stroop, a higher score indicates better performance.

6.3.2.4 Screening tests for cognition and mood

Addenbrooke's Cognitive Examination-Revised (Mioshi et al., 2006)
The ACE-R is a cognitive screening tool that assesses five cognitive domains: attention and orientation, memory, verbal fluency, language and visuospatial perception skills. It also provides the widely used MMSE score. The maximum total score is 100.

National Adult Reading Test-Revised (NART-R: Nelson & Willison, 1991)
The NART-R is a well-established tool for estimating intelligence. It consists of a list of 50 phonetically irregular words (such as chord, ache, etc) that participants read aloud. The score is between 0 and 50 errors with fewer errors indicating a higher IQ. An estimated IQ score was used in the analysis to aid interpretation.

Geriatric Depression Scale-Short Form (GDS-15: Yesavage & Sheikh, 1986)
The GDS-15 is a 15-item measure of depression requiring yes/no responses, designed especially for an older population (Appendix L). The maximum score is 15, with higher scores indicating greater depressive symptoms. Scores between 0 and 4 suggest no evidence

of depression, scores between 5 and 9 suggest mild depression whereas scores between 10 and 15 suggest moderate to severe depression (Alden et al., 1989).

Apathy Scale (Starkstein et al., 1992)
The Apathy Scale is a screening tool for apathy and consists of 14 questions with answers made on a four-point Likert scale (Appendix M). The maximum score is 42 and a score above 14 suggests a clinically significant level of apathy.

Zarit Burden Interview (ZBI: Zarit, Orr, & Zarit, 1985)
The ZBI is a widely used questionnaire designed to measure burden in carers of PwD (Appendix S). It consists of 22 questions rated between 0 and 4. The maximum score is 88, with scores below 21 indicating little or no burden, scores between 21 and 40 indicating mild to moderate burden, scores between 41 and 60 indicating moderate to severe burden and scores between 61 and 88 indicating severe burden (Hébert, Bravo, & Préville, 2000).

6.3.3 Procedure

All participants were visited at home by a researcher. The assessments for the study typically took two or three visits to complete. All participants completed the first visit where informed consent to take part in the study was obtained. The first visit also typically consisted of completing screening tests for cognition and mood, the DAFS, questionnaires assessing iADL, the Map Search and the RBMT. The second visit typically consisted of completing the D-KEFS and the BADS tests of executive function. If a third visit was required the RBMT and the tests from the BADS were typically completed in the second visit with the D-KEFS assessments completed in the final visit. All participants had an informant who provided ratings of the participant as well as completing a questionnaire that measured their self-reported burden; informants typically completed the ratings and questionnaires independently during the first visit while the person with dementia was being assessed.

6.3.4 Planned analyses

To examine the first research question, Spearman's rho correlations were conducted to investigate the intercorrelations between self-rated predictions, self-rated postdictions, informant ratings and an objective assessment of iADL. To test for significant skew, the skew of the ratings and the objective performance score was converted to z scores. For the second research question, scores on the three questionnaires were converted to percentages to form a scale equivalent to the DAFS scores, and paired sample *t* tests were used to evaluate the accuracy of the converted functional ratings against objectively-assessed functional ability. For the third research question, Spearman's rho correlations were conducted to investigate the relationship between raw scores for each type of iADL assessment and neuropsychological test scores, depression, apathy, age, years of education and caregiver burden. Significantly correlated variables were entered into stepwise regressions using the default criterion probability of *F*-to-remove $\geq .10$ with SPSS v.20. The model that accounted for the greatest variance, as indicated by the adjusted R^2, was chosen as the best predictor of functional ability. Holm-Bonferroni correction for multiple comparisons was applied to all analyses.

6.4 Results

Thirty-seven PwD (16 females) took part in the study; see Table 6.1 for participant characteristics. Each participant provided self-ratings of functioning and also completed an objective assessment of functional ability. Each participant also had an informant who provided ratings of functioning; the majority of the informants were spouses or adult children and most lived with the PwD. Two participants withdrew before completing any tests of executive function; one of these also did not provide a depression self-rating. An additional participant withdrew before completing the Zoo Map test and the Stroop test. Additionally, three participants could not complete the Stroop test, one due to colour blindness and two due to mislabelling the colours. One informant did not complete the ZBI as he was a friend of the participant and did not feel the questions were applicable to him. All participants were of white European extraction, which reflects the demographic characteristics of the study area.

Table 6.1 Profile of the sample and mean scores (sds, ranges) on all assessment measures

PwD			*n*
Gender	Female		16
	Male		21
Diagnosis according to ICD-10 criteria (World Health Organization, 1992)	Alzheimer's		33
	Vascular		1
	Mixed		3
	n	Mean (SD)	Range
Age	37	79.22 (7.58)	60 - 91
Years of education	37	13.18 (3.46)	9 - 22
Screening tests			
Mini-Mental State Examination	37	22.92 (2.79)	18 - 28
Addenbrooke's Cognitive Examination-Revised	37	65.81 (10.33)	37 - 83
National Adult Reading Test-Revised IQ	37	103.70 (12.00)	80 - 122
Geriatric Depression Scale-15	36	2.67 (2.41)	0 - 12
Apathy Scale	37	12.41 (5.24)	1 - 24
Executive function tests			
Trail Making Test 4	35	212.06 (40.38)	108 - 240[a]
Letter Fluency	35	30.71 (9.02)	7 - 50
Category Fluency	35	22.34 (7.89)	6 - 45
Switching Accuracy	35	4.51 (3.09)	0 - 10
Design Fluency	35	12.06 (6.53)	1 - 25
Stroop	31	134.39 (46.22)	71 - 180[b]
Map Search	35	29.66 (15.69)	7 - 69
Zoo Map	34	-2.21 (5.06)	-14 - 8
Rule Shift	35	1.49 (1.04)	0 - 4
Key Search	35	1.23 (1.42)	-1 - 4
Everyday memory test			
Rivermead Behavioural Memory Test	37	29.08 (11.31)	7 - 56

Functional ability assessments raw scores			
Direct Assessment of Functional Status	37	65.27 (12.96)	36 - 90
Self-rated predictions of functional ability	37	41.84 (9.49)	23 - 59
Self-rated postdictions of functional ability	37	41.84 (9.20)	23 - 61
Informant ratings of functional ability	37	30.65 (13.13)	9 - 58
Functional ability assessments percent of maximum score			
Direct Assessment of Functional Status	37	66.03% (12.73)	35.00 - 90.79%
Self-rated predictions of functional ability	37	65.37% (14.83)	35.94 - 92.19%
Self-rated postdictions of functional ability	37	65.37% (14.37)	35.94 - 95.31%
Informant ratings of functional ability	37	47.89% (20.52)	14.96 - 90.63%
Informants			*n*
Gender	Female		26
	Male		11
Live with the person with dementia	Yes		26
	No		11
Relationship to the person with dementia	Spouse		21
	Child		14
	Friend		2
	n	Mean (SD)	Range
Age	37	65.30 (14.91)	32 - 87
Zarit Burden Interview	36	26.64 (13.78)	8 - 56

[a] 18 people failed to complete Trail Making Test 4 within the time limit. [b] 12 people failed to complete the Stroop within the time limit. Note: standard deviations in parentheses.

A *t* test indicated that there was no difference in informant ratings of functioning for those who did (mean 30.54, sd 12.90) and those who did not (mean 30.91, sd 14.31) live with the PwD, $t(35) = 0.08$, $p = .939$. The mean screening score for depression was low with most falling in the 'no depression' range; 4 participants fell within the mild depression range and one person displayed symptoms of moderate to severe depression. There was slightly more evidence for apathy, with 15 participants scoring above the cut-off of 14, though there was no difference in scores on any measure between those scoring above and below the cut-off on the Apathy Scale. After Holm-Bonferroni correction, apathy and depression did not correlate with any measure. There were no sex differences for any measure. The intercorrelations

between everyday memory, tests of executive function and cognitive screening measures are shown in Appendix T.

6.4.1 The relationship between self-ratings, informant ratings and objectively-assessed functional ability

There was no evidence of significant skew for informant ratings, z = 1.22, p = .223, self-rated predictions, z = -0.06, p = .952, self-rated postdictions, z = -0.46, p = .646 or objective performance (DAFS), z = -0.16, p = .873, suggesting a relatively normal distribution of scores. The DAFS total score was significantly correlated with self-rated predictions, $r(35)$ = .44, p = .006, self-rated postdictions, $r(35)$ = .64, p < .001, and informant-rated functioning, $r(35)$ = .58, p < .001. Informant-rated functioning did not correlate with self-rated predictions, $rs(35)$ = .19, p = .250 or self-rated postdictions, $rs(35)$ = .28, p = .092. Self-rated predictions were highly correlated with self-rated postdictions, $rs(35)$ = .80, p < .001. The associations between self-rated prediction, self-rated postdiction and objective performance scores suggests that the self-ratings were similar to objective performance scores. Due to the non-significant association between self-ratings and informant ratings the correlation between informant ratings and objective performance suggests that informant ratings may have been measuring different aspects of functioning.

6.4.2 Accuracy of ratings of functioning compared with objectively-assessed performance

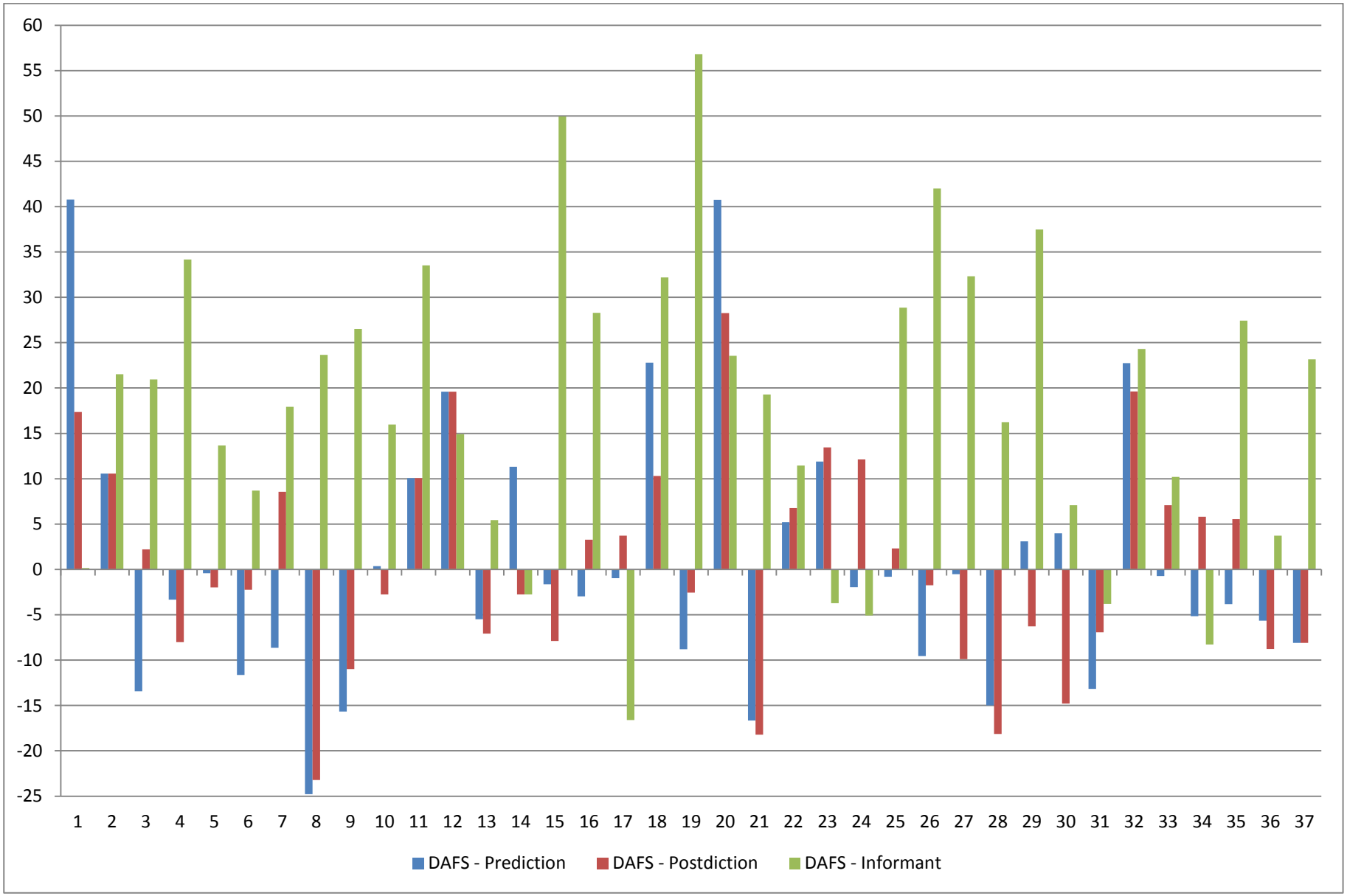
To investigate the accuracy of ratings of perceived functioning, paired-sample t tests were used to compare the DAFS percentage score with the percentage scores for the three questionnaires; see Table 6.1 for mean percentage scores. There was a significant difference between the DAFS scores and informant ratings, $t(36)$ = 6.71, p < .001; informant-rated functional ability was significantly lower than the objective performance score, indicating that informants overestimated functional difficulty. There was no significant difference between the DAFS score and either the self-rated prediction score, $t(36)$ = 0.28, p = .784, or the self-rated postdiction score, $t(36)$ = 0.34, p = .733, suggesting that PwD were accurate when rating their own functional ability. The informant-rated score was significantly lower than the self-rated prediction score, $t(36)$ = 4.65, p < .001, and self-rated postdiction score, $t(36)$ = 4.95, p < .001. Finally, there was no difference between the self-rated postdiction

score and the self-rated prediction score, $t(36) = 0.00$, $p = 1.000$. These findings indicate that the accuracy of self-ratings did not improve after performing the test; in fact the mean scores for prediction ratings and postdiction ratings were identical, suggesting remarkably little variability. However, as the prediction rating was found to be accurate there was little scope for improved accuracy at postdiction. Therefore, self-ratings of functioning in PwD indicate good correspondence with objective performance; this was consistent whether ratings were made immediately before or immediately after objective performance. Informant ratings, however, indicate a perception of greater functional difficulty than is suggested by the objective assessment, so it appears that informants of PwD tend to overestimate functional difficulties.

6.4.3 Within-participant rating variability after controlling for objective performance

To control for objective performance each of the three percentage rating scores was subtracted from the DAFS percentage score; see Figure 6.1. Scores of ±10 and ±20 were arbitrarily chosen to describe the data; these data are not intended to be interpreted as indicating an accuracy cut-off score. There was some variability within the ratings, especially for informants. Eighteen informants underestimated the performance of the PwD and were discrepant from the total DAFS score by more than 20 points. No informant overestimated performance by 20 points expanding upon the above mean analysis that indicated that informants were more likely to underestimate than overestimate functional ability. For the PwD, only five prediction ratings and two postdiction ratings were discrepant from the DAFS total score by more than ±20 points. Indeed, only 10 informants were discrepant by fewer than ±10 points whereas for PwD 21 prediction ratings and 23 postdiction ratings were discrepant from the DAFS by fewer than ±10 points, indicating good correspondence between self-ratings and objectively-assessed performance. When compared with the prediction rating, the postdiction rating became more accurate for 13 participants and became less accurate for 20 participants, with 23 of these scores falling within a difference of ±5 points and 31 falling within a difference of ±10 points. Therefore, the majority of informant ratings of PwD functioning were discrepant from objectively-assessed performance. Both self-rated predictions and self-rated postdictions showed fewer discrepancies and were generally more comparable to objectively-assessed performance than informant ratings, and while there were some PwD who were discrepant, these were in the minority.

Figure 6.1 Distribution of ratings for each participant after controlling for objective functional ability



Note: scores closest to zero display greater concordance with objective performance (DAFS). Negative scores indicate that the rater overestimated performance compared with the DAFS, while positive scores indicate that the rater underestimated performance compared with the DAFS.

Table 6.2 Spearman's rho correlations between neuropsychological tests and iADL

	DAFS		Self-Ratings				Informant Ratings	
	Total score	*p*	Prediction total score	*p*	Postdiction total score	*p*	Total score	*p*
Demographics								
Age	-.227	.177	.291	.080	-.037	.828	-.199	.239
Years of Education	-.227	.177	-.095	.575	-.096	.570	.033	.848
Screening tests								
MMSE	.732	**< .001**	.293	.079	.505	**.001**	.379	.021
ACE-R	.658	**< .001**	.242	.148	.417	.010	.528	**.001**
NART-R	-.288	.084	-.116	.494	-.173	.306	.044	.795
Traditional tests of executive function								
Trail Making Test 4	-.591	**< .001**	-.288	.093	-.324	.057	-.399	.018
Letter Fluency	.016	.926	-.198	.255	-.124	.477	-.063	.720
Category Fluency	.493	**.003**	.203	.241	.242	.161	.327	.055
Switching Accuracy	.377	.026	.219	.206	.369	.029	.218	.207
Design Fluency	.548	**.001**	.247	.153	.297	.083	.374	.027
Stroop	-.523	**.003**	-.451	.011	-.312	.087	-.408	.023
Ecologically-valid tests of executive function and memory								
RBMT	.517	**.001**	.399	.014	.481	**.003**	.276	.099
Map Search	.391	.020	.265	.125	.261	.130	.165	.344
Zoo Map	.209	.235	.118	.508	.088	.622	.169	.339
Rule Shift	.467	**.005**	.410	.014	.316	.065	.282	.101
Key Search	.489	**.003**	.098	.577	.257	.136	.203	.243
ZBI	-.210	.219	.020	.906	.102	.555	-.346	.038

Note: bold indicates significant at the 5% level after Holm-Bonferroni correction. Abbreviations: Addenbrooke's Cognitive Examination-Revised (ACE-R), Direct Assessment of Functional Status (DAFS), Mini-Mental State Examination (MMSE), National Adult Reading Test-Revised (NART-R), Rivermead Behavioural Memory Test (RBMT), Zarit Burden Inventory (ZBI).

