Understanding activities of daily living in people with dementia: Why is there a gap between performance and ability?

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Abstract

People with dementia's (PwD) performance of activities of daily living (ADLs) relates to what the PwD does in their daily routine, while their ability to complete tasks refers to what they could potentially do. The World Health Organization (WHO) launched the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001) which highlighted the importance of identifying the gap between performance and ability to complete tasks and to consider how different factors contribute to disability, to make adjustments and promote participation. Although several studies have examined how intrinsic factors affect the performance and potential ability to carry out ADLs, very few of them have investigated the role of extrinsic factors, including both the physical and the human environment (represented by the primary carer), in PwD's ADL functioning.

Using the ICF model, this thesis aimed to investigate the role of both intrinsic and extrinsic factors on PwD's ADL functioning, and how they may explain the gap that exists between the performance of ADLs and the actual ability to perform them.

A mixed-methods approach was used to address the research questions. The first study used an experimental design to investigate the role of the environment in PwD's ability to perform ADLs. Results showed that PwD performed better at home, even though the level of clutter was higher in their home environment than in the research-lab. Cognition was the only factor that predicted better functioning. The second study investigated how the combination of both intrinsic (cognition and apathy) and extrinsic factors (carer's style) affected ADLs in PwD. Apathy levels and carer's use of criticism style negatively affected ADL performance, while cognition and carer's use of encouragement style improved performance of daily tasks. The next study investigated how the human environment affected the discrepancy between the reported and the observed ADL performance. Results showed a high disagreement between performance and ability to perform ADLs in PwD, and the carer’s use of encouragement and active management style were the factors that predicted this discrepancy. The final study used a qualitative approach to identify the types of assistance provided by carers, when the PwD performs a task. Five different themes were identified, and the findings suggested that the types of assistance used by carers could either enhance or hinder ADL performance of PwD.

This thesis has shown that ADL functioning in PwD is affected by both the human and the physical environment and has revealed how the combination of extrinsic and intrinsic factors contributes to the changes in task performance of PwD. This work has confirmed the important role extrinsic factors play in shaping disability and that disability does not depend exclusively on disease-related factors. The findings provide evidence to support the development of multi-component non-pharmacological interventions that aim to reduce the gap between performance and ability to perform ADLs in PwD.

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List of Abbreviations

ACE-III	Addenbrooke's Cognitive Examination-III
AD	Alzheimer's disease
ADLs	Activities of Daily Living
AMPS	Assessment of Motor and Process Skills
BADLs	Basic Activities of Daily Living
Bv-FTD	Behavioural variant, Frontotemporal dementia
CBI-R	Cambridge Behavioural Inventory-Revised
DAD	Disability Assessment for Dementia
DMSS	Dementia Management Strategies Scale
FTD	Frontotemporal dementia
FRS	Frontotemporal Dementia Rating Scale
HEAP	Home Environmental Assessment Protocol
HRA	Health Research Authority
GAD-7	Generalised Anxiety Disorder Scale
GP	General Practitioner
IADLs	Instrumental Activities of Daily Living
ICC	Intraclass Correlation Coefficient
ICF	International Classification of Functioning, Disability and Health
JDR	Join Dementia Research
LPA	Logopenic Aphasia
MD	Mixed dementia
NEAT	Norwich Electronic Assistive Technology Centre
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute of Health Research
NSFT	Norfolk and Suffolk Foundation Trust
OT	Occupational Therapy/Therapist
PHQ-9	Patient Health Questionnaire
PCA	Posterior Cortical Atrophy
PNFA	Progressive Non-fluent Aphasia
PPA	Primary Progressive Aphasia
PwD	Person/People with Dementia
REC	Research Ethics Committee
Sv-PPA	Semantic-variant Primary Progressive Aphasia
UEA	University of East Anglia
VD	Vascular dementia
WHO	World Health Organization

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Declaration

Not part of this thesis has been submitted for any other degree or qualification at this or other institution.

Author contributions

I was responsible for the design of the studies and formulation of the research questions, data analyses, interpretation and writing up of all chapters of this thesis and dissemination of the results.

Dr Mizanur Khondoker provided support in data analysis for Chapter 5 and 6, and Dr Tamara Backhouse provided support in data analysis for Chapter 7.

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Oral and Poster presentations arising from this thesis

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Camino J. *What carer management style should I use to support people with dementia in daily tasks?* Dementia Open Forum, University of East Anglia, 2021. Online forum. (Oral Presentation)

Camino J. *A different and tidier kitchen: can people with dementia perform tasks in a new environment?* Dementia Open Forum, University of East Anglia, 2020. Online forum. (Oral Presentation)

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Camino J, Bregola A, Kishita N, Mioshi E. *Carer's appraisal of people with dementia's performance of daily tasked. What is the role of the carer management style?* Alzheimer's Association International Conference, 2019. Los Angeles, USA. (Oral Presentation)

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Camino J, Bregola A, Radakovic R, Rabet P, Kishita N, Mioshi E. *Comparing Task Performance in people with dementia in different environments: Does environmental clutter play a role?* Alzheimer's Society Annual Conference, 2019. London, England. (Poster Presentation)

Scientific publications arising from this thesis

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Camino J, Kishita N, Bregola A, Rubinsztein J, Khondoker M, Mioshi E. How does carer management style influence the performance of activities of daily living in people with dementia? *Int J Geriatr Psychiatric.* 2021 Dec;36(12):1891-1898. http://doi.org/10.1002/gps.5607 (Chapter 5)

Camino J, Kishita N, Trucco AP, Khondoker M, Mioshi E. Contributions of caregiver management style to the discrepancy between reported and observed task performance in people with dementia. *J Alzheimers Dis*. 2022;88(4):1605-1614. http://doi.org/10.3233/JAD-220155 (Chapter 6)

Camino J, Trucco AP, Kishita N, Mioshi E, Backhouse T. What type of assistance do carers provide to people with dementia during the performance of ADLs? *Under review*. (Chapter 7)

Chapter 1: Introduction

1.1 Introduction

Dementia is a neurodegenerative disorder that affects the individual's ability to carry out daily activities. Different factors have been associated with the problems that people with dementia present when carrying out these tasks, including intrinsic dementia factors and extrinsic ones.