6.4.4 The relationship between functional ability and cognitive tests

Objectively-assessed performance was significantly related to five of the nine executive function test scores; see Table 6.2. Objectively-assessed performance was also significantly related to RBMT, MMSE and ACE-R scores. Only the MMSE and RBMT scores were significantly correlated with self-rated postdictions whereas no test scores were significantly correlated with self-rated predictions of perceived functioning; there were, however, a number of moderate correlations which were not statistically significant, possibly due to the sample size. Only the ACE-R score was correlated with informant-rated functioning. Unexpectedly, carer burden did not correlate with any functional assessment score. The results therefore confirm that executive function, memory and cognitive screening measures are important correlates of objectively-assessed iADL performance. There were however no significant associations between tests of executive function and ratings of perceived functioning, with only the MMSE, RBMT and ACE-R scores correlating with these ratings.

Table 6.3 Predictors of objective functional ability

	Direct Assessment of Functional Status	
adjusted R^2	.675	
	ß	*p*
Addenbrooke's Cognitive Examination-Revised	.466	**< .001**
Rivermead Behavioural Memory Test	.430	**< .001**
Trail Making Test 4	-.256	.034

Note: bold indicates significance at the 5% level after Holm-Bonferroni correction.
The MMSE score was excluded from the regression as the sample was selected based on the MMSE score and also because the ACE-R includes the MMSE and this led to issues with multicollinearity.

6.4.5 Predictors of objectively-assessed functional ability

Significant correlates of objectively-assessed performance were entered into a stepwise regression; results are summarised in Table 6.3. Total score for the DAFS was significantly predicted by the model, $F(3, 27) = 21.47$, adjusted $R^2 = .68$, $p < .001$, with both ACE-R and RBMT scores individually significant; TMT4 was also included in the model though this was not significant after correcting for multiple comparisons. Therefore, ACE-R and RBMT may be the best predictors of objective iADL performance in PwD. An additional stepwise regression was conducted to investigate how well the five ACE-R subscales predicted objective functional ability. DAFS total score was significantly predicted by the model, $F(3, 33) = 32.37$, adjusted $R^2 = .72$, $p < .001$, with the attention and orientation ($\beta = .64$, $p < .001$), memory ($\beta = .30$, $p = .003$) and visuospatial perception ($\beta = .24$, $p = .014$) subscales individually significant, suggesting that attention and orientation, memory and visuospatial ability may play a role in predicting functional ability.

6.5 Discussion

This study investigated the accuracy of self-rated and informant-rated functioning compared with objectively-assessed performance in people with dementia. Ratings made by PwD were found to be strikingly accurate; this was the case with ratings made both before and after the objective assessment, suggesting that PwD can accurately rate their everyday functional ability. There was evidence of some variability, particularly with informant ratings; a few informants showed good correspondence with objectively-assessed performance, but most were very discrepant. Self-ratings by PwD on the other hand showed relatively good correspondence with objectively-assessed performance though a few were very discrepant. Therefore, despite some variation, self-ratings generally showed fewer discrepancies with objectively-assessed performance. The study also investigated the cognitive correlates of functional ability. Similar to healthy older people (see Chapter 3) there were few significant correlations between ratings of functional ability and cognition, with only the ACE-R, MMSE and RBMT scores correlating with PwD self-ratings. There was however a more consistent association between objectively-assessed performance and cognition, with six tests of executive function, the ACE-R, MMSE and RBMT scores showing significant associations with the DAFS score, which is consistent with the findings presented in Chapter

3. Indeed, only the ACE-R and the RBMT predicted objective functional ability, suggesting that everyday memory and general cognition are good predictors of functional ability in PwD. Therefore objectively-assessed functional ability shows a more consistent and stronger association with tests of executive function, memory and cognitive screening tests than ratings of functioning.

We found evidence that PwD are aware of their functional difficulties. This is consistent with a few studies that have found evidence that PwD are aware of their own functional decline (Clare, Nelis, Martyr, Whitaker, et al., 2012; Kiyak et al., 1994). The finding is, however, inconsistent with the generally-held view that self-ratings made by PwD are inaccurate (Snow et al., 2005), and calls into question the assumption that because self-ratings are often discrepant from informant ratings PwD therefore lack awareness of functioning (DeBettignies et al., 1990; Ott et al., 1996; Vasterling et al., 1995). There has been very little research investigating the accuracy of ratings of iADL functioning in PwD or their informants, and the current study suggests that there is a need for more research to delineate the awareness of iADL functioning held by both PwD and their informants. It should be noted, however, that while the overall means of the two self-ratings were very closely matched to the mean score for objective functional performance, the correlation between self-rated prediction and objectively-assessed performance was only moderate, suggesting that while the group were accurate there was some individual variability in the prediction ratings. The large correlation between self-rated postdiction and objectively-assessed performance suggests that the postdiction rating was more consistent with functional ability than the prediction rating, which is in line with the findings from studies that have investigated performance monitoring of memory in PwD (Clare, Whitaker, et al., 2010). However, after controlling for objectively-assessed performance, for around half of the sample the postdiction rating was less accurate than the prediction rating indicating that not all PwD increase the accuracy of their iADL ratings following an objective functional assessment.

Informants significantly overestimated the level of functional difficulty shown by PwD, suggesting that the confidence shown by researchers and clinicians in the accuracy of informant ratings of functioning may be misplaced. The overestimation by informants was unlikely to be due to carer burden as the association between informant-rated functioning and burden was not statistically significant, although the correlation was moderate. This is inconsistent with a growing body of research which has shown a strong association between

burden and informant ratings of functional ability (Chapter 5; Mangone et al., 1993; Razani, Kakos, et al., 2007; Slachevsky et al., 2013; Zanetti et al., 1999), although the association between burden and objectively-assessed functioning tends to be smaller than the association between burden and informant ratings of functional ability (Razani, Kakos, et al., 2007). The only significant correlation found for informant ratings of functioning was for the ACE-R, suggesting that ratings made by informants may have been influenced by the general cognitive status of the PwD (see Chapter 4). The ACE-R was also found to correlate with objectively-assessed performance and indeed provided the largest correlation after the MMSE score, though interestingly the correlation between MMSE score and informant ratings of functioning was not significant and was considerably lower than the correlation between the ACE-R score and informant ratings. This was unexpected as the ACE-R incorporates the MMSE. Indeed, it will be interesting to see whether the recently-introduced ACE-III is equally as good at predicting functional ability in PwD, given that it has been designed to specifically exclude MMSE items from the test.

In studies of healthy older people it has been suggested that questionnaire items whose wording matches functional assessments may increase rating accuracy (Chapter 3; Mitchell et al., 2011; Myers et al., 1993). In the current study items were worded to match specific functional abilities that participants were asked to perform and this wording may have increased the accuracy of self-rated functioning. This suggests that standard questionnaires assessing functional ability may be worded too vaguely to provide an accurate rating (Davis, 2001), and may partially explain the often-reported discrepancy between self-ratings and informant ratings of functional ability (Chapter 4; DeBettignies et al., 1990; Kiyak et al., 1994; Ott et al., 1996; Vasterling et al., 1995) since the broad descriptions of individual daily functions in these questionnaires may mean that the two raters base their judgements on different aspects of the same tasks (see Chapter 5). Therefore, questionnaires assessing ADL ability should consist of specific items clearly representing individual ADL skills in order to more accurately assess functioning; the addition of extra items may increase administration time, but it should also lead to an increase in accuracy. The performance monitoring metacognitive approach has been used previously in PwD with regards to memory ability (Clare et al., 2013; Clare et al., 2002), but has not to our knowledge been used to investigate everyday functional ability in PwD. The study suggests that extending the use of the performance monitoring metacognitive approach to functional ability may be a useful method of investigating awareness in PwD.

The study offers support for the general finding that tests of executive function correlate with functional ability (see Chapter 2), though interestingly this was only the case for objectively-assessed functioning, as there were no significant correlations between ratings of functioning and tests of executive function. This finding contrasts with previous research where a consistent correlational effect size between the different functional assessment methods has been reported (see Chapter 2). Indeed, the only tests that correlated with ratings of functioning were screening tests (MMSE, ACE-R) and an everyday memory test (RBMT). The findings therefore suggest that tests of executive function are strong correlates of objective functional assessments in PwD (e.g. Chapter 2; Farias et al., 2003; Razani et al., 2011), whereas a test of everyday memory and cognitive screening tests correlate with objective functioning and functional ratings. Interestingly, despite the strong correlational relationship found between objective functional ability scores and scores on both tests of executive function and cognitive screening tests, the only significant predictors of objectively-assessed functional ability were ACE-R and RBMT scores; although TMT4 was included in the model it was not significant after correcting for multiple comparisons. This suggests that tests of memory may be more important predictors of everyday functional ability in PwD than tests of executive function, a finding consistent with Farias et al. (2009) who found that a composite score for memory was a better predictor of functional ability in PwD than a composite score for executive function. However, Cahn-Weiner et al. (2007) found the opposite as, while tests of memory significantly predicted informant-rated decline in functional ability when only memory was added into the model, once executive function was included only executive function predicted informant-rated decline in functional ability. This apparent discrepancy between Cahn-Weiner et al. (2007) and Farias et al. (2009) and the current study may be due to the inclusion by Cahn-Weiner and colleagues of tests of delayed memory which have been found to show weaker associations with functional ability (Chapter 5; Cahn-Weiner et al., 2003; Farias et al., 2003; Hall et al., 2011; Hill et al., 1995). The current study suggests that everyday functioning in PwD may be dependent on memory ability, and that despite the significant associations between tests of executive function and iADL, the ability to remember may be more important than the ability to initiate tasks or to plan how to sequence tasks and switch between them.

This study has some limitations which should be considered when interpreting the results. A large number of predictors were entered into the model given the sample size; we employed stepwise regressions and Holm-Bonferroni correction in an effort to minimise the effect of

the low statistical power and to reduce the number of potentially erroneous significant predictors of iADL. Further studies are needed with larger samples to corroborate the reliability of our finding of striking accuracy of self-rated functioning by PwD, especially as there was some evidence of within-participant variability. Including the self-rated prediction questionnaire as part of the standardised instructions for the objective iADL test may have been a limitation since it may have encouraged participants in the study to monitor their performance more closely than usual and adjust their postdiction ratings accordingly. It is possible that if the prediction questions had been given as a separate questionnaire, similar to the way in which the informant-rated questionnaire was administered, this might have affected the associations between self-rated predictions and cognitive tests. However, after controlling for objectively-assessed performance, about the same number of participants became either more or less accurate at postdiction, which suggests that this methodological concern may not have unduly influenced the accuracy of the self-rated prediction questionnaire. A further limitation may have been the use of a standardised assessment to measure functional ability; the DAFS involved presenting participants with tasks that assess what they can do under optimal conditions rather than what they actually do in their everyday lives (Glass, 1998). However, as the disease progresses PwD tend to remain closer to home (Duggan, Blackman, Martyr, & van Schaik, 2008) and tasks are performed with more supervision from caregivers, suggesting that assessing PwD in a standardised setting with prompts and structured tasks may provide a more typical snapshot of how PwD conduct everyday functional tasks. Therefore, for PwD a structured, standardised assessment may be a reliable method of assessing current functioning.

6.6 Conclusions

Self-ratings of functioning made by PwD show considerable accuracy when compared with objectively-assessed functioning, whereas informant ratings of functioning were found to significantly overestimate functional difficulty. This finding calls into question the value of using informant ratings to assess everyday functioning of PwD and suggests the need for more research to establish the reliability of informant ratings and self-ratings of iADL. Longitudinal studies are required to establish whether self-ratings made by PwD of their everyday functional ability remain accurate as dementia severity increases. The ACE-R was found to significantly predict objectively-assessed performance, suggesting that the ACE-R

may be a useful test to monitor iADL ability in PwD. The RBMT total score also predicted objectively-assessed performance, suggesting that the RBMT may also offer a useful means of monitoring iADL ability in PwD, but the longer administration time makes it less practical than the ACE-R. Further research is required to establish whether the recently introduced replacement for the ACE-R, the ACE-III, is also a good predictor of functional ability in PwD. Longitudinal studies are needed to assess the usefulness of this relatively brief assessment of cognitive status as a means of monitoring functional decline in people with dementia.

Chapter 7

Discussion

7.1. Introduction

This thesis aimed to extend our understanding of how ratings of everyday functional ability made by healthy older people, people with dementia and their key informants compare with the results of an objective assessment of functional ability. The thesis also aimed to explore the extent to which scores on tests of cognition, particularly executive function, are associated with everyday functional ability in both healthy older people and PwD. These are important areas to research as there has been little focus on the reliability of the ratings of iADL made by informants of PwD, and there has been very little research that has attempted to obtain, and investigate the accuracy of, self-ratings of iADL made by both healthy older people and PwD. The association between cognition and everyday functional ability is important as declines in one are often associated with declines in the other (Farias et al., 2009), and tests of cognition may serve as predictors of the risk of developing functional dependence. Therefore, early identification of difficulties with cognition and everyday functional abilities will allow older people to receive appropriate support and treatment earlier, which may enable older people to remain living independently for longer and in the future potentially help to delay the onset of dementia (Galasko et al., 1997).

A focus of the thesis involved exploring the way in which ratings of functional ability made by healthy older people related to the results of an objective assessment of functional ability, and identifying which tests of executive function and which cognitive screening tests best predicted iADL ability. These areas are important to investigate since performance on cognitive tests may help to identify people at risk of developing functional dependence, and because the ability to live independently affects the well-being and quality of life of older people (Covinsky et al., 2003) and is even related to an increased risk of mortality (Guralnik et al., 1991; Klijs et al., 2010). It is therefore important to investigate how changes in functional abilities affect older people and how performance of everyday activities relates to cognition, as changes in iADL in older people often predict changes in cognition and vice versa (Moritz, Kasl, & Berkman, 1995; Sikkes et al., 2011).

The finding that self-ratings of iADL made by PwD were more accurate than informant ratings is a key finding and extends our understanding of how PwD and their informants perceive the ability of PwD to perform everyday functional tasks. The inclusion of

questionnaires worded to match the elements of an objective functional assessment may have increased the accuracy of the ratings, since a criticism of most questionnaires assessing everyday functional ability is that the wording tends to be overly broad and it is difficult to interpret which aspect of the question people are rating (Davis, 2001; Guralnik et al., 1989). The fact that ratings of iADL made by informants of PwD were influenced by carer stress and overestimated the everyday functional difficulties of PwD has important implications for the continued use of informant ratings in research and especially in clinical settings where they are frequently used as part of the dementia diagnostic process (Sikkes et al., 2009). Additionally, if PwD are aware of their functional limitations this may make it easier for PwD to ask for help and to benefit from rehabilitation where this is available.

A consistent and robust association between iADL and cognition has been widely reported; however, this consistent association may have arisen as a result of the limited range of cognitive tests that have been explored in relation to iADL. The studies presented in this thesis extended our understanding of the important association between cognition and iADL in healthy older people and PwD by including both traditional and ecologically-valid tests of memory and executive function.

In the following sections the results of the thesis will be summarised and discussed with regard to the research questions and existing research literature. Then, practical implications and limitations will be considered and recommendations for future research presented. Finally, implications for clinical practice will be discussed.

The thesis was focused around five overarching research questions, which are summarized below along with the key findings for each research question.

The first research question was addressed with a meta-analysis (Chapter 2). The second and third research questions were addressed by quantitative analyses based on cross-sectional data from 59 healthy older people (Chapter 3). The fourth and fifth research questions were addressed with quantitative analyses based on cross-sectional data from secondary analysis of 101 PwD and their key informants (Chapters 4 and 5) in addition to data from a sample of 37 PwD and their key informants (Chapter 6). PwD completed an assessment covering instrumental activities of daily living, executive function, memory, mood and well-being, and apathy, and informants provided ratings of activities of daily living and also rated their own

level of burden associated with caring for a PwD. Healthy older people completed a similar, though shorter, assessment battery.

7.2. Review of the key findings

Research question 1 - What is the relationship between different tests of executive function and different methods of assessing activities of daily living in people with dementia?

In Chapter 2 the literature on ADL and executive function in people with Alzheimer's disease was systematically searched and data from 49 studies were entered into a series of meta-analyses. A wealth of research has examined the association between ADL and executive function in people with Alzheimer's disease and the results of the meta-analysis were surprisingly consistent. A moderate association was found between assessments of ADL and most of the executive function tests including tests such as the Trail Making Test-Part B, Letter Fluency and the Clock Drawing Test which are widely used by clinical neuropsychologists (Rabin et al., 2005). There was some variability in the results, with tests such as the Stroop and the Token Test not associating with ADL, though every test that was not significantly related to ADL was used in three or fewer studies and tended to have a large confidence interval and a large degree of heterogeneity, indicating that the findings for these tests should be considered preliminary.