Intrinsic dementia factors such as the person with dementia's level of cognitive function and their behavioural symptoms, have been widely investigated as possible components associated with the person with dementia's difficulties with activities of daily living.

Extrinsic factors, such as the environment in which the person with dementia performs daily activities, and the carer's level of burden and depression, have also been associated to some extent with the daily difficulties that this population present. Other extrinsic factors, such as the style that carers use when dealing with dementia-related problems or even the types of assistance they provide, have not been sufficiently investigated. As such, little is understood in relation to the strategies or daily actions that carers use when they support the person with dementia in their performance of daily tasks.

Over the course of my clinical career as an occupational therapist, I have worked with hundreds of people with dementia and their family carers. Most of them have recurrently asked me how to maintain their independence for as long as possible. The non-pharmacological interventions available for people with dementia that can support task performance are scarce, so I decided to apply for a PhD studentship offered at the School of Health Sciences of the University of East Anglia (UEA), while I worked part-time as a research assistant for the TASKed study. This was the opportunity to pursue my two main passions: developing my research skills and academic career while contributing to the understanding of how to support task performance of people with dementia.

The aim of this thesis is to investigate extrinsic factors as possible contributors to people with dementia's activities of daily living and how they affect the gap between what the individual performs and what they could potentially do. Focusing on extrinsic factors will allow clinicians and researchers to target new non-pharmacological interventions on potentially modifiable aspects of the PwD's external context, to support task performance while also reducing the gap between performance and ability to perform daily activities.

1.2 Structure of the thesis

Chapter 1 offers a general introduction to the thesis including my motivation for doing research and a glossary of terms.

Chapter 2 introduces the reader to a narrative literature review on the performance and the ability to perform daily tasks in people with dementia and their associated factors. It also contains information about the different assessments used to collect information on performance and ability to perform daily tasks in this population.

Chapter 3 describes the methods used in the various studies in this thesis, participants' inclusion and exclusion criteria, participant recruitment, ethical considerations, data collection methods, including procedures and instruments used, treatment of missing data, sample size and data analyses.

Chapter 4 is dedicated to the investigation of the role of the environment in relation to people with dementia's ability to perform daily tasks, with a focus on environmental clutter.

Chapter 5 explores how both intrinsic dementia factors (cognition and apathy) and extrinsic factors (carer's styles when managing dementia-related problems) can influence people with dementia's performance of daily tasks.

Chapter 6 investigates the discrepancy between the carer's report of ADL performance and the PwD's ability to perform a task. It also investigates the role of carer-related associated factors, such as the carer's level of depression and anxiety and the carer's styles when managing dementia-related problems, on this discrepancy.

Chapter 7 uses a qualitative approach to explore the types of assistance provided by carers during the performance of a daily task. In addition, this study explores why carers assist the PwD and the consequences of using different types of assistance.

Finally, Chapter 8 provides a general discussion of the thesis, highlights results, discusses limitations and aims to integrate all the results reported along the thesis. It also includes a summary of possible future research directions in the field.

1.3 Glossary of terms

Dementia refers to a brain condition that progressively affects the individual's cognitive functions and behaviour. These changes in the brain will impact on the person's ability to perform daily activities.

Person/people with dementia (*PwD)* is the term used along this thesis to refer to those individuals who were diagnosed with this condition. Includes those diagnosed with Alzheimer's disease and any other type of dementia.

Carer is the term used to refer to a member of the family or a friend of the person with dementia who provides with at least seven hours of unpaid support each week and knows the person well. The term will be sometimes referred to as a primary carer or family carer.

Activities of Daily Living (ADLs) refer to those tasks that humans complete on a daily basis, and that are essential to maintain habits and successfully live in their community. General classification of ADLs includes both basic (personal care tasks) and instrumental (community-related tasks) ADLs. ADL functioning will be also used when referring to the PwD carrying out ADLs.

Performance of ADLs is used in this thesis to describe any of those activities in which the PwD continue to complete independently and daily.

Ability to perform ADLs is used in this thesis to refer to the PwD's potential capacity (ability) to perform ADLs without direct assistance or the use of equipment, as described by the World Health Organization, through the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001).

Discrepancy between reported and observed ADL performance denotes the divergence that occurs between what a person with dementia does in their daily routine or performance, as reported by their carers, and what they could potentially do or ability, as measured by direct observation. Carer's appraisal of ADL performance is also used to refer to reported ADL performance.

Physical environment refers to the area or setting in which the person with dementia performs ADLs. This includes specific areas of the home environment, such as the kitchen and the bathroom or other settings, such as the research-lab.

Research-lab is the Norwich Electronic Assistive Technology Centre (NEAT), located at the Queen's Building, at the University of East Anglia. The NEAT is a fully equipped bungalow that is routinely use for teaching, training and research activities.

Environmental clutter refers to the presence of an excessive number of objects on a surface or the presence of items that are not required for a task (Gitlin, 2002).

Human environment refers to those individuals who provide support to the person with dementia, including family members and friends. In this thesis, the human environment is represented by the primary carer.

Carer's styles when managing dementia-related problems refer to the practical strategies that carers use daily when supporting people with dementia. Criticism, active management and encouragement are the three carer management styles that are used in this thesis.

Carer management criticism style is a management style used by carers of people with dementia that includes actions such as yelling, criticising and threatening the person with dementia.

Carer management active management style is a management style used by carers of people with dementia that includes strategies such as assisting and stimulating the person with dementia while modifying the environment or daily routine.

Carer management encouragement style is a management style used by carers of people with dementia where the carer employs strategies that tend to praise the individual, get them to discuss feelings or look on the bright side of things.

Carer's symptoms of depression refer to the persistent feeling of sadness, tiredness and lack of interest in doing things.

Carer's symptoms of anxiety refer to the carer's feelings of tension, sensation of worry or fear.

Assistance provided by carers during the performance of daily tasks refers to the support that carers provide to a person with dementia when they complete activities.

Types of assistance refer to the different and specific actions a carer takes to support the person with dementia during the performance of daily tasks, including the use of prompts, instructions, corrections, organisation of the space and hesitation.