A moderate association was found between tests of executive function and each of the four methods of assessing ADL: objective assessment measures, informant ratings, self-ratings and clinician ratings. The meta-analysis found a moderate association between driving ability and scores on executive function tests, consistent with a previous meta-analysis (Reger et al., 2004), suggesting that executive function test scores are only moderately associated with driving even though driving is a complex and cognitively demanding everyday functional ability.

The observed association between ADL and tests of executive function may have arisen due to the meta-analysis combining assessments of iADL, which tend to show more impairments

in early dementia (C. R. Green et al., 1993; Njegovan et al., 2001) and basic ADL, which tend to be preserved in early dementia (Boyle et al., 2002).

Findings from the meta-analysis, therefore, suggest a consistently moderate association between executive function and ADL in Alzheimer's disease. However, the findings from the empirical studies were not consistent with the results of the meta-analysis and this will be addressed in the relevant sections below.

Research question 2 - Which cognitive screening tests or tests of executive function best predict ability to perform instrumental activities of daily living in healthy older people?

Extending the meta-analysis which focussed on executive correlates in people with Alzheimer's disease, one of the objectives of the study reported in Chapter 3 was to explore the cognitive correlates of everyday functional ability in healthy older people. Previous studies have identified a number of tests that predict functional ability in older people, with the Trail Making Test-Part B consistently shown to be a good predictor of functional ability (Bell-McGinty et al., 2002; Cahn-Weiner et al., 2002; Mitchell & Miller, 2008b). The results of Chapter 3 supported these studies, showing that the analogous Trail Making Test 4 was a strong predictor of iADL ability in healthy older people. The set-switching aspect of the Trail Making Test may therefore be a useful test to monitor functional decline in older people. There was less support for the potential of ecologically-valid tests of executive function to serve as good predictors of functional ability, since few ecologically-valid tests correlated with iADL and none predicted iADL. For example, the Zoo Map Test was not significantly correlated with iADL ability in healthy older people or in PwD, suggesting that the planning aspect of this task may not be indicative of everyday functioning.

In terms of the tests that predict objectively-assessed iADL ability the Trail Making Test 4 significantly predicted objectively-assessed iADL in healthy older people which is generally consistent with Farias et al. (2009) who suggested that executive function predicts iADL decline in healthy older people. The Addenbrooke's Cognitive Examination-Revised also significantly predicted objectively-assessed iADL performance in healthy older people. The findings appear to suggest that the Trail Making Test 4 and the Addenbrooke's Cognitive Examination-Revised may be good predictors of iADL for healthy older people, a conclusion

similar to Royall et al. (2007) who found that tests of cognitive screening and executive function explained more of the variance in everyday functional ability than tests of memory. This was especially significant as the Addenbrooke's Cognitive Examination-Revised was the only test to correlate with both objectively-assessed iADL and ratings of iADL.

Consistent with Mitchell and Miller (2008a), scores on tests of executive function were found to correlate more strongly with objectively-assessed iADL performance than with ratings of perceived functioning, suggesting that ratings of everyday functional ability were more weakly associated with tests of cognition than objectively-assessed performance. Therefore, objectively-assessed functional ability may be more closely related to the cognitive function of older people than is the case for self-ratings or informant ratings (Randolph & Chaytor, 2013). An alternative explanation may be that ratings of functional ability and objective assessments of functional ability are measuring different aspects of the same tasks (Zanetti et al., 1995). It should be noted however that the findings presented in Chapter 3 employed questionnaires that were specifically worded to match the objective assessments. The intercorrelations between the questionnaires and the objective assessment measure in Chapter 3 were considerably stronger than the correlations reported by Zanetti et al. (1995) who used a standard questionnaire of ADL. Therefore, standard functional questionnaires may be too broad and may not investigate the same aspect of iADL that is being assessed by objective assessment measures (Davis, 2001), and this may have partly explained the reduced correlations reported in Zanetti et al. (1995).

The findings suggest that the Addenbrooke's Cognitive Examination-Revised and the Trail Making Test 4 are good predictors of objectively-assessed everyday functional ability in healthy older people.

Research question 3 - How accurate are ratings of instrumental activities of daily living made by healthy older people when compared with an objective assessment?

Another objective of the study reported in Chapter 3 was to explore whether healthy older people were able to accurately rate their everyday functional ability. There has been relatively little research to ascertain the accuracy of self-rated iADL in community-dwelling healthy older people, though recent studies suggest that older people overestimate their functional

ability when compared with objectively-assessed iADL performance (Mitchell & Miller, 2008a; Mitchell et al., 2011). The accuracy of older people in rating their own everyday functional ability and that of others is an important consideration, as the ability to accurately assess one's own limitations may have implications for the ability of older people to continue living independently.

Compared with scores on an objective iADL assessment, the findings presented in Chapter 3 suggest that older people underestimate their level of iADL ability. Informant ratings tended to be more accurate, though they also significantly underestimated functional ability compared with objectively-assessed iADL performance. Interestingly, 46 of the 59 participants included in Chapter 3 were spouses and each member of the dyad acted as both participant and informant, suggesting that older people are able to rate the functional ability of their partner with greater accuracy than they are able to apply when rating their own iADL performance. The findings presented in Chapter 3 suggest that objective assessment measures or informant ratings should be used in place of self-rated questionnaires to accurately assess functional ability in healthy older people.

Research question 4 - Which tests of cognition best predict ability to perform instrumental activities of daily living in people with dementia?

While the meta-analysis reported in Chapter 2 focused on how tests of executive function *correlated* with activities of daily living, the studies reported in Chapters 4, 5 and 6 extend these findings by also investigating the *predictors* of functional ability. Previous studies have suggested that Letter Fluency may be a good predictor of functional ability in PwD (Chen et al., 1998; Razani, Casas, et al., 2007) and this was examined in Chapter 4. Letter Fluency was found to predict self-rated iADL but not informant-rated iADL, which contrasted with the findings presented in Chapter 6 and findings from previous studies using informant ratings (Chen et al., 1998; Razani, Casas, et al., 2007), although when other tests were included in the analysis Letter Fluency was a non-significant predictor of self-ratings (Chapter 5). However, even with the addition of other tests, Letter Fluency remained the only significant predictor of the discrepancy between self-ratings and informant ratings. Therefore, there was mixed support for Letter Fluency being a good predictor of iADL in people with dementia.

Based on the findings of the meta-analysis, the relationship between different tests of executive function and different methods of assessing activities of daily living appears to be moderate in nature. In contrast, the results presented in Chapter 6 include large correlations between tests of executive function and objectively-assessed functional ability, but smaller and non-significant correlations with ratings of iADL. For example, the study presented in Chapter 6 found a large correlation (.61) between objectively-assessed performance and the Trail Making Test 4, analogous to the Trail Making Test-Part B, whereas non-significant though moderate correlations were found between the Trail Making Test 4 and iADL ratings. Indeed, the correlational effect size presented in Chapter 6 between objectively-assessed iADL and the Trail Making Test 4 was above the upper 95% confidence interval presented in the meta-analysis. Additionally, the findings presented in Chapter 6 found a large correlation (.51) between the Stroop test and objectively-assessed functional performance. This finding was inconsistent with the meta-analysis and the findings of Razani, Casas, et al. (2007) who also used an objectively-assessed measure of iADL. The lack of association between informant ratings of iADL and the Stroop test was, however, consistent with the few studies that have investigated the Stroop in relation to iADL in people with dementia (Back-Madruga et al., 2002; Razani, Casas, et al., 2007; Sabbagh et al., 2007). Interestingly, the correlations between the Stroop test and the different iADL assessment methods presented in Chapter 6 were above the upper 95% confidence interval presented in the meta-analysis, even for the correlations which were not statistically significant. Therefore, there was some disparity between the findings presented in Chapter 6 and the results of the meta-analysis in Chapter 2 for individual executive function tests. This disparity may have been due to the meta-analysis combining data from studies that used objective assessments of everyday functioning and studies that used ratings of ADL. The study presented in Chapter 6 is consistent with this as most tests of executive function correlated more strongly with objectively-assessed functional ability than with questionnaire ratings of iADL.

The meta-analysis indicated that there tended to be a bias towards the use of more traditional tests of executive function when investigating everyday functional ability, since only one study (Perry & Hodges, 2000) incorporated ecologically-valid tests of executive function. The results presented in Chapter 6 extend the meta-analysis by including four ecologically-valid executive function tests. The Rule Shift test, which is a test of set-switching, and the Key Search test, which is a test of search strategy and planning (Oosterman, Molenveld, Olde Rikkert, & Kessels, 2010; B. A. Wilson et al., 1996), were found to be significantly

correlated with everyday functioning, though only with an objectively-assessed performance-based assessment. Ecologically-valid tests of executive function therefore appear to associate to a similar degree as more traditional tests of executive function with everyday functional tasks, although no ecologically-valid test of executive function predicted iADL ability. Therefore, including ecologically valid tests of executive function is likely to yield few benefits when investigating iADL ability in healthy older people (Chapter 3) and PwD (Chapter 6).

The moderate correlation between tests of executive function and ADL found in the meta-analysis (Chapter 2) suggests that executive function explained only part of the relationship between these two factors in PwD. Indeed, in Chapter 6 there was only one executive function test (the Trail Making Test 4) that predicted, although not significantly, objectively-assessed functional ability. This contrasted with the healthy older people included in Chapter 3 where the Trail Making Test 4 was a significant predictor of objectively-assessed iADL. Everyday memory meanwhile was found to be a good predictor of objectively-assessed iADL ability in Chapter 6, and it was found to be a non-significant predictor of informant ratings in Chapter 5. There have been mixed findings in the literature regarding the extent to which memory ability predicts everyday functioning. Breen et al. (1984), for example, found that memory was a strong correlate of ADL but when entered into a regression it did not significantly predict ADL, although the small sample size likely explained the lack of statistical significance. A recent five-year longitudinal study found that memory and executive function composite scores were independently associated with informant-rated iADL (Farias et al., 2009); people who declined in either memory or executive function tended to decline in iADL ability, and those who declined in both memory and executive function showed the greatest evidence of iADL decline. Farias et al. (2009) also suggested that memory predicts iADL decline in PwD whereas executive function predicts iADL decline in healthy older people. This was generally consistent with the findings presented in Chapters 3 and 6 where the Trail Making Test 4 predicted iADL in healthy older people whereas everyday memory predicted iADL in PwD. Therefore, for PwD everyday memory may be a good predictor of everyday functional ability (Chapter 6) and informant-rated iADL (Chapter 5).

A recent review found that cognitive screening measures were better predictors of ADL than tests of either executive function or memory (Royall et al., 2007). One of the largest estimated effect sizes in the meta-analysis (Chapter 2) was found for the correlation between MMSE score and ADL. Indeed, findings presented in Chapter 4 support this since the general cognitive status (MMSE score) of the PwD rather than Letter Fluency ability predicted informant ratings of PwD everyday functional ability. This was consistent with Chen et al. (1998) who reported that, once MMSE score was controlled for, the associations between executive function and informant-rated iADL were much reduced suggesting that MMSE score may be an important correlate of functional ability in PwD. However, in Chapter 5 MMSE score did not predict informant-rated total iADL score; indeed MMSE score only predicted one informant-rated item. Meanwhile, the Addenbrooke's Cognitive Examination-Revised was a significant predictor of objectively-assessed iADL performance and was the only test that correlated with informant ratings in Chapter 6. The findings of the thesis suggest that tests of memory and cognitive screening, particularly the Addenbrooke's Cognitive Examination-Revised, predict iADL in PwD. Executive function, as measured by the Trail Making Test 4 and also Letter Fluency, was weakly predictive of iADL in PwD when tests of memory and cognitive screening were included in regression models.

Research question 5 - How accurate are ratings of instrumental activities of daily living made by people with dementia and their informants when compared with an objective assessment?

The meta-analysis in Chapter 2 found a consistent moderate correlational effect size between executive function and the four different methods of assessing ADL, thereby suggesting that if the primary question of interest is the relationship between executive function and ADL, then an ADL questionnaire may provide the same information as a performance-based measure of ADL. However, the analysis was only concerned with how executive function associates with ADL and could not address the issue of reliability, since studies that compare ratings of ADL with actual performance are rare. Therefore, one of the aims of the thesis was to specifically address the issue of rating accuracy. This was done using three methods; the first method compared self-ratings and informant ratings of PwD with cognitive and psychological test scores and inferred accuracy based on how well the ratings were predicted by the test scores, as presented in Chapters 4, 5 and 6. The second method compared ratings

made by PwD with ratings made by their informants, as presented in Chapters 4 and 6. The third method compared ratings made by PwD and their informants with performance on an objective assessment of everyday functional ability, as presented in Chapter 6.

Informant ratings of functioning are nearly always assumed to be accurate (Smyth et al., 2002) and the majority of studies and dementia diagnostic clinics rely on informant ratings to assess the everyday functional ability of PwD (Sikkes et al., 2009). However, evidence presented in Chapter 4 suggests that informant ratings of iADL are influenced by the age and cognitive status of the PwD (see also, Kiyak et al., 1994) while the analysis presented in Chapter 5 found that informant ratings were strongly influenced by carer stress (see also Mangone et al., 1993; Razani, Kakos, et al., 2007; Slachevsky et al., 2013; Zanetti et al., 1999). This suggests that informant ratings of iADL may reflect other factors rather than serving as accurate representations of current functional ability. In fact, the individual item analysis in Chapter 5 seemed to suggest that the influence of carer stress is pervasive across most of the iADL items included in the questionnaire. Additionally, evidence presented in Chapter 6 found that the only significant correlate of informant-rated iADL was the Addenbrooke's Cognitive Examination-Revised, indicating that cognitive status may influence this overestimation of functional difficulty. The findings presented in Chapter 6 however found a moderate relationship between carer burden and informant ratings, though this relationship was not significant after correcting for multiple comparisons. Caregiver burden was not related to objectively-assessed functional ability. This is generally consistent with previous findings where a stronger relationship was found between carer burden and informant-rated iADL than objectively-assessed iADL performance (Razani, Kakos, et al., 2007). The findings therefore seem to suggest that informant ratings of everyday functional ability of PwD may not be as accurate as researchers and clinicians assume. In some cases carers could be encouraged to find ways of continuing to involve PwD in iADL activities especially where the activity could still be carried out by the person with dementia either independently or with a small amount of support and assistance.

Self-ratings of iADL are rarely used in research or clinical settings, as evidenced by the inclusion of only three studies reporting use of this method in the meta-analysis (see Chapter 2) and the reliance on informant ratings for diagnostic purposes (Sikkes et al., 2009). The findings presented in Chapter 5 found convincing evidence that the cognitive function or mood of PwD is closely related to PwD ratings of their iADL ability. For example, people

with poorer memory scores rated their ability to shop alone as poorer than did those with better memory scores, those with impaired Letter Fluency rated themselves as less able to use a telephone and those who were more depressed generally had fewer hobbies and interests. These findings were generally consistent with previous studies that have investigated the correlates of individual objectively-assessed functional abilities (Farias et al., 2003; Loewenstein et al., 1992; Razani, Casas, et al., 2007; Razani, Kakos, et al., 2007).

The study presented in Chapter 6 was specifically designed to investigate the accuracy of self-ratings and informant ratings of PwD compared with performance on an objective functional assessment. Self-ratings of iADL were generally found to be remarkably accurate, with similar mean scores for both self-rated and objectively-assessed iADL functioning. In fact, the findings in Chapter 6 seem to suggest that while informants consistently overestimate the functional limitations of PwD, self-ratings were more accurate. There was evidence of variability, however, since some PwD slightly overestimated performance while others slightly underestimated performance; this contrasted with informant reports, the majority of which overestimated the level of functional difficulty. This finding differed somewhat from the informants of healthy older people in Chapter 3, whose ratings were less discrepant from objectively-assessed performance. The fact that the informants in both groups were cognitively healthy suggests that they should have been able to accurately rate the other person in the dyad. However, the informants in Chapter 6 were found to significantly underestimate the ability of PwD, which seems to indicate that the process of caring for someone with dementia increases the likelihood of inaccuracy in informant-rated iADL. As reported in Smyth et al. (2002), the widely held assumption that carers of PwD are able to accurately rate the everyday functional ability of PwD was seriously undermined.

The findings presented in Chapter 6 were relatively consistent with those presented in Chapters 4 and 5 and with the results of previous longitudinal studies which have reported evidence of an awareness of functional decline in PwD (Clare, Nelis, Martyr, Whitaker, et al., 2012; Kiyak et al., 1994). An awareness of declining everyday ability suggests that PwD may benefit from rehabilitation interventions which may help to maintain functioning and slow the rate of functional decline, and hence level of dependency.

7.3. Methodological considerations

Researching executive function, everyday functional ability and rating accuracy is associated with a number of challenges that might have impacted on the presented studies, and these potential limitations should be considered when interpreting the results presented in this thesis.

The most frequent method of assessing functional ability in PwD is to use informant ratings. Most studies employ standardised assessments such as the Functional Activities Questionnaire (Pfeffer et al., 1982) or the Instrumental Activities of Daily Living questionnaire (Lawton & Brody, 1969). A criticism of these measures is that the questions tend to be worded in broad, global terms that are open to multiple interpretations (Davis, 2001; Guralnik et al., 1989). For example, the "remembering appointments, family occasions, and medications" question in the Functional Activities Questionnaire has three different aspects to it, a person may be able to remember family occasions but be unable to remember to take medication. As the questionnaire makes no effort to separate the tasks or to ascertain which part or parts the subsequent rating relates to, it is difficult to know which aspect of the tasks a person is rating. It is possible that this may partly explain the often-reported discrepancy between self-ratings and informant ratings. Therefore, moving away from the use of overly-broad everyday functional ability questionnaires may lead to more accurate ratings and better diagnostic information. The studies presented in Chapters 3 and 6 tried to rectify the criticism of the use of overly-broad questions by including a specially-worded questionnaire that was based around an objective assessment measure. However, despite the findings in Chapter 6 suggesting that PwD were more able to accurately rate their everyday functional ability than their informants, there was still evidence of a discrepancy between self-ratings and informant ratings; therefore, fundamental biases may still exist and accurate information from ratings may be difficult to achieve.

Including the self-rated prediction questionnaire as part of the standardised instructions for the objective iADL assessment may have influenced the results, as it may have encouraged people to adjust their ratings in line with their test performance depending on how they performed. It is possible that if the prediction questions had been given as a separate questionnaire, similar to the way in which the informant-rated questionnaire was

administered, this might have affected the associations between self-rated predictions and objectively-assessed iADL performance. Results of previous studies indicate that, when standard questionnaires of functional ability are employed, older people and PwD typically overestimate their functional ability compared with performance on an objective assessment measure (Kempen et al., 1996; Mitchell et al., 2011; Sager et al., 1992; Vaughan & Giovanello, 2010; Wadley et al., 2003; Willis, 1996). Interestingly, when compared with objectively-assessed functional ability, informant ratings in Chapter 3 were more accurate than self-ratings made by healthy older people, whereas in Chapter 6 self-ratings made by PwD were more accurate than informant ratings. Therefore, if including the self-rating predictions within the task affected rating accuracy, the discrepancy between Chapters 3 and 6 seems to suggest that healthy older people underestimate their everyday functional ability whereas PwD make more accurate judgements of their ability to perform everyday tasks. Perhaps healthy older people underestimate their everyday functional ability because they feel they should be able to perform as well on tasks as they once did when they were younger, whereas PwD may accept their limitations and rate their abilities more accurately. Further research is required to investigate whether administering the self-rated predictions as a questionnaire separate from the objective iADL assessment affects rating accuracy in PwD and healthy older people.

Relying on questionnaires to accurately assess everyday functional ability is open to numerous biases, as demonstrated in previous research (e.g. Argüelles et al., 2001; Dassel & Schmitt, 2008; Kiyak et al., 1994; Mangone et al., 1993; Razani, Kakos, et al., 2007; Slachevsky et al., 2013; Zanetti et al., 1999) and in the informant ratings presented in Chapter 5. A measure of objective functioning was employed in Chapters 3 and 6 to obviate the limitation of relying on subjective ratings. However, throughout this thesis, objectively-assessed performance was assumed to be an accurate representation of everyday functioning due to the greater face validity of individual items compared with questionnaire ratings (Guralnik et al., 1989). There are some limitations to this assumption, since objective assessments of ADL tend to be rigidly structured with scores based on either correct or incorrect completion of tasks; there is little or no adjustment for how well someone performed the tasks. For example, in the objective iADL assessment used in Chapters 3 and 6, participants are presented with 25 items of shopping and they have to find four items of shopping from a list (See Appendix J). Healthy older people found the four items quickly and without much difficulty. The PwD were also able to find the first three items (milk, eggs and

crackers) quickly and easily; however most struggled to find the last item, the laundry detergent. Despite the difficulty in finding this particular item, only six PwD were scored as failing to find the laundry detergent since, while it took most of the PwD a relatively long time to find the item, most eventually did. The clear group difference for this particular item between PwD and healthy older people was masked by the scoring system. Most objectively-assessed measures of everyday functional ability fail to account for this variability in the scoring systems (though see the Assessment of Motor and Process Skills (Fisher & Bray Jones, 2010) for an assessment that tries to evaluate overall ability rather than successful task completion), and this may partly explain why measures of objectively-assessed everyday functioning often fail to accurately measure real world performance or predict functional independence (Moore et al., 2007). Future research may adapt these kinds of tasks to include items with which the PwD is more familiar, since familiarity may affect how PwD perform on certain everyday functional tasks (Guralnik et al., 1989; Myers et al., 1993).

The validity of converting the total iADL scores to a percentage should also be considered. This conversion method was necessary as the scoring system of the objective iADL measure used in the studies reported here, the Direct Assessment of Functional Status, does not lend itself to an easy comparison with the Likert-type scoring system used in the rating questionnaires. For example, only half of the Direct Assessment of Functional Status items were scored on a scale that matched the questionnaire ratings, while the other half of the items were scored as 0-5, 0-6, 0-8 and in one case 0-13. The questionnaires were worded to match exactly the item that participants were asked to complete. Therefore, calculating a percentage score so that each subtest was equally weighted to match the questionnaire was considered to be a logical and statistically valid way of comparing measures. This approach may prove useful in future metacognition research where scoring systems used in objective assessments do not enable easy comparisons to be made.

These methodological concerns need to be considered when interpreting the data in this thesis since they have important implications for the accuracy of the ratings on which so much of the thesis relies.

Finally, a widely-reported limitation of executive function tests is that no single test is able to tap one aspect of executive function (see Chan et al., 2008, for review). For example, the Trail Making Test 4 has been used and labelled as a test of set-shifting in this thesis. However, memory is required to remember to switch between numbers and letters; indeed, it could be argued that for PwD when completing this task it would be helpful to provide a card that lists the switching instructions to reduce the amount of memory that is required. Visual search is also required to find the next number or letter that needs to be connected. Therefore, the interpretation of executive function performance is complicated by the fact that other cognitive functions are necessary to complete the tests, and impairment in a non-executive component may also lead to impaired performance. A strength of the studies presented in Chapters 3 and 6 is that a relatively large battery of executive function tests, including ecologically-valid tests of executive function, were employed which may have alleviated some of these concerns.

7.4. Directions for future research

The studies presented in this thesis have contributed to our understanding of how instrumental activities of daily living are performed and rated by PwD and their informants. The studies have also contributed to our knowledge of how tests of cognition correlate with different methods of assessing iADL. The findings and methodologies contained herein raise further questions and suggest some directions for future research.

Despite the relatively frequent use in research settings of assessments of objectively-assessed performance, as noted in Chapter 2, these are less commonly used as part of the diagnostic process (Sikkes et al., 2009). In Chapters 5 and 6 there was compelling evidence that informant ratings, which are most commonly used to make a judgement about the everyday functional ability of a person with dementia, may be inaccurate. Studies are needed that can fully delineate the key factors determining the tendency for carers of PwD to overestimate functional difficulty. Previously, carer burden and stress (Mangone et al., 1993; Razani, Kakos, et al., 2007; Slachevsky et al., 2013; Zanetti et al., 1999), carer depression (Argüelles et al., 2001) and other variables such as the age and the cognitive status of the person with dementia (Kiyak et al., 1994) and even the executive function capacity of the informant

(Dassel & Schmitt, 2008) have all been shown to influence informant ratings. Understanding the reasons why informants tend to overestimate the functional difficulty of PwD may allow researchers and clinicians to correct for this when interpreting informant ratings of iADL. For example, if an informant scores highly on a measure of caregiver burden or stress, his/her ratings of the iADL ability of the person with dementia could be adjusted to take the level of carer stress into account. An alternative approach would be to employ objective iADL assessments more frequently to obviate some of the difficulties associated with the reliability of informant ratings, although until more valid iADL assessments are created these too may lack the ability to accurately predict real-world everyday functioning.

Longitudinal studies are required to determine whether dementia severity affects the accuracy of self-ratings of everyday functional ability. Self-ratings and informant ratings of iADL show evidence of longitudinal decline, suggesting that PwD are aware to some degree that their ability to undertake everyday functional abilities declines over time (Clare, Nelis, Martyr, Whitaker, et al., 2012; Kiyak et al., 1994). These studies relied on questionnaires to assess iADL, but it has been suggested that objectively-assessed functional ability may be a more reliable measure of functional decline (Guralnik et al., 1989), indicating that an objective assessment may be needed to accurately assess longitudinal changes in iADL performance. Few studies have extended the investigation of awareness of functional ability to people beyond the mild to moderate stage of dementia. A potential barrier is that most functional assessments may be too demanding for PwD as they progress through the course of the disease. However, a functional assessment for people with more advanced dementia has recently been designed, and this has been validated in people with MMSE scores between 0 and 23 (Luttenberger, Schmiedeberg, & Gräßel, 2012), suggesting that this assessment measure may be useful in plotting the longitudinal course of functional decline in PwD.

Most assessments investigating iADL have been designed for PwD (Moore et al., 2007), and therefore there is a need for a valid test of iADL that is specifically tailored to the assessment of older people without cognitive impairment. If subtle functional difficulties are identified at an early stage, rehabilitation interventions could be implemented. This is especially critical since as the population continues to age (United Nations, 2002) the number of older people with age-related functional disability is likely to increase dramatically and with it the concomitant risk of developing dementia (Sikkes et al., 2011). The design of a new test of everyday functioning especially for older people who may be at risk of developing functional

dependence or those who need to be assessed to make sure they are capable of living independently, such as those about to return home after a stay in hospital, may help to identify those at risk so that a package of help can be implemented, thereby targeting support more effectively; this will also enable those most at risk of developing additional impairment to be monitored, and subsequently additional care, such as rehabilitation interventions, can be provided quickly. Timely assessment of the everyday functional ability of older people would help to target appropriate and individually-tailored support more effectively.

The performance-monitoring metacognitive approach was shown to be a useful methodology for investigating the accuracy of iADL ratings in both healthy older people and PwD. It has previously been applied to assessing memory awareness in people with early-stage dementia (Clare et al., 2013; Clare et al., 2002). This thesis reported evidence that PwD are able to accurately rate their everyday functional ability using this approach, suggesting that extending the use of the metacognitive approach to everyday functional ability will be a useful method of investigating awareness in PwD. The specially-worded questions in the prediction and postdiction assessments may have also increased the level of accuracy (Myers et al., 1993). Further research is required to fully explore this exciting new research avenue into the assessment of everyday functional ability.

The meta-analysis (Chapter 2) and the empirical studies reported in Chapters 3 to 6 included a range of executive tests. Based on the results of the meta-analysis, it is difficult to recommend specific tests that should be considered when comparing executive function with ADL ability, as all tests had strengths and weaknesses. For example, the Trail Making Test-Part B was used in a large number of studies (k = 15) with a low level of heterogeneity, but the estimated effect size was only moderate. Additionally, some authors excluded this test from their analysis as they found it to be too demanding for PwD (Chen et al., 1998; Tomaszewski, 2000); indeed, half of the sample included in Chapter 6 and six healthy older people in Chapter 3 were unable to complete the test within the four minute timeframe. This limits the usefulness of the test in dementia research and memory clinic settings although there was still a large correlation (.61) between the test and objectively-assessed iADL ability (Chapter 6). The Trail Making Test-Part B may, however, be useful for monitoring decline in both cognition and everyday function in older people at risk of developing dementia (Chapter 3). Letter Fluency and the Clock Drawing Test were also used in a large number of studies (22 and 11 respectively), and these had low to moderate heterogeneity, but produced a

moderate effect size. Both tests are quick to administer and PwD rarely refuse to complete them, although in Chapter 6 it was reported that Letter Fluency was unrelated to all iADL assessment methods, in contrast to the findings of Chapter 4. The reasons for this disparity are unclear; the samples in each chapter were approximately the same age, had similar mean scores for Letter Fluency and had similar MMSE scores. Years of education may have been a factor, since the PwD in Chapter 6 had on average two more years of education than the sample in Chapter 4. The sample size in the study presented in Chapter 6 was considerably smaller than the sample size in the study presented in Chapter 4, which may also have affected the associations.

The Block Design task (Wechsler, 1981) may be a good test to consider; the meta-analysis found that it was used in 9 studies, the effect size was moderate (.37), and there was no evidence of heterogeneity, suggesting that the effect size was reliable. Whether Block Design is a test of executive function is questionable, as it is commonly considered a test of visuospatial ability (Groth-Marnat & Teal, 2000), although it has been found to strongly correlate with the Trail Making Test-Part B (.62; Willis et al., 1998) and includes executive components such as planning, error detection and correction and performance monitoring (Séguin, Boulerice, Harden, Tremblay, & Pihl, 1999). The Similarities Test may be a good test to include in an executive function battery as the meta-analysis found a moderate to large effect size (.47) and no evidence of heterogeneity. It is also quick to administer, is widely available as part of the Frontal Assessment Battery (Dubois, Slachevsky, Litvan, & Pillon, 2000) and the Montreal Cognitive Assessment (Nasreddine et al., 2005), and forms the main part of the Conceptualization subtest from the Mattis Dementia Rating Scale (Jurica et al., 2001; Mattis, 1988). Finally, Category Fluency may also be a good test to use to investigate the association between iADL and cognition since, while the meta-analysis found large heterogeneity, it also found a large correlation (.54). This was consistent with the correlation between Category Fluency and objective functional ability found with PwD in Chapter 6 (.50) and the correlation with objective functional ability found with healthy older people in Chapter 3 (.50). Therefore, while the Trail Making Test-Part B may be unsuitable for studies involving PwD, there are alternatives which show a similar effect size and are potentially more reliable with less of a chance of finding a floor effect.

7.5. Practical implications of the study findings

The studies presented here have demonstrated that self-ratings of everyday functional ability made by PwD may be accurate. More importantly, the evidence is compelling that informant ratings of PwD may be generally inaccurate, which has many practical implications for researchers and clinicians. Self-ratings made by healthy older people may also be inaccurate, with evidence that healthy older people generally underestimate their functional ability.

Self-ratings of functioning made by PwD showed evidence of awareness, whereas ratings made by informants of PwD were significantly influenced by carer stress (Chapter 5), though not caregiver burden (Chapter 6). These findings have implications for the use of ratings of functional ability in clinical and research settings and suggest that self-ratings by PwD should be employed more frequently in research and clinical settings as they may provide accurate assessments of functional ability. The accuracy of iADL ratings made by PwD found in Chapter 6 calls into question the assumption that because self-ratings are often discrepant from informant ratings PwD therefore lack awareness of functioning (DeBettignies et al., 1990; Ott et al., 1996; Vasterling et al., 1995). The findings in Chapter 6 question the value of using informant ratings to assess everyday functioning of PwD as these are likely to be influenced by carer stress or burden, and by other factors such as the cognitive status of the person with dementia, rather than reflecting how well a person with dementia may be able to perform iADL.

The findings suggest that, where practical, an objective assessment of iADL should be used in place of questionnaires to ascertain current functional ability. An important consideration is the length of time measures take to administer. However, in clinical recommendations a dementia diagnostic assessment should be a detailed and thorough process, especially in the mild stages (NICE, 2006). An objective assessment of everyday ability, which takes less time to administer than a typical neuropsychological battery, may be a useful tool to include, especially as there is growing evidence that informant ratings may not be accurate. The need for a relatively brief yet comprehensive assessment of everyday functional ability is urgently required (Moore et al., 2007). For people who are able to undertake such an assessment, comprehensive, reliable and accurate information should be more important than speed and convenience (NICE, 2006).

Memory awareness is well-researched in PwD but there has been relatively little research investigating awareness of functional ability in PwD. This has important clinical implications since an awareness of functional decline may affect the ability to ask for assistance when required, and may affect the length of time people are able to remain living in their own homes. A thorough understanding of these issues is crucial for the provision of appropriate care for PwD.

Self-ratings made by healthy older people also displayed evidence of inaccuracy, which has clinical implications. If healthy older people consistently underestimate their functional ability this may have a profound effect on their willingness to perform everyday functional tasks. They may begin to believe that they are unable to complete tasks and this may begin the gradual shift towards functional dependence which has such a devastating effect on the well-being of older people. Longitudinal studies are required to see if interventions can be implemented to enable older people to accurately assess their own functional abilities and whether this has an effect on their ability to continue to live independently.

7.6. Conclusions

Despite substantial research in the area of iADL functioning and decline, the performance monitoring aspect of everyday functional ability is not well-understood. The results presented in this thesis have contributed new knowledge with regard to everyday functional ability, especially in the domain of rating accuracy, and may lead to greater clarity in future research studies as well as having implications for clinical practice.

The thesis has demonstrated the usefulness of the performance monitoring aspect of the metacognitive approach to investigating iADL in healthy older people and in PwD. The findings suggest that caution should be used when interpreting self-ratings made by healthy older people, as they may significantly underestimate everyday functional ability. Informant ratings or objective assessments of iADL should be employed in place of self-ratings in healthy older people. Research is required to see if increasing the accuracy of iADL ratings made by older people has a beneficial effect on their ability to live independently. Self-ratings of iADL by PwD were found to be generally accurate when compared with

objectively-assessed functional performance, suggesting that interventions to improve the everyday functional ability of PwD and delay the onset of dependency may be successfully employed in this group. Informant ratings indicated the presence of more functional impairment than was suggested by the objectively-assessed performance of the PwD; informants may benefit from support that helps them to enable PwD to continue to perform for as long as possible those activities of daily living which are often taken over by carers.

The thesis has shown that relatively brief assessments of cognition, particularly the Addenbrooke's Cognitive Examination-Revised and the Trail Making Test 4, are useful in predicting the functional ability of healthy older people. The Addenbrooke's Cognitive Examination-Revised and the Trail Making Test 4 should be included in any future studies that aim to assess the functional ability of older people. The Trail Making Test 4 may be less useful for monitoring functional decline in PwD as the test may be too demanding. However, the Addenbrooke's Cognitive Examination-Revised may have the potential to identify people at risk of functional decline and also to predict longitudinal functional decline in both healthy older people and PwD.