Chapter 2: Performance and ability to perform daily tasks in people with dementia. A Narrative Literature Review.

This chapter introduces the reader to a narrative literature review (Baker, 2016) to provide the context in which this thesis bases the studies that were carried out.

2.1 Dementia

The term dementia refers to neurodegenerative disorders that present with cognitive deficits and/or behavioural changes that are sufficiently severe to interfere with social functioning and performance in work tasks or/and activities of daily living (ADLs) (American Psychiatric Association, 2013). Different dementia subtypes have been identified, including Alzheimer's disease, vascular dementia, mixed dementia, frontotemporal dementia and Lewy Body disease, among others.

It is believed that 850,000 people live with dementia (PwD) in the UK and over one million will be diagnosed by 2025 (Prince, 2014). The Alzheimer's Association's latest report estimates that there are more than 5 million people living with dementia in the United States (Alzheimer's Association, 2018). It is estimated that 50 million people live with dementia worldwide (GBD 2016 Dementia Collaborators, 2019) causing much of the disability among the elderly (WHO, 2021) and where care is mainly provided by family members (Schulz and Martire, 2004).

2.1.1 Alzheimer's Disease

Alzheimer's disease (AD) is the leading cause of dementia, as well as the one that is most studied (McKhann, 2011). It has been estimated that one in 10 people diagnosed with dementia presents with AD in the United States (Hebert, 2013), while in the UK, it represents 62% of the people with this dementia (Prince, 2014).

The diagnostic criteria for Alzheimer's disease were revised in 2011. An individual can be diagnosed with AD if they present with insidious and gradual symptoms of cognitive deterioration over months and sometimes years, that is evident from the report of family members or the observation by a clinician and that are not the result of another brain condition. This change in their cognitive abilities or behavioural symptoms will lead to a deterioration of global occupational function, including difficulties performing daily tasks (McKhann, 2011).

The diagnosis of AD includes a series of assessments and clinical examinations, as there is no single test that can be used in order to detect this condition. A medical professional would get information about health and psychiatric history, which will focus on possible cognitive and/or behavioural changes (Alzheimer's Association, 2018). Neuropsychological tests, including the assessment of episodic memory, executive functioning (verbal fluency, attention, speed and alternating between sets) language and visuospatial abilities, are an essential part of the diagnosis. Finally, information about the performance of ADLs is required to confirm what impact these symptoms are having on the person (Alzheimer's Association, 2018).

Other supporting tests include blood testing and brain imaging, such as a magnetic resonance imaging (MRI) scan, which can detect changes in regional brain areas allowing the identification of diagnostic patterns (Rossor, 2010).

2.1.2 Vascular and mixed dementia

Vascular dementia (VD) is the second most common form of dementia, thus approximately 17% of those diagnosed with dementia in the UK presents with vascular subtype (Prince, 2014).

The diagnosis of VD can be controversial as there is no clear consensus on diagnosis criteria, and several terms have been described over the past few decades, including vascular cognitive impairment (Hachinski, 2006) and multi-infarct dementia (Hachinski, 1974), among others (O'Brien, 2015). For this reason, in this thesis I will use the diagnostic criteria published in a report by the National Institute of Neurological Disorders and Stroke – Association Internationale pour la Recherche et l'Enseignement en Neurosciences (NINDS-AIREN) International Workshop for research studies (Roman, 1993). The criteria include evidence of cerebrovascular disease on both clinical examination and neuroimaging, variability in disease progression, multiple cognitive domains affected and the presence of specific clinical features, such as gait problems or mood changes (Roman, 1993). People with VD usually present with problems in executive functions, i.e., slow processing of information and difficulties with planning; perseveration in behaviour and depression (Bowler, 2007), shuffling, increasing loss of balance and falls (Bowler, 2007).

Mixed dementia (MD) is the term used when an individual present with both AD and vascular dementia pathologies (vascular and neurodegenerative brain lesions) (Roman, 1993). It is the third most common cause of dementia (10%) (Prince, 2014) and individuals with MD usually present with depression and motor and sensory difficulties (including problems with gait and walking) (Corey-Bloom, 1993). The cognitive presentation includes a deterioration of both verbal fluency and processing speed (Eckerström, 2020). As the disease progresses, people with MD tends to present with a worse global performance, including problems on attention and visuospatial abilities (Dong, 2013), when compared with people with Alzheimer's disease.

In summary, AD, VD and MD are the most frequent forms of dementia, and studies have suggested the possible relation between the three (Chui and Ramirez-Gomez, 2015; de la Torre, 2002; Massoud, 1999). Both vascular dementia and Alzheimer's disease brain lesions are typically seen in both presentations occurring at the same time and interacting in several different ways (Custodio, 2017). For this reason, this thesis will include people with a diagnosis of Alzheimer's disease, vascular and mixed dementia interchangeably. For clarity, each chapter will include a brief description of the participants' inclusion and exclusion criteria that were applied in each study.

2.1.3 Other dementias

Other forms of dementia include frontotemporal dementia (FTD) and posterior cortical atrophy (PCA). I will briefly describe each of these conditions as some of the participants included in Chapters 4, 6 and 7 presented with one of these dementia subtypes.

FTD is one of the less common causes of dementia in older people. However, along with AD, it is the leading cause of dementia in people aged 65 or younger, the so-called early-onset dementia group. Amid the clinical characteristics are the progressive changes in behaviour, language problems and deficits in executive function (Neary, 1998).

FTD encompasses two main clinical subtypes: behavioural-variant FTD (bv-FTD), and primary progressive aphasia (PPA); which is, at the same time, divided between three main variants that are called progressive non-fluent aphasia (PNFA), semantic-variant (sv-PPA) and logopenic aphasia (LPA) (Gorno-Tempini, 2011). The PPA presentations, or also called '*language'* variants, are characterised mainly by deficits on that area. LPA presents with problems repeating sentences and slow speech, defined by word-finding difficulties. Sv-PPA patients present with severe naming problems and severely compromised single-word comprehension. People with PNFA show apraxia of speech as an early symptom and also present with agrammatism in language production (Gorno-Tempini, 2011).