There has been relatively little research into awareness of everyday functional ability in older people and PwD. The findings presented in this thesis suggest that people with early-stage dementia are aware of their functional limitations; therefore, employing the performance monitoring aspect of the metacognitive approach to functional ability opens up an exciting new area of research with considerable clinical implications. For example, the dementia diagnostic process should rely less on the iADL ratings made by informants but should listen to the voice of the person with dementia and employ objective assessments of everyday functional ability more frequently. The results of this thesis also have implications for the future care of older people and PwD since early identification of difficulties with everyday functioning may make it easier for PwD to ask for and to receive rehabilitation that enables them to live independently for longer. The early identification of difficulties in older people may delay the onset of dementia by allowing older people to receive preventative treatments as these become available. Therefore, the early identification of difficulties will have a profound effect on the reduction of caregiver burden, the increased availability of appropriate treatments and reduce the financial cost to society as well as increase the well-being and independence of older people and people with dementia.

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Appendices

Subject: Planning and managing everyday tasks in later life Ethics proposal 2010-1847
From: Everil McQuarrie <e.mcquarrie@bangor.ac.uk>
Date: 04/01/2011 16:24
To: Martyr Anthony <a.martyr@bangor.ac.uk>, "Clare,Linda" <l.clare@bangor.ac.uk>

Dear Colleagues,

Planning and managing everyday tasks in later life Ethics proposal 2010-1847

Your research proposal as above has been reviewed by the School of Psychology Ethics and Research Committee and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation.

This approval lasts for a maximum of five years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

Governance approval is granted for the study as it was explicitly described in the application and we are happy to confirm that this study is now covered by the University's indemnity policy.

If any new researchers join the study, or any changes are made to the way the study is funded, or changes that alter the risks associated with the study, then please submit an amendment form to the committee.

Yours sincerely

Everil

--

Everil McQuarrie,
Research and PhD Administrator,
Room 113,
School of Psychology
Brigantia Building,
Penrallt Road,
Bangor
LL57 2AS

Subject: Ethics proposal 1630
From: Everil McQuarrie <e.mcquarrie@bangor.ac.uk>
Date: 29/07/2010 11:36
To: "Clare,Linda" <l.clare@bangor.ac.uk>, Martyr Anthony <a.martyr@bangor.ac.uk>

Dear Colleagues

Executive function and activities of daily living in people with early-stage Alzheimer's disease: implications for intervention Ethics proposal 1630

Your research proposal referred to above has been reviewed by the School of Psychology Research Ethics Committee and they are satisfied:

(i) That the research proposed accords with the relevant ethical guidelines.
(ii) That the research proposed is appropriate for sponsorship by Bangor University.
Approval is granted subject to you submitting Welsh translations of your information/consent and debrief forms to me.

If you wish to make any non-trivial modifications to the research project please inform the committee in writing before proceeding. Please also inform the committee as soon as possible if research participants experience any unanticipated harm as a result of participating in your research.

You should now forward the application to NRES and to the appropriate Local Research Ethics Committee (LREC). **If you need a signature on the form regarding research sponsorship by the University, and/or a letter confirming this sponsorship, please send the final version of your NRES form to me and I will make arrangements for this.**

The NHS Research Ethics Committee expect one of the investigators to make an oral presentation in support of the proposal at their meeting. You will be contacted by their committee with details as to the date and place of the meeting at which your proposal will be considered.

You may not proceed with the research project until you are notified of the approval of the Local Research Ethics Committee and have R&D approval from the relevant NHS Trusts.

The approval for this project is given on the understanding that you will complete a review form on the project when requested; to this end I would be grateful if you could complete the form below and return it to me.

Yours sincerely

Everil

--

Everil McQuarrie,
Research and PhD Administrator,
Room 113,
School of Psychology
Brigantia Building,
Penrallt Road,
Bangor
LL57 2AS

Pwyllgor Moeseg Ymchwil Gogledd Cymru (Y Orllewin)
North Wales Research Ethics Committee (West)

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Penrallt Road
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Betsi Cadwaladr University Health Board
Ysbyty Gwynedd
Clinical Academic Office
Bangor, Gwynedd
LL57 2PW

Telephone/ Facsimile: 01248 - 384.877
Email: Rossela.Roberts@wales.nhs.uk

26 August 2010

Dear Mr Martyr,

Study Title:	**Executive function and activities of daily living in people with early-stage Alzheimer's disease: implications for intervention**
REC reference number:	**10/WNo01/38**
Protocol number:	**Version 1 dated 15/06/2010**

Thank you for your letter of 25 August 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations. It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
REC application 52995/139924/1/147		03 August 2010
Protocol	1	15 June 2010
Response to request for further information	No version	25 August 2010
~~Participant Information Sheet: Person with dementia~~ superseded	~~1~~	~~13 June 2010~~
Participant Information Sheet: Person with dementia	2	25 August 2010
Participant Information Sheet: Informant	1	13 June 2010
~~Participant Consent Form: Person with dementia~~ superseded	~~1~~	~~13 June 2010~~
Participant Consent Form: Person with dementia	2	25 August 2010
~~Participant Consent Form: Informant~~ superseded	~~1~~	~~13 June 2010~~
Participant Consent Form: Informant	2	25 August 2010
GP/Consultant Information Sheets	1	15 June 2010
Advertisement: Recruitment Flyer	1	29 June 2010
Reply Sheet	1	13 June 2010
Description of measures	1	10 June 2010
Questionnaire: DEX (Self Rating)	No version	No date
Questionnaire: DEX (Informant/Independent rating)	No version	No date
Questionnaire: MIADL Scale (Self)	No version	No date
Questionnaire: MIADL Scale (Informant)	No version	No date
Questionnaire: Modified Functional Behavioural Inventory	No version	No date
Questionnaire: MARS MFS-S (Self)	No version	No date
Questionnaire: MARS MFS-I (Informant)	No version	No date
Questionnaire: MARS MPS	No version	No date
Questionnaire: Geriatric Depression Scale	No version	No date
Questionnaire: Modified direct Assessment of Functional Status	No version	No date
Questionnaire: The Zarit Burden Interview	No version	No date
Questionnaire: The Apathy Scale	No version	No date
Questionnaire: HADS	No version	No date
Lone worker Policy	1	26 June 2010
Protocol for Protection of vulnerable adults	2	26 June 2010
Letter from Sponsor	No version	28 July 2010
Evidence of insurance or indemnity	UMAL	01 August 2010
Investigator CV (Mr. Anthony Martyr)	No version	13 June 2010
Supervisor CV (Prof. Linda Clare)	No version	No date

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/WNo01/38	**Please quote this number on all correspondence**

Yours sincerely

Rossela Roberts

Mr David Owen
Chairman

Email: rossela.roberts@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Sponsor: Prof. Oliver Turnbull, School of Psychology, Bangor University*
Academic Supervisor: Prof. Linda Clare, School of Psychology, Bangor University
R&D office for Betsi Cadwaladr University Health Board (West)

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D – Y Gorllewi
R&D Internal Review Panel – West Divisio

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PRIVATE & CONFIDENTIAL
Mr Anthony Martyr,
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Brigantia Building, Penrallt Road
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16 September 2010

Dear Mr Martyr ,

Re: Project Review:

Martyr 10/38 Executive function and activities of daily living in people with early-stage Alzheimer's disease: implications for intervention

The above research project was reviewed at the meeting of the Internal Review Panel held on 6 September 2010. Thank you for responding to the Committee's request for further information.

The Chairman considered the response on behalf of the Committee and is satisfied with the scientific validity of the project, the risk assessment, the review of the NHS cost and resource implications and all other research management issues pertaining to the revised application.

I have pleasure in confirming that the Internal Review Panel is pleased to grant approval to proceed at Betsi Cadwaladr University Health Board (West sites).

The study should not commence until the Ethics Committee reviewing the research has confirmed final ethical approval - favourable opinion.

All research conducted at the Betsi Cadwaladr University Health Board sites must comply with the Research Governance Framework for Health and Social Care in Wales (August 2009).
An electronic link to this document is provided on the Trust's R&D WebPages.
Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research in the Betsi Cadwaladr University Health Board.

If you would like further information on any other points covered by this letter please do not hesitate to contact me. On behalf of the Committee, may I take this opportunity to wish you every success with your research.

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

Panel Arolygu Mewnol Y&D – Y Gorllewi
R&D Internal Review Panel – West Divisio

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List of documents reviewed and approved:

Documents reviewed:	Version	Date
CV of CI (Mr Anthony Martyr)	1.0	13/06/2010
Participation Letter - Consultant	1.0	15/06/2010
Protocol	2.0	18/06/2010
Geriatric Depression Scale	1.0	16/06/2010
Hospital anxiety and depression scale	1.0	21/06/2010
List of measures to be used in the study	1.0	10/06/2010
Lone worker policy	1.0	26/06/2010
(MFS-I) Memory Functioning Scale - Informant	1.0	21/06/2010
(MFS-S) Memory Functioning Scale – Self-Report	1.0	21/06/2010
(MPS) Memory Performance Scale	1.0	21/06/2010
Modified Direct Assessment of Functional Status (DAFS)	1.0	21/06/2010
Modified Functional Behavioural Inventory	1.0	16/06/2010
Modified Instrumental Activities of Daily Living-Informant	1.0	15/06/2010
Modified Instrumental Activities of Daily Living-Self	1.0	15/06/2010
NHS R&D Form - 52995/139941/14/736	1.0	15/06/2010
NHS SSI Form - 52995/139943/6/857/66945/185378	1.0	03/08/2010
Participant Consent form	2.0	25/08/2010
Participant Information Sheet	2.0	25/08/2010
Protocol	1.0	15/06/2010
REC Form - 52995/139924/1/147	1.0	03/08/2010
Recruitment Flyer	1.0	29/06/2010
Relative Information Sheet	1.0	13/06/2010
Relative/Friend Consent Form	2.0	25/08/2010
Reply Slip	1.0	13/06/2010
The Apathy Scale	1.0	15/06/2010
The Zarit Burden Interview	1.0	16/06/2010
UMAL 2010 - 2011	-	01/08/2010
Response to request for further infomration		13/09/2010
Checklist for assessing capacity	1	13/09/2010

Yours sincerely

Rossela Roberts

Dr Richard Tranter
Consultant Psychiatrist, Associate Director of R&D
Chairman R&D Internal Review Panel

GIG CYMRU NHS WALES | Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board

Ysbyty Glan Clwyd Hospital, Ysbyty Maelor Wrexham Hospital
Adran Ymchwil a Datblygu,
Ysbyty H M Stanley, Llanelwy,
Sir Ddinbych, LL17 0RS

Research and Development Department,
H M Stanley Hospital, St Asaph LL17 0RS

Mr. Anthony Martyr
Bangor University
School of Psychology
Bangor
Gwynedd
LL57 2AS

Ein cyf / Our ref: LTJ
Eich cyf / Your ref:
Rhif Ysbyty / Hospital Number:
Rhif GIG / NHS Number:
☎: 01745 589624
Gofynnwch am / Ask for: Lona Tudor Jones
Ffacs / Fax: 01745 589717
E-bost / Email: Lona.TudorJones@wales.nhs.uk
Dyddiad / Date: 27.10.2010

PRIVATE & CONFIDENTIAL

Dear Mr. Anthony Martyr

Re: Executive function and activities of daily living in people with early-stage Alzheimer's disease: implications for intervention

Ref: MARTYR 10/WNo01/38

The above research project was reviewed at the meeting of the Research Governance Committee / Internal Review Panel held on 25th October 2010 at Ysbyty Glan Clwyd and Wrexham Maelor Hospital.

I have pleasure in confirming that the Internal Review Panel has approved to proceed at Ysbyty Glan Clwyd Hospital.

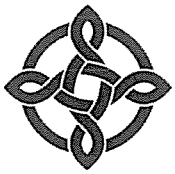
The study should not commence until the Ethics Committee reviewing the research has confirmed final ethical approval (favorable opinion and no objection to site specific assessment).

As part of the regular monitoring undertaken by the Research Governance Committee you will be required to complete a short progress report. This will be requested on a six monthly basis. However, please contact me sooner should you need to report any particular successes or problems concerning your research. Whilst the Health Board is keen to reduce the burden of paperwork for researchers failure to produce a report may result on withdrawal of approval.

All research conducted at Betsi Cadwaladr University Health Board must comply with the Research Governance Framework for Health and Social Care in Wales (November 2001). An electronic link to this document is provided on the Trust's R&D WebPages. Alternatively, you may obtain a paper copy of this document via the R&D Office.

Attached you will find a set of approval conditions outlining your responsibilities during the course of this research. Failure to comply with the approval conditions will result in the withdrawal of the approval to conduct this research at the Betsi Cadwaladr University Health Board.

If you would like further information on any other points covered by this letter please do not hesitate to contact me. On behalf of the Committee, may I take this opportunity to wish you every success with your research.



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Yours Sincerely

Lona Tudor Jones

pp Dr D A Parker
Director R&D

Cc ***Dr Linda Clare***
Copy to R&D

Documents reviewed:	**Version:**	**Date:**
CV Mr A Martyr	1.0	13.06.2010
CV Dr Linda Clare	-	14.01.2010
Participation letter – Consultant	1.0	15.06.2010
Dementia Research Group: Protocol	2.0	18.06.2010
Geriatric depression Scale	1.0	16.06.2010
Hospital Anxiety and depression scale	1.0	21.06.2010
List of measures to be used in the study	1.0	10.06.2010
Lone worker policy	1.0	26.06.2010
(MFS-I) Memory Functioning Scale – Informant	1.0	21.06.2010
(MFS-S) Memory functioning scale – self report	1.0	21.06.2010
(MPS) Memory functioning Scale	1.0	21.06.2010
Modified direct assessment of functional status (DAFS)	1.0	21.06.2010
Modified Functional Behavioural Inventory	1.0	16.06.2010
Modified Instrumental activities of daily living – informant	1.0	15.06.2010
Modified Instrumental activities of daily living – self	1.0	15.06.2010
NHS R&D form	1.0	15.06.2010
NHS SSI form	1.0	03.08.2010
Participant Consent form	2.0	25.08.2010
Participant Information Sheet	2.0	25.08.2010
Protocol	1.0	15.06.2010
Recruitment Flyer	1.0	29.06.2010
Relatives Information Sheet	1.0	13.06.2010
Relative/friend consent form	2.0	25.06.2010
Reply slip	1.0	13.08.2010
The Apathy Scale	1.0	15.06.2010
The Zarit Burden Interview	1.0	16.06.2010
UMAL 2010 – 2011	-	01.08.2010
Checklist for assessing capacity	1	13.09.2010
Letter from Sponsor	-	28.07.2010
Letter from REC – Favourable opinion	-	26.08.2010

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PARTICIPANT INFORMATION SHEET

Planning and managing everyday tasks in later life

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Ask the researchers if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part. Thank you for reading this information sheet.

What is the purpose of the study?
This study aims to explore how healthy older people who live independently manage daily tasks and activities. In particular, we are interested in how older people plan and organize activities that are part of everyday life. The purpose of the study is to understand more about how planning for everyday activities changes as people get older.

Why have you been chosen?
You have been invited to take part because you are physically healthy and over the age of 65. We are asking you to take part in pairs so you can each tell us how you think the other person will do at different tasks. Usually this will be a husband, wife, other family member of a similar age, or a close friend of a similar age.

Do you have to take part?
You do not have to take part. It is up to you to decide. If you decide to take part in the study, we will ask you to sign a consent form. You can keep this information sheet and please remember you will be free to withdraw from the study at any time without giving a reason. A decision not to take part, or to withdraw from the study, will not affect your legal rights in any way.

What do you need to do if you take part?
If you take part in the study, you can meet the researchers at the University, or if you prefer, the researchers will come to see you at your home. The researchers will make one visit, lasting approximately two and a half hours, and will:

1. Ask you to do some simple tasks relating to activities that you would normally do in your everyday life like managing finances, remembering shopping items and preparing a letter ready for posting.

2. Ask you to fill in some questionnaires that explore your thoughts and feelings about yourself and your current situation, including your mood, and how well you do things in your daily life.
3. Ask you to carry out some simple tasks that allow us to measure your planning abilities. These will involve looking at a variety of pictures, patterns and words; making plans and following them; and solving problems.
4. Before we start some tasks, we will explain the tasks and ask you to tell us how well you think you will do, and after you complete the tasks we will ask you how well you think you did.

What would you have to do?
If you decide to take part in the study, you would have to be willing to set aside some time to meet with the researchers. The researchers will meet you at the School of Psychology in Bangor University or if you prefer, they will visit you at home.

What are the possible disadvantages and risks of taking part?
We do not anticipate that there are any risks to people taking part in this research. You may find some of the tasks a little tiring or frustrating. If this happens you can take a break at any time, or the visit can be continued on another occasion.

What are the possible benefits of taking part?
We do not think you will benefit directly from taking part in this study, although people who have taken part in this type of study in the past have said that they found the tasks enjoyable and stimulating. The information we get from this study may help us to understand how planning ability changes as we get older.

What if new information becomes available?
If any relevant information becomes available during the course of study, the researchers will advise you and ask you if you wish to continue with the study.

What if there is a problem?
We do not consider that taking part in the study will cause any risk to you. If you have a concern about any aspect of this study, please contact one of us and we will do our best to answer your questions and resolve any concerns. If you remain unhappy and wish to complain formally, you can do this through the School of Psychology. The contact details are given below.

Will my taking part in the study be kept confidential?
Yes. In normal circumstances all information collected about you during the study will be kept confidential. All data will be stored securely and separately from any of your personal details. Only the researchers involved in the study will have access to this data. However, if any of the researchers observe or hear something that causes very serious concern about your well-being, then they must inform their supervisors, and it may be necessary to share this information with other professionals. We would make every effort to first inform you of the need to share this information.

What will happen if you don't want to carry on with the study?
You may withdraw from the study at any time without giving a reason and this will not affect your legal rights in any way. We may need to use the data collected before you decide to withdraw.

What will happen to the results of the research?
We will publish the results of the study in scientific journals. All information about those who have taken part will be anonymous, so you personally will <u>not</u> be identifiable in any publication. We will inform you of the findings of the study if you wish.

Who has reviewed the study?
All research carried out at Bangor University is scrutinized by a group of people, called a Research Ethics Committee. The purpose of this committee is to protect your safety, rights, well-being, and dignity. This study has been reviewed and granted approval by the School of Psychology Ethics Committee at Bangor University.

Who is organising and funding the research?
The research is unfunded and is being undertaken as part of a Masters degree in Clinical Psychology. The project is being led by Mr Anthony Martyr, a Ph.D. student at Bangor University, and is being supervised by Professor Linda Clare, a clinical psychologist who works at Bangor University.

Who can I contact for further information?

If you would like to write or telephone for more information you can contact:
Mr Anthony Martyr,
School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS
Tel: 01248 388210
Email: a.martyr@bangor.ac.uk

Professor Linda Clare,
School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS
Tel: 01248 388178
Email: l.clare@bangor.ac.uk

If you have any complaints about the conduct of this study you can contact:
Mr. Hefin Francis, School Manager,
School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS
Tel: 01248 388339
Email: h.francis@bangor.ac.uk

Thank you for considering taking part in this research study!

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What is the purpose of the study?
This study aims to explore how healthy older people who live independently manage daily tasks and activities. In particular, we are interested in how older people plan and organize activities that are part of everyday life. The purpose of the study is to understand more about how planning for everyday activities changes as people get older.

Why have you been chosen?
You have been invited to take part because your relative/friend has been approached to participate in this study. If your relative/friend agrees to take part, we would like to ask you to consider participating as well.

Do you have to take part?
You do not have to take part. It is up to you to decide. If you decide to take part in the study, we will ask you to sign a consent form. You can keep this information sheet and please remember you will be free to withdraw from the study at any time without giving a reason. A decision not to take part, or to withdraw from the study, will not affect your legal rights in any way.

What do you need to do if you take part?
If you take part in the study, you can meet the researchers at the University, or if you prefer, the researchers will come to see you at your home. The researcher will make one visit and will ask you to fill in several questionnaires relating to the experience of your relative/friend.

What would you have to do?
If you decide to take part in the study, you would have to be willing to set aside some time to meet with the researchers. The researchers will meet you at the School of Psychology in Bangor University or if you prefer, they will visit you at home.

What are the possible disadvantages and risks of taking part?
We do not anticipate that there are any risks to people taking part in this research. You may find some of the tasks a little tiring or frustrating. If this happens you can take a break at any time, or the visit can be continued on another occasion.

What are the possible benefits of taking part?
We do not think you will benefit directly from taking part in this study, although people who have taken part in this type of study in the past have said that they found the tasks enjoyable and stimulating. The information we get from this study may help us to understand how planning ability changes as we get older.

What if new information becomes available?
If any relevant information becomes available during the course of study, the researchers will advise you and ask you if you wish to continue with the study.

What if there is a problem?
We do not consider that taking part in the study will cause any risk to you. If you have a concern about any aspect of this study, please contact one of us and we will do our best to answer your questions and resolve any concerns. If you remain unhappy and wish to complain formally, you can do this through the School of Psychology. The contact details are given below.

Will my taking part in the study be kept confidential?
Yes. In normal circumstances all information collected about you during the study will be kept confidential. All data will be stored securely and separately from any of your personal details. Only the researchers involved in the study will have access to this data. However, if any of the researchers observe or hear something that causes very serious concern about your well-being, then they must inform their supervisors, and it may be necessary to share this information with other professionals. We would make every effort to first inform you of the need to share this information.

What will happen if you don't want to carry on with the study?
You may withdraw from the study at any time without giving a reason and this will not affect your legal rights in any way. We may need to use the data collected before you decide to withdraw.

What will happen to the results of the research?
We will publish the results of the study in scientific journals. All information about those who have taken part will be anonymous, so you personally will <u>not</u> be identifiable in any publication. We will inform you of the findings of the study if you wish.

Who has reviewed the study?
All research carried out at Bangor University is scrutinized by a group of people, called a Research Ethics Committee. The purpose of this committee is to protect your safety, rights, well-being, and dignity. This study has been reviewed and granted approval by the School of Psychology Ethics Committee at Bangor University.

Who is organising and funding the research?
The research is unfunded and is being undertaken as part of a Masters degree in Clinical Psychology. The project is being led by Mr Anthony Martyr, a Ph.D. student at Bangor University, and is being supervised by Professor Linda Clare, a clinical psychologist who works at Bangor University.

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Thank you for considering taking part in this research study!

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CONSENT FORM

Planning and managing everyday tasks in later life
Lead Researcher: Mr Anthony Martyr

Please initial box

1. I confirm that I have read and understood the information sheet for the above study, dated 24/11/2010, and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. ☐

3. I agree to take part in the above study. ☐

   Optional:

4. I agree for my contact details to be kept securely by the lead investigator for future studies conducted by the lab. I understand that my details will not be passed on to other researchers without my explicit consent. I understand that if I agree to my details being kept that I am free to decline to take part in any future studies. ☐

_____	_____	_____
Name of Participant	Date	Signature

_____	_____	_____
Name of Researcher	Date	Signature

1 for participant; 1 for researcher

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PARTICIPANT INFORMATION SHEET

Planning and managing everyday tasks

Invitation to participate in a research study

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Ask the researcher if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part. Thank you for reading this information sheet.

What is the purpose of the study?

This study aims to explore how people who have been to a memory clinic manage daily tasks and activities. In particular, we are interested in how people who have been to a memory clinic plan and organize activities that are part of everyday life. We would like to understand more about this in order to improve the future care and support of people who attend the memory clinic and who experience memory problems. For each person who has attended the memory clinic, we would also like to ask someone who knows the person well for their views on how that person is managing with his/her memory. Usually this will be a husband, wife, other family member, or close friend.

Why have I been chosen?

You have been invited to take part because you have attended a Memory Clinic in North Wales and have had a memory assessment.

Do I have to take part?

You do not have to take part. It is up to you to decide. If you decide to take part in the study, we will ask you to sign a consent form. You can keep this information sheet and please remember you will be free to withdraw from the study at any time without giving a reason. A decision not to take part, or to withdraw from the study, will not affect the standard of care you receive in any way.

What do I need to do if I take part?

If you take part in the study, a researcher will come to see you at your home (or if you prefer, you can meet the researcher at the University, or another location of your choice). The researcher will make two visits, lasting approximately one and half hours each, over the course of a few weeks, and will:

1) Ask you to do some simple tasks relating to activities that you would normally do in your everyday life like managing finances, managing medication, remembering shopping items and preparing a letter ready for posting.
2) Ask you to fill in several questionnaires that explore your thoughts and feelings about yourself and your current situation, including your mood and how well you do things in your daily life.
3) Ask you to carry out some simple tasks that allow us to evaluate your attention, memory, and concentration abilities. These will involve looking at a variety of pictures, patterns and words; listening to stories; answering general knowledge questions; making plans and following them; and solving problems.
4) With your permission, we will also ask a family member or someone else who knows you well to complete some questionnaires.

What would I have to do?

If you decide to take part in the study, you would have to be willing to set aside some time to meet with the researcher. The researcher will visit you at home, unless you prefer to meet at Bangor University, in which case we will pay your travel expenses.

What are the possible disadvantages and risks of taking part?

We do not anticipate that there are any risks to people taking part in this research. You may find some of the tasks a little tiring or frustrating. If this happens you can take a break at any time, or the visit can be continued on another occasion.

What are the possible benefits of taking part?

We do not think you will benefit directly from taking part in this study, although people who have taken part in this type of study in the past have said that they found the tasks enjoyable and stimulating. The information we get from this study may help us to understand and support people with memory difficulties better in the future.

What if new information becomes available?

If any relevant information becomes available during the course of study, the researcher will advise you and ask you if you wish to continue with the study.

What if there is a problem?

We do not consider that taking part in the study will cause any risk to you and there are no special compensation arrangements if you are harmed by taking part in the study. If you are harmed due to someone's negligence, then you may have grounds for a legal action, but you may have to pay your legal costs. If you have a concern about any aspect of this study, you should speak to the researcher and he will do his best to answer your questions and resolve any concerns. If you remain unhappy and wish to complain formally, you can do this through the School of Psychology. The contact details are given below.

Will my taking part in the study be kept confidential?

Yes. In normal circumstances all information collected about you during the study will be kept confidential. All data will be stored securely and separately from any of your personal details. Only the researchers involved in the study will have access to this data. However, if the researcher observes or hears something that causes very serious concern about your well-being, it may be necessary to share this information with other professionals. The researcher would make every

effort to first inform you of the need to share this information. The researcher will ask your permission to inform your GP and your hospital consultant that you are taking part in the study.

What will happen if I don't want to carry on with the study?

You may withdraw from the study at any time without giving a reason and this will not affect the standard of medical care you receive in any way. We may need to use the data collected before you decide to withdraw.

What will happen to the results of the research?

We will publish the results of the study in scientific journals. All information about participants will be anonymous, so you will not be identifiable in any publication. We can inform you of the findings of the study if you wish.

Who has reviewed the study?

All research in the NHS is analysed by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, well-being and dignity. This study has been reviewed and granted approval by the North West Wales Research Ethics Committee.

Who is organising and funding the research?

The research is being funded by a Welsh Assembly Government Health Studentship Award. The project is being led by Mr Anthony Martyr (PhD student) and supervised by Professor Linda Clare, a clinical psychologist who works at Bangor University.

Who can I contact for further information?

For more information, please contact:
Mr Anthony Martyr,
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Email: a.martyr@bangor.ac.uk

Professor Linda Clare
School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS
Tel: 01248 388178
Email: l.clare@bangor.ac.uk

If you have any complaints about the conduct of this study you can contact:
Dr E. Charles Leek (Head of School)
School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS.
Tel: 01248 382948
Email: e.c.leek@bangor.ac.uk

Thank you for considering taking part in this research study!

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INFORMATION SHEET FOR RELATIVES/FRIENDS

Planning and managing everyday tasks

Invitation to participate in a research study

You are being invited to take part in a research study as the relative/friend of a person who has attended a memory clinic. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Ask the researcher if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part. Thank you for reading this information sheet.

What is the purpose of the study?

This study aims to explore how people who have been to a memory clinic manage daily tasks and activities. In particular, we are interested in how people who have been to a memory clinic plan and organize activities that are part of everyday life. We would like to understand more about this in order to improve the future care and support of people who attend the memory clinic and who experience memory problems. For each person who has attended the memory clinic, we would also like to ask someone else who knows the person well for their views. This will usually be a husband, wife, other family member, or close friend of the person with memory difficulties.

Why have I been chosen?

You have been invited to take part because your relative/friend has attended a Memory Clinic in North Wales and has had a memory assessment. Your relative/friend has been approached to participate in this study. If your relative/friend agrees to take part, we would like to ask you to consider participating as well.

Do I have to take part?

You do not have to take part. It is up to you to decide. If you decide to take part in the study, we will ask you to sign a consent form. You can keep this information sheet and please remember you will be free to withdraw from the study at any time without giving a reason. A decision not to take part, or to withdraw from the study, will not affect the standard of medical care that you or your relative/friend receive.

What do I need to do if I take part?

If you take part in the study, a researcher will come to see you at your home or the home of your relative/friend (or if you prefer, you can meet the researcher at the university, or another location of your choice). The researcher will make one visit and will ask you to fill in several questionnaires relating to your own experience and the experience of your relative/friend.

What would I have to do?

If you decide to take part in the study, your relative/friend will be asked to set aside two visits to complete the tasks and questionnaires they will be asked to do, while you need to be willing to set aside an hour to complete the questionnaires in a single visit. The researcher will visit you at home, unless you prefer to meet at Bangor University, in which case we will pay your travel expenses.

What are the possible disadvantages and risks of taking part?

We do not think that participation will involve any specific risks.

What are the possible benefits of taking part?

The information we get from this study may help us to understand and support people with memory difficulties better in the future.

What if new information becomes available?

If any relevant information becomes available during the course of study, the researcher will advise you and ask you if you wish to continue with the study.

What if there is a problem?

We do not consider that taking part in the study will cause any risk to you and there are no special compensation arrangements if you are harmed by taking part in the study. If you are harmed due to someone's negligence, then you may have grounds for a legal action, but you may have to pay your legal costs. If you have a concern about any aspect of this study, you should speak to the researcher and he will do his best to answer your questions and resolve any concerns. If you remain unhappy and wish to complain formally, you can do this through the School of Psychology. The contact details are given below.

Will my taking part in the study be kept confidential?

Yes. In normal circumstances all information collected about you during the study will be kept confidential. All data will be stored securely and separately from any of your personal details. Only the researchers involved in the study will have access to this data. However, if the researcher observes or hears something that causes very serious concern about the well-being of your relative/friend, it may be necessary to share this information with other professionals. The researcher would make every effort to first inform you of the need to share this information.

What will happen if I don't want to carry on with the study?

You may withdraw from the study at any time without giving a reason and this will not affect the standard of medical care you or your relative/friend receive in any way. We may need to use the data collected before you decide to withdraw.

What will happen to the results of the research?

We will publish the results of the study in scientific journals. All information about participants will be anonymous, so you will <u>not</u> be identifiable in any publication. We can inform you of the findings of the study if you wish.

Who has reviewed the study?

All research in the NHS is analysed by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, well-being and dignity. This study has been reviewed and granted approval by the North West Wales Research Ethics Committee.

Who is organising and funding the research?

The research is being funded by a Welsh Assembly Government Health Studentship Award. The project is being led by Mr Anthony Martyr (PhD student) and supervised by Professor Linda Clare, a clinical psychologist who works at Bangor University.

Who can I contact for further information?

For more information, please contact:

Mr Anthony Martyr,
School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS
Tel: 01248 388210
Email: a.martyr@bangor.ac.uk

Professor Linda Clare
School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS
Tel: 01248 388178
Email: l.clare@bangor.ac.uk

If you have any complaints about the conduct of this study you can contact:
Dr E. Charles Leek (Head of School)
School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS.
Tel: 01248 382948
Email: e.c.leek@bangor.ac.uk

Thank you for considering taking part in this research study!

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e-mail: a.martyr@bangor.ac.uk
Tel: (01248) 388210

ID: _____

PARTICIPANT CONSENT FORM

Planning and managing everyday tasks
Lead Researcher: Mr Anthony Martyr

Please initial box

1. I confirm that I have read and understood the information sheet for the above study, version 3 dated 30/11/2011, and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical or legal rights being affected. ☐

3. I agree to my GP and hospital consultant being informed by letter that I am taking part in this study. ☐

4. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the Betsi Cadwaladr University Health Board, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

5. I agree to take part in the above study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

1 for participant; 1 for researcher; 1 to be kept with hospital notes

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ID: _____

CONSENT FORM FOR RELATIVE/FRIEND

Planning and managing everyday tasks
Lead Researcher: Mr Anthony Martyr

Please initial box

1. I confirm that I have read and understood the information sheet, version 2 dated 30/11/2011, for the above study, and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical or legal rights being affected. ☐

3. I agree to take part in the above study. ☐

_____	_____	_____
Name of relative/friend	Date	Signature
_____	_____	_____
Name of person taking consent (if different from researcher)	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

1 for participant; 1 for researcher

The following assessment was used in Chapter 3 and Chapter 6. More subtests were included to assess healthy older people in Chapter 3; however, in this appendix both assessments have been combined.

The following subtests were included only in the healthy older people study (Chapter 3):

1) Communication; Item A: using a telephone book (page 225)
2) Medication; Item C: prescription refill (page 236)
3) Medication; Item D: pillbox task (page 240)

Some items were also amended to make them more applicable to UK residents. In the original DAFS (Loewenstein et al., 1989) the Communication - item A subtest accounted for 6 points but it is very rare in the UK to include a return to sender address; consequently none of the participants in either study included a return to sender address on the envelope, so this item was dropped from the total.

In the Financial - item B counting currency subtest £1 notes stopped being legal tender in the United Kingdom in 1988; therefore the three $1 bills were replaced with five £1 coins and the participant was asked to count out £5.02 pence instead of $1.02 cents.

Finally, in the extended DAFS (McDougall Jr. et al., 2010) using a telephone book accounted for one point but it was amended in the current study so that it would be more applicable to the prediction and postdiction scoring system: remembers the name (if prompt required score as incorrect), finds the number, uses the area code, dials the correct six-digit number; 1 point was awarded for each correct item. The names and telephones numbers that were used in the telephone book task have been redacted from this appendix.

ID: _____

Direct Assessment of Functional Status (DAFS)

The tests we are asking you to perform include a broad range of activities which are usually carried out daily. Some of these tasks may be more difficult than others. Other tasks are relatively simple but we request you do these tasks as you would normally do them.

I will be asking you to do some things you may already be familiar with. You may find some of the tasks harder than others, but that is okay. Just try to answer as best as you can.