Bv-FTD's recently updated diagnosis criteria consortium comprised the diagnosis confirming the presence of at least three out of six different features, including apathy, disinhibition, perseverative behaviours, loss of empathy, hyperorality and dysexecutive functions (Rascovsky, 2011).

PCA is a progressive neurodegenerative condition that primarily affects the area of the brain that controls visual function, while other cognitive functions such as memory and language are relatively preserved (Crutch, 2012). Recent diagnostic criteria included syndrome-level and disease-level descriptions to support researchers in the identification of this disorder (Crutch, 2017). The syndrome-level description is defined based on core clinical and cognitive characteristics, plus supporting neuroimaging evidence and the disease-level description based on pathophysiological biomarker evidence (Crutch, 2017). The presence of at least three cognitive features supports a diagnosis of PCA, which includes simultanagnosia, oculomotor apraxia, dressing apraxia, space and object perception deficit, among others (Crutch, 2017). All these visuospatial deficits also contribute to problems in text reading (Yong, 2015).

Among with a slow deterioration of their cognitive abilities and/or behavioural changes, PwD gradually lose their ability to carry out daily tasks (Reisberg, 1982). The next sections will introduce the reader with information about ADLs, and how different dementia subtypes present with different problems when completing daily tasks.

2.2 Activities of daily living and theoretical framework

ADLs are those activities that everyone, repeatedly and automatically, performs throughout the day. Each person has their own personal way of doing them, which include the utilisation of different objects, frequency, likes and preferences that have been forged and carried out all their lives. Therefore, they include several different types of abilities such as conceptual knowledge, sequencing of action, and the manipulation needed to achieve the initial goal (Bieńkiewicz, 2014).

ADLs are generally classified within two main categories: basic activities of daily living (BADLs) and instrumental activities of daily living (IADLs). BADLs mainly refers to personal self-care tasks such as eating, dressing, personal hygiene, bathing, grooming and mobility. IADLs are related to more complex activities, such as cooking meals, managing finances, community mobility (including driving a car), using the telephone, managing medications, shopping and doing household chores. BADLs are universally performed as they are related to a person's survival. However, IADLs' participation depends on an individual's personal roles within their home and their community.

ADLs used as outcome measures and predictors of recovery have been central to different research health scenarios such as stroke (Gialanella, 2013), aging (Mendes de Leon, 2003), and hip fracture (Córcoles-Jiménez, 2015). In dementia, clinical drug trials have included ADLs questionnaires to evaluate the effectiveness of medications (Galasko, 2004).

The difficulties that PwD present with when carrying out ADLs have been described using different terminology, including terms such as 'functional impairment' (Desai, 2004), 'functional disability' (Leon and Lair, 1990), 'functional limitations' (Gure, 2010; Verbrugge and Jette, 1994), 'functional cognition' (Wesson, 2016) and 'functional abilities' (Mahurin, 1991). It seems that the large majority of them refer to the same fact, which is well documented – namely, the gradual loss of independence that these individuals face as the disease progresses (Brickman, 2002; Hsiao, 2015; Mioshi and Hodges, 2009) that consequently leads to increased disability (Verbrugge and Jette, 1994).

In light of this, a theoretical framework seems particularly necessary when investigating ADL functioning in dementia. Over the last couple of decades, several frameworks have been proposed to increase the awareness and understanding of disability in different clinical and research settings. The biomedical model, the main focus of which was the study of diseases, assumes that illness is the main factor responsible for an individual's disability (Engel, 1977; Ludwig, 1975). To counteract this purely medically focused model, a social model of disability that concentrates on the barriers that people encounter, rather than on the nature of the physical impairment (Oliver and Barnes, 1998), is then proposed to promote changes at the societal level (Hughes and Paterson, 1997). However, a solely medical or social approach to assessing ADL functioning in dementia will not take into consideration both external and internal aspects of the individual that may contribute to their participation in daily activities.

Other models were described with the aim of integrating both aspects of the medical and the social models. The ‘Nagi’ model proposed a disablement concept that included four main elements, including Active Pathology, Impairment, Functional Limitation and Disability (Nagi, 1965), where disability is seen as the result of the difficulty that an individual experiences to fulfilling their desired roles, both at the personal and social level. While it provided structured definitions for disability, it also set the basis for newer and evolved models, such as the ‘Disablement Process’ model (Verbrugge and Jette, 1994). This model is characterised by different elements that interact during an identified pathway between pathologies, impairments, and functional limitations on disability. Disability is then defined as experiencing difficulties carrying out activities in any area of life due to a health or physical impediment (Verbrugge and Jette, 1994).

More recently, the International Classification of Functioning, Disability and Health (ICF), launched by the World Health Organization (WHO), provided health practitioners and researchers with a new theoretical framework for the organisation and description of health and the definition of disability and functioning (WHO, 2001). The ICF was proposed to encompass components of both the medical and the social model of disability by suggesting that the person’s functioning depends on both their bodily features (medical model) and the individual’s social context (social model). As such, disability is seen as the consequence of interacting components of those elements, i.e., a person’s disability can be explained by the interaction between their health condition and their contextual factors.

The ICF framework becomes a classification when qualifiers are used to record the presence and severity of a problem at the components level. This particular aspect of the model determines a dynamic perspective to approach disability (Jette, 2006), which is extremely important when assessing ADL functioning, as different non-static factors may determine improvement or decline of function. For this reason, and considering that the ICF model is intended to become an international paradigm to measure, classify and investigate disability to improve health care provision (Jette, 2006), I will use this framework to support and guide the research conducted as part of this thesis.

The ICF encompasses two parts: 1) Functioning and Disability and 2) Contextual Factors. Functioning includes three components (aspects of functioning) such as Body Functions and Structures, Activities and Participation. Disability represents the impairments (at the Body level), activity limitations (Activity) and participation restrictions (Participation) which results of the interactive combination between the health condition and the Contextual factors (WHO, 2001) (Figure 2.1).