I. Time Orientation (16 Points)

A) Telling Time

Prediction: **I'm going to show you four clocks each telling a different time. I'm going to ask you to tell me the correct time being shown.**

Using these words, how do you think you will do on this test:

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

The rater shows the first picture of the clock and asks, "**Tell me what time this is.**" The rater should not tell the participant whether s/he is correct, but should continue to the next clock setting.

	Correct (2 points)
1) 3:00	_____
2) 8:00	_____
3) 10:30	_____
4) 12:15	_____
	_____/ 8

Postdiction: **You were asked to tell the time four times. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

B) Orientation to Date

Prediction: **I'm going to ask you to tell me today's date, the day of the week, the month and the year. Using these words, how do you think you will do on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

1) **What is today's date?** _____
2) **What day is it today?** _____
3) **What month are we in?** _____
4) **What year are we in?** _____

_____/ 8

Orientation Total: _____

Postdiction: **You were asked to tell me today's date, the day of the week, the month and the year. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

II. Communication (18 Points)

A) Using the telephone

Prediction: **I'm going to ask you to use and dial a number on this telephone. Using these words, how do you think you will do on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Prediction: **I'm going to ask you to dial the operator and three other numbers, one from a list, one that I will read out and one on a card.**

Using these words, how do you think you will do on this test?

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Show me how you would call the operator.
If the participant merely starts dialling without picking up the receiver, the rater should instruct the participant by stating, **"I want you to do everything you need to do to call the operator."**

Correct (1 point)

1) Dial the operator (Correct if participant dials 100) _____

(2-5 are scored during dialling the operator task)

2) Pick up the receiver _____
3) Ability to dial _____
4) Hang up phone _____
5) Correct sequence across all previous trials _____

(2-5) ____/ 4

Postdiction: **You were asked to use and dial a number on this telephone. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Encourage the participant to keep lifting the receiver on and off the hook correctly, but this is not necessary for scoring purposes.

I want you to dial the number for John Ford. The number is not to be presented orally, rather the participant must select the correct name from the written list on the stimulus card and dial the exact number. The participant is permitted to self-correct and is allowed to start over at any time during the sequence.

6) Dial number from book _____

I would like you to dial the number: 596-9669
If the participant has trouble remembering the number, when s/he is dialling, the rater can present the whole number again orally with a longer pause between the area code (596) and the number (9669).

7) Dial number presented orally _____

Please, dial this number. (Show card: 235-2762)
The number is visible throughout the task, but it is never presented orally.

8) Dial number written down _____

(1, 6-8) ____/ 4

Postdiction: **You were asked to dial the operator and three other numbers. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Prediction: **Next, I'm going to ask you to find and dial a specific number from this phonebook. Using these words, how do you think you will do on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Please look up the name [redacted] (or [redacted] if participant is in the same dialling code area) **and dial her number.**

	Correct (1 point)
9) Remembers the name (if prompt required score zero)	_____
10) Finds the number	_____
11) Uses the area code	_____
12) Correct if right number dialled	_____
[redacted]	
[redacted]	_____/ 4

Postdiction: **You were asked to find and dial a specific number from this phonebook. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Telephone total: _____

B) Preparing a letter for posting

Place before the participant a piece of paper, pen, envelope, stamp and address card.

Prediction: **Now I'm going to test your ability to post a letter. Imagine that this piece of paper is a completed letter and you are going to mail this letter to John Smith. Using these words, how do you think you will do on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

I want you to do everything you need to do to prepare this letter for posting.

The participant is allowed only two prompts during this subtest. If the participant stops in the middle of the task; prompt: **Is there anything else you have to do to prepare this letter for posting?** If the participant successfully completes all components of the task but does not place the letter in the envelope or seal the envelope, the participant should then be asked again: **Is there anything else you have to do to prepare this letter for posting?**

	Correct (1 point)
1) Fold in half	_____
2) Put in envelope	_____
3) Seal envelope	_____
4) Stamp envelope	_____
5) Address (exact copy)	_____
6) Return address for undelivered mail (has to be placed on the reverse of the envelope, near the top)	_____
	_____/ 6

C) Postdiction: **You were asked to prepare a letter for posting. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Communication Total: _____

III. *Pre-shopping instructions*

In ten minutes you will be going to a little grocery store that contains some grocery items. You should try hard to remember these items as I would like you to select them from memory. I would like you to repeat each of the six items as I tell them to you so that you can remember them when we go to the grocery store later.

Prediction: **Using these words, how well do you think you will do with remembering the six items?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Each grocery item is repeated by the participant with a three second interval before presentation of the next word. If the participant repeats the incorrect word, such as soup for corn flakes or if the participant does not respond, the rater should say: **What did you hear me say?** Then, if the incorrect word is given in response, the rater should say, **No, say corn flakes.**

No repeats or reminders are permitted once the participant has successfully repeated an item.

Be certain to have the participant recall the grocery store items after exactly ten minute

A) Orange juice	**D)** Tuna fish	Time: _____
B) Soup	**E)** Rice	
C) Corn flakes	**F)** Jam	

GO TO THE (MOCK) GROCERY STORE AFTER 10 MINUTES HAVE ELAPSED

IV. Financial (28 Points)

Prediction: **I'm going to ask you to identify different denominations of money. Using these words, how do you think you will do on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Place currency in front of participant from your right to left as follows:

One £10 note	one £5 note	five £1 coins	
two 50ps	three 10ps	one 5p	three 1ps

A) Identifying currency (The participant is asked to identify each)

	Correct (1 point)
1) Identify penny	_____
2) Identify five pence piece	_____
3) Identify ten pence piece	_____
4) Identify fifty pence piece	_____
5) Identify one pound coin	_____
6) Identify five pound note	_____
7) Identify ten pound note	_____
	_____/ 7

Postdiction: **You were asked to identify different coins and notes. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

B) Counting currency

Prediction: **I'm going to ask you to count out different amounts of money. Using these words, how do you think you will do on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

	Correct (1 point)
1) **Show me how you make six pence in coins.**	_____
2) **Show me how you make five pounds and two pence in coins.** If participant uses £5 note, repeat that s/he should use only coins.	_____
3) **Make six pounds and seventy-three pence.**	_____
4) **Make twelve pounds and seventeen pence.**	_____
	_____/ 4

Postdiction: **You were asked to count out different amounts of money. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

C) Writing a cheque

Prediction: **I'm going to ask you to write a cheque to yourself for £400.00. Using these words, how do you think you will do on this test:**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Hand participant a cheque and a pen and say:

Write a cheque to yourself for £400.00	Correct (1 point)
1) Signature	_____
2) Pay to the order of/"cash"	_____
3) Written amount	_____
4) Numeric amount	_____
5) Date (location; date does not have to be correct)	_____
	_____/ 5

Postdiction: **You were asked to write a cheque to yourself for £400.00. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

D) Balancing a chequebook

Prediction: **I'm going to ask you to balance a chequebook four times. You can work out the sums anywhere on the ledger sheet as long as the correct amount is posted on the ledger sheet in the proper space. Using these words, how do you think you will do on this test:**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

	Correct (1 point)
1) £500.00 - £350.00 = Correct £150.00	_____
2) £323.00 - £23.50 = Correct £299.50	_____
3) £21.75 - £3.92 = Correct £17.83	_____
4) £673.16 - £79.23 = Correct £593.93	_____
	_____/ 4

Postdiction: **You were asked to balance a chequebook four times. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

E) Making change for a purchase
(Add in 'Shopping skills D' score from page 11 now) _____/ 8

Financial Total: _____

V. Shopping skills (20 Points) (Ten minutes after first given the list)
Ten minutes after giving the instructions; **Can you tell me those six items of shopping I asked you to remember ten minutes ago?** The participant is allowed one minute to recall as many grocery items as possible. The rater does not tell the participant whether s/he is right or wrong.

A) Shopping recall (from memory) — Correct (1 point)

1) Orange juice _____
2) Soup _____
3) Corn flakes _____
4) Tuna fish _____
5) Rice _____
6) Jam _____

_____/ 6

Postdiction: **You were asked to remember six items of shopping from ten minutes ago. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

B) Shopping recognition (from memory)

Prediction: **I'm now going to take you a grocery store that I have set up nearby. When we get there I'm going to ask you to pick out the six items I asked you to remember earlier. Using these words, how do you think you will do on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Stop the participant after selecting the sixth item. Correct (1 point)

1) Orange juice _____
2) Soup _____
3) Corn flakes _____
4) Tuna fish _____
5) Rice _____
6) Jam _____

_____/ 6

Postdiction: **You were asked to pick out the six items I asked you to remember earlier. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

C) Shopping from a written list

Prediction: **I'm now going to ask you to pick out four new items of grocery from a shopping list and give them to me. Using these words, how do you think you will do on this test:**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Take participant to the shop (participant is stopped after picking the fourth item).

Correct (2 points)

1) Milk _____
2) Crackers _____
3) Eggs _____
4) Laundry detergent _____

_____/ 8

Postdiction: **You were asked to pick out four items of shopping from a list. Using these words, how do you think you did on this test:**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Return to testing room Shopping Total: _____

D) Making change for a purchase

Place the currency from the earlier identification and counting task before the participant.

Prediction: **Imagine that you are working at the checkout till at the grocery store, and I buy something for less than five pounds. Here is my five pound note. I would like you to give me the correct amount of change you should give me using the money here. Using these words, how do you think you will do on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

My bill comes to £2.49. Show me how much change I should get back.

Repeat the instructions for the other three quantities.	Correct (2 points)
1) £5.00 - £2.49 = £2.51	_____
2) £5.00 - £1.68 = £3.32	_____
3) £5.00 - £3.22 = £1.78	_____
4) £5.00 - £3.83 = £1.17	_____

Add the making change for a purchase score to the financial total

Postdiction: **You were asked to give me the correct amount of change. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

VI. Transportation (13 Points)

Have you ever driven a car? Yes / No (if no and they get the first three wrong, skip to medication)

Prediction: **I'm going to show you some road signs and road markings. I would like you to tell me what you would do at each sign if you were driving a car. Using these words, how do you think you will do on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

The rater should state: **If you are driving down the road, what would you do when you see the following sign?** It should be clear to the rater that the participant knows the correct driver's response rather than just having him or her merely read a road sign (e.g. **What do you do with your car?**).

A) Participant has to correctly identify a driver's response to these road signs: Correct (1 point)

1) Stop (slow down and when reach the sign stop) _____
2) Give way (give way to oncoming traffic) _____
3) One way (can only drive one-way down the road) _____
4) No right turn (can't turn right) _____
5) Green light (go, or keep driving) _____
6) Amber light (slow down, or drive at the same speed if unsafe to slow down) _____
7) Red light (stop, wait for green to drive) _____
8) No "U" turn (can't turn around) _____
9) Level crossing (railway junction up ahead) _____
10) No entry (no entry allowed) _____

For next two, participant is asked: **if you are driving on this side of the road** (*indicate which side of the road and in which direction*) **what does this mean you can or cannot do?**

11) Double white line(No overtaking) _____
12) Passing line (can overtake) _____
13) Speed limit (can't drive faster than 40 mph) _____

Transportation Total: _____/ 13

Postdiction: **You were asked to tell me what you would do at each sign if you were driving a car. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

VII. Medication skills (28 Points)

A) Identifying medication: place the bottle in front of the participant.

Prediction: **If I asked you to tell me five specific details relating to this medication, such as the name of the medication and the name of the doctor that prescribed it. Using these words, how well do you think you would be able to answer the questions?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

	Correct (1 point)
1) **Is the medication prescription or over-the-counter medication?** (Prescription)	_____
2) **Who has the medication been prescribed to?** (Mr John Smith)	_____
3) **What is the name of the medication?** (OxyDigitate XL)	_____
4) **What is the name of the GP who prescribed the medication?** (Dr B Thomas)	_____
5) **Are there any special instructions?** (to be taken with food)	_____
	_____/ 5

Postdiction: **You were asked to give me five specific details relating to this medication. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

B) Managing medication

Prediction: **If I asked you for more details about taking and refilling the medication, using these words, how well do you think you would be able to answer those questions?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Correct (1 point)

1) **I would like to know how many tablets are to be taken at a time.** (Two) _____
2) **I would like to know how many tablets are to be taken in a day.** (Four) _____
3) **How would you get a refill of this prescription?** (Call GP for refill) _____
4) **Can you tell me the steps needed to be taken to refill the prescription?** (Call GP for refill, collect prescription, take to pharmacy for medication) _____
5) **If you had a question about this medication what would you do?** (Ask the pharmacist) _____

_____/ 5

Postdiction: **You were asked to provide me with more information about taking and refilling the medication. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

C) Prescription refill

The next medication task that we will do has to do with refilling prescriptions over the phone, using an automated phone system. Before we do that, have you ever refilled a prescription over the phone using an automated phone system? Yes/No/Don't know

Your goal for this activity is to refill this prescription. (Present participant with the medication bottle)

In order to refill the prescription you will need to know the prescription number. Can you find the prescription number on this bottle of medication and tell me what it is please?

_____

(If incorrect, show the participant the prescription number)

For the purposes of this activity, I want you to <u>pick up</u> the prescription <u>tomorrow at 10 AM</u> from the pharmacy. Please take a moment now to remember <u>tomorrow at 10 AM</u> is when you want to pick up your prescription from the pharmacy. You will also need to know your home phone number. What is your home phone number: _____

Because you can't actually order this prescription over the phone, I am going to read out a pretend automated phone system. Like a real automated phone system, you will hear instructions and you will respond by pushing the numbers on this phone.

I will not be able to answer any of your questions once we begin. If you get stuck, please do the best you can without my help. Let's do a practise run before we start so you can get used to the phone system.

Practice 1: **Please pick up the phone and follow the instructions.**

Hello and welcome to the Bangor University Pharmacy.
If you live in Bangor, Gwynedd - press 1
If you live in Anglesey - press 2
If you live somewhere else in North Wales - press 3
To repeat this message - press 8 (If they push 8, repeat this section)
To end this call, press 9.

Write down everything the participant presses on the phone:
_____
_____
_____

Practice 2:

Good, now we'll do a second task. I need to know your postcode. Please key in your postcode on the phone.

Write down everything the participant presses on the phone:
_____

Do you have any questions before we start?

Prediction: **The two tasks you have just practised are very similar to what we'll be doing next. Now we're going to order the prescription over the phone using an automated service. Using these words, how do you think you will do on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

1) Pharmacy activity script:

Thank you for calling the Bangor University Pharmacy
If you are a doctor or clinic, press 1.
To refill a prescription, press 2.
To check on the status of a prescription order that was already placed, press 3.
For Pharmacy information, press 4.
To repeat this message, press 8. (If they push 8, repeat this section)
To end this call, press 9.
Write down everything the participant presses on the phone:
_____
_____

Correct (1 point)

Correct if press 2 _____

2) **Now, please key in the prescription number.**

Write down everything the participant presses on the phone:
_____
_____

Correct if dial 73426157 _____

3) **Please enter the last 4 digits of your home phone number.**
Write down everything the participant presses on the phone:
_____

Correct if last four digits _____

4) **If you want your prescription to be posted to you, press 1.**
If you want to pick up your prescription from the pharmacy, press 2.
To repeat this message, press 8. (If they push 8, repeat this section)
To end this call, press 9.

Write down everything the participant presses on the phone:
_____

Correct if press 2 _____

5) **If you would like to pick up your prescription today, press 1.**
If you would like to pick up your prescription tomorrow, press 2
To repeat this message, press 8. (If they push 8, repeat this section)
To end this call, press 9.

Write down everything the participant presses on the phone:
_____

Correct if press 2 _____

6) **If you would like to pick up your prescription before noon, press 1.**
If you would like to pick up your prescription after noon, press 2.
To repeat this message, press 8. (If they push 8, repeat this section)
To end this call, press 9.

Write down everything the participant presses on the phone:
_____

Correct if press 1 _____

7) **Using the numbers on your phone, punch in the time you would like to pick up your prescription using a 4-digit number. For example, if you want to pick up your prescription at 8 AM, you would key in 0800.**

Write down everything the participant presses on the phone:
_____

Correct if press 1000 _____

8) **Your prescription will be ready to be picked up tomorrow at 10 AM.**
Press 1 if this is correct, press 2 if this is incorrect.

Write down everything the participant presses on the phone:
_____

Correct if press 1 _____

_____/ 8

Postdiction: **You were asked to order a prescription over the telephone using an automated service. Using these words, how do you think you did on this test?**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

D) Pillbox task

The last medication activity involves preparing a pillbox. Here is a one week pill box and 10 different bottles of pills, the pills are actually beads. A pillbox is useful because it helps you sort your pills so that you remember when to take them. Please fill the box according to the labels on each of the bottles, as you would do if you were taking these medications. Using these words, how well do you think you would be able to do this:

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

			Correct (1 point)
1	Aspirin (white)	Take 1 pill everyday	_____
2	Lopressor (blue)	Take 1 pill twice a day	_____
3	Ambien (yellow)	Take 1 pill at bedtime for sleep	_____
4	Lipitor (dark blue)	Take 2 tablets every evening with dinner	_____
5	Isordil (orange)	Take 2 tablets in AM and 1 tablet in the PM	_____
6	Lasix (purple)	Take 1 tablet twice a day before 3 PM	_____
7	Marinol (red)	Take 1 tablet before lunch and dinner	_____
8	Levaquin (pink)	Take 1 tablet every morning for 3 more days	_____
9	Coumadin (green)	Take 1 tablet Monday, Wednesday & Friday AND 2 tablets Sunday, Tuesday, Thursday & Saturday	_____
10	Tramadol (grey)	Take every 6 hours as needed for pain	_____

_____/ 10

Postdiction: **You were asked to preparing a pillbox for one weeks' worth of medication. Using these words, how do you think you did on this test:**

Very poor	Poor	Alright	Good	Very good
0	1	2	3	4

Medication Total: _____

Scoring

		Subtest score
I.	**Time orientation**	_____
	Telling time	_____
	Orientation to date	_____
II.	**Communication**	_____
	Using the telephone	_____
	Preparing a letter for mailing	_____
III.	**Transportation**	_____
IV.	**Pre-shopping** (no score)	
V.	**Financial**	_____
	Identifying currency	_____
	Counting currency	_____
	Writing a cheque	_____
	Balancing a chequebook	_____
	Making change for a purchase	_____
VI.	**Shopping**	_____
	Shopping from recall	_____
	Shopping from recognition	_____
	Shopping with written list	_____
VII.	**Medication skills**	_____
	Identifying medication	_____
	Managing medication	_____
	Prescription Refill	_____
	Pillbox task	_____
	Total Score	_____

Comments:

Description	Debit (-)	Credit (+)	Balance
Previous balance			£500.00
Visa bill	£350.00		
New balance			

Description	Debit (-)	Credit (+)	Balance
Previous balance			£323.00
Dry cleaning	£23.50		
New balance			

Description	Debit (-)	Credit (+)	Balance
Previous balance			£21.75
Postage	£3.92		
New balance			

Description	Debit (-)	Credit (+)	Balance
Previous balance			£673.16
Supplies for party	£79.23		
New balance			

The Bank
The High Street

The Bank

Sort Code
40 24 32

Date:_____

Pay: _____ £

_____

_____

Account Payee

Cheque Number
0000001

Sort Code
40 24 32

Account Number
123456789 08

John Smith
16 The High Street
Bangor
Gwynedd
LL57 4AD

Dear Mr Smith,

I would like to take this opportunity to express my heartfelt thanks to you for your very active participation in our recent conference in Montreal on the "future of aviation". The Chairman and Board Members have also asked me to pass on their sincere appreciation for your efforts in supporting the Institute in this important undertaking.

Your skill in chairing the controversial panel on "The Role of Developing Countries in the Future of Aviation Management" was very much appreciated by those representing all sides of that extremely sensitive topic. As well, we have received numerous post-conference requests for the paper you delivered on "The Critical Issue of Cooperation between Airlines and Airports." It appears that you may have penned a best-seller with that one.

Yours sincerely

Appendix K. Informant rating questionnaire for the Direct Assessment of Functional Status

Below are some everyday situations that your relative/friend may find themselves needing to do. I would like you to think about how your relative/friend will manage with these tasks if s/he has to do them by him or herself at some point today. Circle the number which you think best describes how s/he would do.	**0 = Very Poor** **1 = Poor** **2 = Alright** **3 = Good** **4 = Very Good**				
1) Your relative/friend has to tell the time four times on an old-style analogue clock.	0	1	2	3	4
2) Your relative/friend has to say today's date, the day of the week, the month and also the year.	0	1	2	3	4
3) Your relative/friend has to use a telephone and dial a number.	0	1	2	3	4
4) Your relative/friend has to know the number for and dial the operator, dial a specific number from a list, dial a number that is read aloud to him/her and dial a number written down	0	1	2	3	4
5) Your relative/friend has to find and dial a specific number from the telephone book.	**0**	**1**	**2**	**3**	**4**
6) Your relative/friend has to prepare a letter ready for posting, including writing the exact address and putting a stamp on the envelope.	0	1	2	3	4
7) Your relative/friend has to identify five different British coins and a £10 and a £5 note.	0	1	2	3	4
8) Your relative/friend has to correctly count out four different amounts of money.	0	1	2	3	4
9) Your relative/friend has to write a cheque to him/herself for £400.	0	1	2	3	4
10) Your relative/friend has to balance a chequebook four times.	0	1	2	3	4
11) Your relative/friend has to remember six items of shopping after ten minutes.	0	1	2	3	4
12) After ten minutes your relative/friend has to go to a small grocery store and, from memory, pick out the six items of shopping.	0	1	2	3	4
13) Your relative/friend has to pick out four different items of shopping from a written list.	0	1	2	3	4
14) Your relative/friend has to calculate the correct amount of change for four different purchases under £5.	0	1	2	3	4
15) Your relative/friend has to recognise and know what to do at 11 road signs and 2 road markings.	0	1	2	3	4
16) Your relative/friend has to answer five questions about information found on the label of a medication bottle.	0	1	2	3	4
17) Your relative/friend has to manage some medication, such as refilling a prescription and knowing how many tablets to take.	0	1	2	3	4
18) Your relative/friend has to use a new automated telephone service to refill a prescription.	**0**	**1**	**2**	**3**	**4**
19) Your relative/friend has to sort 10 different types of daily medication ready for the coming week.	**0**	**1**	**2**	**3**	**4**

Note: items in bold were included in Chapter 3 only

Instructions: Choose the best answer for how you felt over the past week.

		Yes	No
1	Are you basically satisfied with your life?	0	1
2	Have you dropped many of your activities and interests?	1	0
3	Do you feel that your life is empty?	1	0
4	Do you often get bored?	1	0
5	Are you in good spirits most of the time?	0	1
6	Are you afraid that something bad is going to happen to you?	1	0
7	Do you feel happy most of the time?	0	1
8	Do you often feel helpless?	1	0
9	Do you prefer to stay at home, rather than going out and doing new things?	1	0
10	Do you feel you have more problems with memory than most?	1	0
11	Do you think it is wonderful to be alive now?	0	1
12	Do you feel pretty worthless the way you are now?	1	0
13	Do you feel full of energy?	0	1
14	Do you feel that your situation is hopeless?	1	0
15	Do you think that most people are better off than you are?	1	0
		Total:	

Appendix M. Apathy Scale

		Not at all	Slightly	Some	A lot
1	Are you interested in learning new things?	3	2	1	0
2	Does anything interest you?	3	2	1	0
3	Are you concerned about your condition?	3	2	1	0
4	Do you put much effort into things?	3	2	1	0
5	Are you always looking for something to do?	3	2	1	0
6	Do you have plans and goals for the future?	3	2	1	0
7	Do you have motivation?	3	2	1	0
8	Do you have the energy for daily activities?	3	2	1	0
9	Does someone have to tell you what to do each day?	0	1	2	3
10	Are you indifferent to things?	0	1	2	3
11	Are you unconcerned with many things?	0	1	2	3
12	Do you need a push to get started on things?	0	1	2	3
13	Are you neither happy nor sad, just in between?	0	1	2	3
14	Would you consider yourself apathetic?	0	1	2	3
				Total:	

Appendix N. Spearman's rho correlations between tests of executive function and cognitive screening measures

	ACE-R	NART-R IQ	TMT4	Letter Fluency	Category Fluency	Switching Accuracy	Zoo Map	Map Search	Hayling Category A
NART-R IQ	**.507*****								
TMT4	**-.567*****	-.379**							
Letter Fluency	**.562*****	**.604*****	-.403**						
Category Fluency	**.691*****	**.413*****	-.399**	**.596*****					
Switching Accuracy	.316*	.209	-.072	.309**	.334**				
Zoo Map	.264*	.280*	-.314*	.114	.168	.072			
Map Search	**.438*****	.289*	-.305*	.243	.347**	.365**	.347**		
Hayling Category A	-.401**	**-.492*****	.241	-.404**	-.257*	-.222*	-.092	-.375**	
Hayling Category B	-.152	-.101	.115	-.135	.109	-.144	.090	-.127	.378**

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Note: bold indicates significant at the 5% level after Holm-Bonferroni correction.

Abbreviations: Addenbrooke's Cognitive Examination-Revised (ACE-R), National Adult Reading Test-Revised estimated IQ score (NART-R IQ), Trail Making Test 4 (TMT4).

I would like to ask about how well you perform in the following 11 activities.

3 - Dependent
2 - Require assistance
1a - Have difficulty, but can do by myself
1b - Never did, and would have difficulty now
0a - Normal
0b - Never did, but could do now

1. Can you write cheques, pay bills, and keep financial records? ……....

2. Can you assemble tax records, make out business or insurance papers? ……....

3. Can you shop alone for clothes, household necessities and groceries? ……....

4. Can you play a game of skill (e.g. bridge, chess, cards, crosswords) or working on a hobby (e.g. gardening)? ……....

5. Can you heat water for coffee or tea and turn off the stove? ……....

6. Can you prepare a balanced meal? ……....

7. Can you keep track of current events? ……....

8. Can you pay attention to, understand and discuss a TV programme, book or magazine? ……....

9. Can you remember appointments, family occasions and to take your medication? ……....

10. Can you travel out of the immediate local area - driving, arranging to take buses etc.? ……....

11. Are you able to use the telephone appropriately (e.g. finding & dialling correct numbers)? ……....

Total **……....**

Please rate the performance of your relative/friend in the following 11 activities.

You can rate them as someone who is dependent, requires assistance, or has difficulty but does engage in the activities independently or as someone who never did the activity in question.

Circle the response you think best reflects their current ability:

1. Writing cheques, paying bills, keeping financial records

Dependent	Requires assistance	Has difficulty but does by self	Never did, and would have difficulty now	Normal	Never did, but could now

2. Assembling tax records, making out business or insurance papers

Dependent	Requires assistance	Has difficulty but does by self	Never did, and would have difficulty now	Normal	Never did, but could now

3. Shopping alone for clothes, household necessities and groceries

Dependent	Requires assistance	Has difficulty but does by self	Never did, and would have difficulty now	Normal	Never did, but could now

4. Playing a game of skill (e.g. bridge, chess, cards, crosswords) or working on a hobby (e.g. gardening)

Dependent	Requires assistance	Has difficulty but does by self	Never did, and would have difficulty now	Normal	Never did, but could now

5. Heating water for coffee or tea and turning off the stove

Dependent	Requires assistance	Has difficulty but does by self	Never did, and would have difficulty now	Normal	Never did, but could now

6. Preparing a balanced meal

Dependent	Requires assistance	Has difficulty but does by self	Never did, and would have difficulty now	Normal	Never did, but could now

7. Keeping track of current events

Dependent	Requires assistance	Has difficulty but does by self	Never did, and would have difficulty now	Normal	Never did, but could now

8. Paying attention to, understanding and discussing a TV programme, book or magazine

Dependent	Requires assistance	Has difficulty but does by self	Never did, and would have difficulty now	Normal	Never did, but could now

9. Remembering appointments, family occasions and medication

Dependent	Requires assistance	Has difficulty but does by self	Never did, and would have difficulty now	Normal	Never did, but could now

10. Travel out of the immediate local area: driving, arranging to take buses etc.

Dependent	Requires assistance	Has difficulty but does by self	Never did, and would have difficulty now	Normal	Never did, but could now

11. Able to use telephone appropriately (e.g. finding & dialling correct numbers).

Dependent	Requires assistance	Has difficulty but does by self	Never did, and would have difficulty now	Normal	Never did, but could now

Total: _____

Thank you – please ensure you have answered all questions

Appendix Q. Mean scores for individual self-ratings and informant ratings of functional items and paired-sample *t* tests between individual functional items

	FAQ-S Mean	FAQ-I Mean	*t*	*p*
Write cheques or pay bills	0.58 (0.95)	1.84 (1.11)	-8.68	**<.001**
Tax or insurance documents	1.04 (1.07)	2.07 (1.07)	-6.78	**<.001**
Shopping alone	0.73 (0.95)	1.75 (1.21)	-7.52	**<.001**
Hobbies or games of skill	0.32 (0.61)	1.16 (1.17)	-6.51	**<.001**
Make tea or coffee	0.15 (0.54)	0.59 (0.88)	-4.67	**<.001**
Prepare balanced meal	0.56 (0.94)	1.66 (1.23)	-7.17	**<.001**
Keep track of current events	0.42 (0.68)	1.33 (1.19)	-6.05	**<.001**
Discuss book or TV programme	0.34 (0.72)	1.24 (1.05)	-6.74	**<.001**
Remember appointments and to take medication	0.89 (1.00)	2.00 (1.01)	-8.53	**<.001**
Travel out of local area	0.85 (1.16)	1.91 (1.21)	-7.60	**<.001**
Use telephone appropriately	0.25 (0.58)	1.02 (1.05)	-6.34	**<.001**

Note: bold indicates significant at the 5% level after Holm-Bonferroni correction.
Abbreviations: Functional Activities Questionnaire self-report (FAQ-S), Functional Activities Questionnaire informant-report (FAQ-I).

Appendix R. Relative Stress Scale

0 = Not at all
1 = Rarely/a little
2 = Sometimes/moderately
3 = Frequently/quite a lot
4 = Always/considerably

Please think about how often/how much each of the statements below applies to you during the past two weeks (and circle your response)

1. Do you ever feel that you can no longer cope with the situation?	0	1	2	3	4
2. Do you ever feel that you need a holiday?	0	1	2	3	4
3. Do you ever get depressed by the situation?	0	1	2	3	4
4. Has your own health suffered at all?	0	1	2	3	4
5. Do you worry about accidents happening to your relative?	0	1	2	3	4
6. Do you ever feel there will be no end to the problem?	0	1	2	3	4
7. Do you find it difficult to get away on holiday?	0	1	2	3	4
8. How much has your social life been affected?	0	1	2	3	4
9. How much has the household routine been upset?	0	1	2	3	4
10. Is your sleep interrupted by your relative?	0	1	2	3	4
11. Has your standard of living been reduced?	0	1	2	3	4
12. Do you ever feel embarrassed by your relative?	0	1	2	3	4
13. Are you prevented from having visitors?	0	1	2	3	4
14. Do you ever get cross or angry with your relative?	0	1	2	3	4
15. Do you ever feel frustrated with your relative?	0	1	2	3	4
Total score:					

The questions below reflect how persons sometimes feel when they are taking care of another person. After each statement, circle the word that best describes how often you feel that way. There are no right or wrong answers. Circle the number that best describes how you feel.		**0 = Never** **1 = Rarely** **2 = Sometimes** **3 = Quite frequently** **4 = Nearly always**				
1	Do you feel that your relative/friend asks for more help than s/he needs?	0	1	2	3	4
2	Do you feel that because of the time you spend with your relative/friend that you don't have enough time for yourself?	0	1	2	3	4
3	Do you feel stressed between caring for your relative/friend and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4	Do you feel embarrassed over your relative's/friend's behaviour?	0	1	2	3	4
5	Do you feel angry when you are around your relative/friend?	0	1	2	3	4
6	Do you feel that your relative/friend currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
7	Are you afraid what the future holds for your relative/friend?	0	1	2	3	4
8	Do you feel your relative/friend is dependent on you?	0	1	2	3	4
9	Do you feel strained when you are around your relative/friend?	0	1	2	3	4
10	Do you feel your health has suffered because of your involvement with your relative/friend?	0	1	2	3	4
11	Do you feel that you don't have as much privacy as you would like because of your relative/friend?	0	1	2	3	4
12	Do you feel that your social life has suffered because you are caring for your relative/friend?	0	1	2	3	4
13	Do you feel uncomfortable about having friends over because of your relative/friend?	0	1	2	3	4
14	Do you feel that your relative/friend seems to expect you to take care of him/her as if you were the only one s/he could depend on?	0	1	2	3	4
15	Do you feel that you don't have enough money to take care of your relative/friend in addition to the rest of your expenses?	0	1	2	3	4
16	Do you feel that you will be unable to take care of your relative/friend much longer?	0	1	2	3	4
17	Do you feel you have lost control of your life since your relative's/ friend's illness?	0	1	2	3	4
18	Do you wish you could leave the care of your relative/friend to someone else?	0	1	2	3	4
19	Do you feel uncertain about what to do about your relative/friend?	0	1	2	3	4
20	Do you feel you should be doing more for your relative/friend?	0	1	2	3	4
21	Do you feel you could do a better job in caring for your relative/friend?	0	1	2	3	4
22	Overall, how burdened do you feel in caring for your relative/friend?	0	1	2	3	4
		Total:				

Appendix T. Spearman's rho correlations between everyday memory, tests of executive functioning and cognitive screening measures.

	RBMT	ACE-R	NART-R IQ	TMT4	Letter Fluency	Category Fluency	Switching Accuracy	Design Fluency	Stroop	Map Search	Zoo Map	Rule Shift
ACE-R	.306											
NART-R IQ	-.264	.143										
TMT4	-.155	-.414*	.104									
Letter Fluency	-.150	.170	.093	-.141								
Category Fluency	.181	**.554*****	-.167	-.509**	.379*							
Switching Accuracy	.171	.484**	-.041	-.514**	.263	**.601*****						
Design Fluency	.216	.446**	-.148	**-.546*****	.117	.453**	.238					
Stroop	-.180	-.264	.118	.552***	.116	-.342	-.168	-.473**				
Map Search	.227	.338*	-.204	-.394*	-.091	.243	.132	.418*	-.268			
Zoo Map	.169	.141	-.134	-.135	-.100	-.004	-.066	.462**	-.158	.331		
Rule Shift	.310	.320	-.083	-.322	.021	.442**	.311	.480**	-.372*	.414*	.330	
Key Search	.140	.403*	-.163	-.223	.149	.229	-.005	**.683*****	-.141	.398*	.504***	.398*

* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$

Note: bold indicates significant at the 5% level after Holm-Bonferroni correction.

Abbreviations: Rivermead Behavioural Memory Test (RBMT), Addenbrooke's Cognitive Examination-Revised (ACE-R), National Adult Reading Test-Revised estimated IQ score (NART-R IQ), Trail Making Test 4 (TMT4).