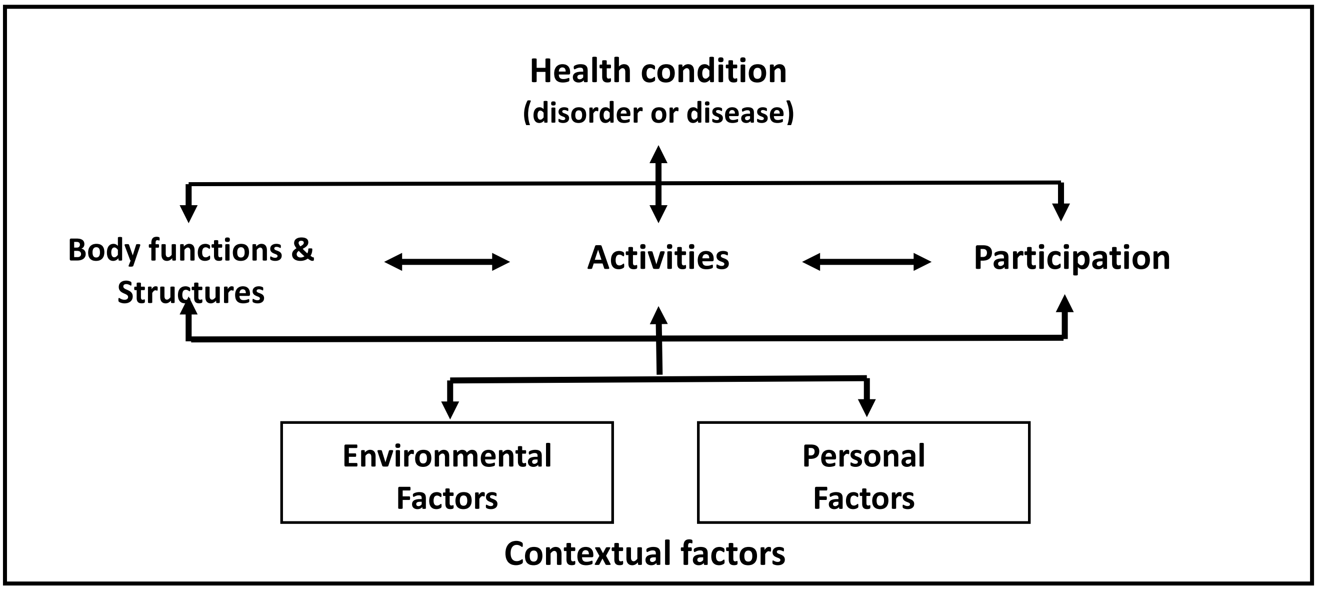

Figure 2.1 *Diagram representing the model of disability according to the International Classification of Functioning, Disability and Health (ICF).*

To simplify the terminology used in my thesis, the components 'Activity' and 'Participation' of the ICF model will be referred in one category, ADLs. To assess the ADLs' component the ICF proposed two qualifiers: the performance and the capacity to perform activities. *Performance* refers to what a person does in their daily life in their current environment and the *capacity*[1] describes the person's *ability* to execute a task or what a person could do, without direct personal assistance or the use of equipment or assistive devices (WHO, 2001).

The second part of the model, namely Contextual factors, is made of two main components: Environmental and Personal factors. Environmental factors not only refer to the physical features of the individual's architectural space but includes the social environment, including attitudes, technology and services, that the person needs to fulfil their lives. Personal factors include gender, age, race, habits, social background and education among other characteristics that could play a role on the person's disability (WHO, 2001). These environmental factors are assessed by a general qualifier, that uses a code that classifies an environmental factor as either a 'barrier' or a 'facilitator' of performance.

The ICF model is particularly relevant in dementia (Hopper, 2007) as it encompasses how the changes in the person's body structures (cognition and behavioural changes in the PwD's brain) affect the individual's participation in daily tasks (ADL functioning). Later in this chapter and throughout the thesis, I will refer to the ICF framework to explain the rationale used in the investigation of ADL functioning in dementia.

2.3 Activities of daily living in dementia

Section 2.1 presented the reader with how information about the PwD's decline in ability to carry out ADLs independently is essential for the diagnosis of dementia according to the DSM-V criteria (American Psychiatric Association, 2013). In addition, ADLs, or errors when completing everyday actions in dementia (Giovannetti, 2002), are an important predictor of the persons' essential care needs

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[1] As mentioned before, the Capacity qualifier refers to the person's ability to execute a task. I favour and will use the term *Ability*, when referring to the Capacity qualifier, to simplify the terminology used in this thesis.

(Gaugler, 2003), institutionalization (Luppa, 2010) and poor quality of life (Chan, 2015).

The problems that PwD experience when performing ADLs have been widely reported over the past 30 years (Bier, 2019; Giovannetti, 2002; Gure, 2013; Hartman, 1999; Jang, 2012; Mioshi, 2007; O'Connor, 2016; Razani, 2011; Takechi, 2012; Wicklund, 2007; Yassuda, 2018). A hierarchical deterioration pattern has been identified in older people (Njegovan, 2001) and people with AD (Carswell, 1993) where the individual initially experiences difficulties within the IADLs' domain, such as managing finances, cooking and driving (Green, 1993), and progress to the failure to complete less complex personal care tasks (Desai, 2004; Green, 1993). More recent studies have shown mixed results (Fields, 2010; Mioshi, 2007); this hierarchical description of the deterioration of ADLs in PwD may not be entirely applicable in the dementia field (Mlinac and Feng, 2016) and may differ with dementia subtypes.

The investigation and understanding of the differences in the performance of ADLs among dementia subtypes are important to recognise the help these individuals and their families may need, and it is a first step needed in order to develop successful interventions to promote PwD's performance of daily activities.

Studies showed that everyday activity impairment in AD is associated with behavioural and cognitive changes (Teri, 1989) as well as deficits in executive function (Boyle, 2004; Royall, 2004). Using a naturalistic action approach to assess everyday problems in dementia, a study found that people with AD tended to abandon the task earlier than people with VD, and this may have been associated with problems related to memory and executive functions (Giovannetti, 2006). A study showed that people with AD have stopped driving due to safety problems (Dubinsky, 1992) and they reported having difficulties with shopping and managing their finances (Gauthier and Gauthier, 1990).

Relating to this, several studies have described the variances that exist in performances of ADLs across dementia subtypes (Jang, 2012; Mioshi, 2007; Wicklund, 2007). For example, one study investigated the differences that exist in ADLs' performance between people with AD and those who present with bv-FTD

(Mioshi, 2007). It was found that this FTD group had more difficulties than the AD group, even when assessing BADLs, where bv-FTD showed worst scores on dressing, hygiene and eating a meal. The bv-FTD group also showed the worst performance on IADLs in comparison with AD, with clear problems regarding managing medication, cooking, using the telephone and household chores tasks (Mioshi, 2007).

Covering the same area and including other types of dementia, researchers have analysed the differences that patients with FTD, including the language variants, and AD present when performing ADLs (Jang, 2012). When comparing these groups, it was found that the AD group had the worst level of functioning while LPA had the best performance, followed by the PNFA group. However, these differences were not significant when they took account of the total scores of their ADLs' measure. Nevertheless, when analysing longitudinally changes, they found that PNFA patients had a greater drop in IADLs and BADLs, which is consistent with what had been previously shown (Mioshi and Hodges, 2009).

People with PCA also presents with greater difficulties when performing basic ADLs than those people with Alzheimer's disease (Ahmed, 2020). In addition, the ability to use the phone, making a hot drink and pay bills was also shown to be more affected in the case of those with PCA (Shakespeare, 2015). In a single case study using a performance-based assessment, the participant had problems completing several basic and instrumental ADLs, in particular using everyday objects (Bier, 2019).

This current section aimed to describe how dementia affects ADL functioning and how different presentations can affect different types of activities. The next section will describe the different assessments that can be applied to detect these problems and how the different methods used provide different types of information.

2.4 Identification of changes in activities of daily living in dementia

The identification of problems in ADLs in PwD have relied on the use of two main types of approaches, informant-based and performance-based assessments (Carswell, 1993; Lima-Silva, 2015; Mioshi 2009; Nielsen and Wæhrens, 2015; Oakley, 2003; Park, 1994). The most common way of assessing ADLs is the use of *informant-based questionnaires* or *interviews*, where the information is obtained from the report of the family members (Camino and Mioshi, 2017) and is based on the carer's appraisal of ADL performance.

A more recent standardised method of assessing the ability to perform activities is through the use of *performance-based assessments,* which entail direct observation. Using this technique, the PwD is required to perform live everyday tasks (e.g., prepare a hot drink) and the observer rates their performance according to each of the assessments' instructions (Camino and Mioshi, 2017).

A third method of obtaining information is by using *self-report questionnaires*. Although they are easy to administer and are helpful when there is no carer available and direct observation is not possible (Mlinac and Feng, 2016), there is a large body of evidence regarding PwD's poor level of insight into their ADLs limitations (Desai, 2004; Jekel, 2015) and how this is affected by the PwD's cognitive impairment (Miller, 2013). Self-report instruments are seldom used in the dementia field.

2.4.1 Informant-based questionnaires

Informant-based questionnaires capture information about the performance of daily tasks, and, as explained in Section 2.2, the performance refers to what a person does in their daily life (WHO, 2001). This type of assessment has proven to be a successful way of measuring longitudinal changes while the disease progresses. They can replace the cognitive assessment when the individuals are not fit enough to do them and they are used cross-culturally (Lorentz, 2002).

The main advantages of these instruments are how easy they are to use, their affordability and the reduced need for administrator training when compared with performance-based instruments (Desai, 2004). However, as mentioned earlier, the use of this method is dependent on someone who knows the PwD well, such as a carer or family member. This highlights one of the disadvantages of this approach as the information gathered may be influenced by the carer's understanding of the patient's difficulties (Mlinac and Feng, 2016).

2.4.2 Performance-based assessments

In contrast to the method described above, the performance-based assessments involve the individual performing day-to-day tasks that are carried out in a natural or controlled environment (Camino and Mioshi, 2017). This type of assessment allows clinicians and researchers to directly and objectively evaluate the PwD by capturing information about the person's abilities to complete a task. Following the ICF model explained in Section 2.2, performance-based assessments would essentially evaluate what an individual could potentially do (WHO, 2001).

Performance-based assessments are not free of limitations. Although direct-observation measures can supply objective information about the patient's ability to perform daily activities (Desai, 2004), they commonly entail more training which means further expense and administration time (Sikkes and Rotrou, 2014) in contrast to other types of measures (Mlinac and Feng, 2016).

This section described the different methods that can be applied to identify changes in ADL functioning in PwD and their potential benefits and disadvantages. Performance-based assessments contribute to our knowledge of what the person is actually capable of. However, this is not still enough to know if the individual actually participates and completes tasks in her or his own environment (Mahurin, 1991). For instance, to obtain a clear picture of the PwD's ADL functioning, scientific evidence suggests that different methods should be applied when collecting information on ADLs (Mlinac and Feng, 2016) to investigate if there is a gap between the performance (using informant-based questionnaires) and the ability to perform daily tasks (via the use of performance-based assessments) in PwD.

As the performance of ADLs depends on a number of different specific abilities such as physical, perceptual, emotional and cognitive skills (Mlinac and Feng, 2016), the next section will explore and describe what is the role of different factors in the PwD's ADL functioning and how these factors are described in the ICF framework.

2.5 Factors associated with performance of daily activities among people with dementia

There are several different factors that have been associated with the performance of ADLs in PwD, and for the purposes of this thesis they will be grouped in two main categories: intrinsic dementia factors and extrinsic factors. Following the ICF framework, the intrinsic dementia factors, including changes in cognition and behaviours, are part of the Body Functions and Structures components of the ICF, while the extrinsic ones, including the physical and the human environment are part of the Contextual factors. I have mapped the rationale of my thesis against the ICF model (Figure 2.2).

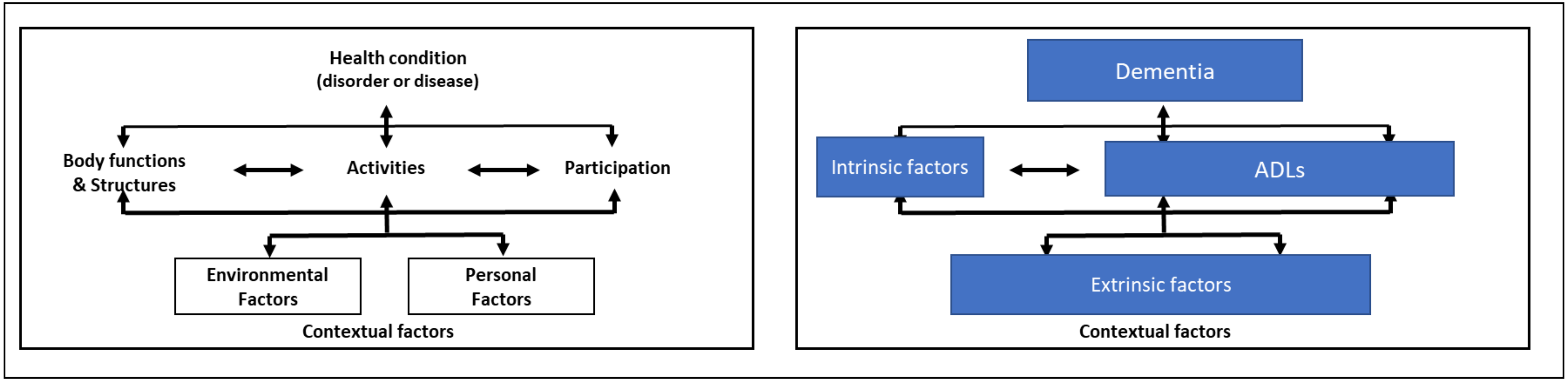


Figure 2.2 *Thesis factors mapped on to the International Classification of Functioning, Disability and Health (ICF) framework. On the left, the ICF's diagram, while the figure on the right includes examples of the factors that will be studied in this thesis and how they fit the ICF model. Dementia is the health condition which is the focus of this thesis that produces intrinsic factors, such as cognitive and behavioural changes. ADLs refer to the ICF components 'Activity and Participation' as explained in Section 2.2. The ICF so-called Environmental factors' component comprises the extrinsic factors (both the physical and the human environment) proposed for this thesis.*

2.5.1. Intrinsic dementia factors

Intrinsic dementia factors refer to those inherent characteristics of the disease which are generated by the damage at the neuronal level and that produce certain symptoms. The most common intrinsic dementia factors are the difficulties with cognitive functions and behavioural changes.

The investigation of everyday functioning in dementia has traditionally been dedicated to the investigation of the relationship between ADLs impairment with different cognitive functions (Bennett, 2002; Farias, 2013; Martyr and Clare, 2012; Perry and Hodges, 2000; Razani, 2011).

Problems with global cognition, including memory, have been associated with poor performance of IADLs (Barberger-Gateau, 1992) and the person’s ability to multitask (Giovannetti, 2012). Impaired memory was also found to affect PwD’s abilities to complete shopping tasks, while problems with episodic memory were associated with the person’s difficulties when managing finances (Razani, 2011). When completing familiar but complex daily tasks, people with AD made greater errors than healthy adults, and long-term memory was the main predictor of these problems (Ramsden, 2008).

Visuospatial function includes the identification of a stimulus such as objects and their location, and some activities related to this function include reading, being able to discriminate form and colour and being able to use visual strategies, indicating involvement of the visual association cortex (Mendez, 1990). Studies into the relationship between ADL performance and visuospatial function in people with AD showed a significant relationship between the two, and visuospatial function was the main predictor on basic task performance (Perry and Hodges, 2000). Loss of visuospatial abilities was also found to be associated with poor performance in grooming tasks (Freilich and Hyer, 2007).

In a meta-analysis, the relationship between executive functions and ADLs in people with AD was investigated (Martyr and Clare, 2012). Thus, executive functions were shown to have a stronger association with everyday tasks limitations, although the results of different studies (Bennett, 2002; Boyle, 2004) are still controversial, showing only a moderate relationship between the two components (Martyr and Clare, 2012). Attention has been associated with poorer basic ADLs outcome, especially bathing (Freilich and Hyer, 2007).

Behavioural symptoms and ADLs in dementia have also been largely investigated (Mioshi and Hodges, 2009; O'Connor, 2016; Yassuda, 2018). Apathy is the most common behavioural symptom reported in dementia (Mega, 1996). It was associated with decline in ADL functioning in people with bv-FTD (O'Connor, 2016; Yassuda, 2018) and VD (Zawacki, 2002). In addition, apathy is a significant contributor to the change in the performance of daily tasks in people with AD (You, 2015) especially of basic ADLs (Boyle, 2003), such as basic hygiene activities (Yeager, 2008).

The study of different intrinsic dementia factors is a very well-established approach when investigating the causes of ADL impairment in PwD (Desai, 2004; Lechowski, 2003; Royall, 2007). However, intrinsic dementia factors do not solely explain the problems that PwD experience when performing ADLs. This is also confirmed by the ICF classification, where the interaction between the person's health condition and the external environment in which they live, determines their ADL performance. As such, task performance is seen as a wider concept which merits the inclusion of both intrinsic and extrinsic factors to explain everyday functioning. This is why there is a clear need to open the investigation of the role that extrinsic factors play in ADL functioning.

2.5.2 Extrinsic factors

Extrinsic factors refer to those external elements that can modify an individual's behaviour or performance, and as such, could affect the way a PwD completes ADLs. One of the most important contributions of the ICF framework was the introduction of the Contextual factors to the disability model, which play a significant role on the individual's participation in daily tasks. These Contextual factors include both the Environmental and the Personal factors, as explained earlier in this chapter. The ICF defines the component Environmental factors' as those that 'make up the physical, social and attitudinal environment in which people live and conduct their lives' (WHO, 2001). However, for clarity, this thesis will use the term *physical environment* to refer to the physical built setting with architectural characteristics where the PwD completes daily tasks i.e., the different rooms of their house. For the social environment, which includes the Support and Relationships' chapter in the Environmental factors' section of the ICF framework, I will use the term *human environment*, which is represented by the primary carer. The attitudinal environment is represented by the Attitudes' chapter of the ICF model, which is beyond the scope of this PhD work.

This section will present the current evidence on how extrinsic factors, such as the physical and the human environment, affect task performance in dementia.

Physical Environment

The person's physical environment is the area or setting where the PwD performs a task.

The environment has been shown to affect an individual's performance (Lawton, 1983; Verbrugge and Jette, 1994). Historically, the interest in the environment was firstly triggered by the need of older frail adults to remain living independently in their own homes (Branch, 1987; Provencher, 2009; Provencher, 2012). Thus, their inability to perform ADLs was explained by studying the differences that arose when matching the demands of a particular environment with the older adult's current abilities (Verbrugge and Jette, 1994).

Gradually, over time the focus has been shifted to the dementia field, and how the environment may play a part on PwD's everyday functioning. Moreover, since the majority of PwD live in their own home (Prince, 2014), the living environment has become an essential aspect in the management of the dementia (Gitlin, 2003).

Many dementia and carer websites promote the idea that the PwD benefits from a familiar and tidy environment. However, the evidence in this area is scarce and controversial. A review on the influence of the environment when assessing independence in ADLs (Bottari, 2006) revealed that the individuals performed better at their homes rather than at the clinic when using performance-based ADLs measures. However, this conclusion could not be completely representative for PwD, as they could only analyse the results of five publications, and of those, only two studies involved PwD (Nygard, 1994; Hoppes, 2003). These two experimental studies revealed contradictory results, where no significant differences were found when people with suspected dementia performed ADLs at home or in the clinic (Nygard, 1994). On the contrary, PwD had better performance at home, but this difference was only significant in relation to motor skills, rather than cognitive abilities (Hoppes, 2003). Thus, there is a clear need for more studies that can help to address this matter.

A more recent review comparing the performance of IADLs between home and clinic settings (Provencher, 2009) analysed the factors that may explain performances on both environments. The authors found that among the environmental features that could have explained IADL performance were the equipment used in the clinic setting and the familiarity of the participants with each of the settings. They concluded that those participants who performed better at home were actually living in their own home, while those who performed better at the clinic setting were staying at the hospital due to a rehab programme (Provencher, 2009). In this review, none of the studies included PwD, and the type of equipment used was not specified. In the same line, a study conducted with frail older adults, found that they performed cooking tasks better at their own home, and the two factors that contributed to this were familiarity with the environment and the participants' executive functions (Provencher, 2012).

Environmental modifications, such as prescribing adaptations and equipment, or modifying the layout of the individual's home, are a goal standard approach when working with PwD (van Hoof, 2010) and psychosocial interventions that feature them have been tested in dementia (Dooley and Hinojosa, 2004; Gitlin, 2001; Graff, 2006). While the benefits of those interventions were prominent, the specific changes made to the environment were not fully reported. Consequently, the role of the environment, and in particular, the benefits of changing specific aspects of the setting in which the PwD performs tasks, is not fully known.

Human environment

Family members are the main providers of the care and support the PwD needs (Schulz and Martire, 2004), and the evidence shows that the carer's personal-related factors have an effect on the way the PwD completes daily tasks. For example, age, gender and relationship with the PwD as well as the carer's educational level have been associated with ADL functioning in the past (Dassel and Schmitt, 2008; Conde-Sala, 2013). Aspects related to the carers' wellbeing, such as mental health-factors, have also been shown to affect the performance of ADLs of the PwD (Conde-Sala, 2013). For example, PwD's ADL performance was poorer when their carers' level of burden (Conde-Sala, 2013) and depression (Argüelles, 2001) were high.

The way carers support the PwD when they perform daily tasks could be a potential factor that contributes to the performance of ADLs in PwD. This is also included in the ICF, which contains a domain called Support and Relationships, which is part of the Environmental factors' component. This domain, refers to the people or animals that provide physical or emotional support, including assistance in the home or daily activities.

Providing support to a PwD can be described in different ways and studies have look at how health care professionals, such as occupational therapists or nurses, provide verbal assistance to people with brain injury (Gagnon-Roy, 2021) or dementia (Wilson, 2012) during certain tasks. Another approach is based on the strategies that carers use on a daily basis to support their family members (Hinrichsen, 1994) and were defined as management styles (Corcoran, 2011; de Vugt, 2004; Hinrichsen, 1994) in an attempt to identify how the carers' daily habits, strategies and attitudes when supporting PwD can change their behaviour (Fishbein, 2008).

A commonly used classification of carers' management styles includes three styles that carers have when dealing with dementia-related problems. For example, *criticism style*, describes efforts to manage the patient by yelling, criticising, threatening, and other related behaviours. *Active management style* includes activities to assist, engage, stimulate, and associated behaviours primarily directed toward modifying the environment or daily routine. Finally, *encouragement style* includes efforts to praise the patient, getting him or her to discuss feelings or look on the bright side of things, and similar efforts (Hinrichsen, 1994).

The scientific literature revealed that criticism appears to be the most prominent style, reducing PwD's quality of life (Gitlin, 2014), increasing carer's burden (Hinrichsen, 1994; Leggett, 2019; Lim, 2011) and frustration levels (Leggett, 2019) while also increasing carer's use of home and social services (Leggett, 2019). Encouragement style, on the other hand, has been associated with carer's feeling of gain (Lim, 2011) denoting a positive experience.

A second way to provide support to the PwD is by providing direct assistance during the performance of a daily task. Even though family members are the main providers of the support needed by the PwD, they may lack the appropriate knowledge or information to deliver the type of care the PwD may need (Reinhard, 2008). Therefore, carers may compensate for the difficulties that the PwD daily experiences (Desai, 2004) ultimately affecting their performance of ADLs. However, studies into the type of assistance provided by carers when the PwD performs a task are rare and have mainly measured the amount of general assistance they provide (Amato, 2021; Riffin, 2017) instead of how they have provided it. In addition, the research has mainly focused on investigating the role of dementia intrinsic factors in ADL functioning, leaving a clear gap in how the carer can support or hinder participation in daily tasks.

This section described how intrinsic and extrinsic factors are associated with ADL functioning in PwD. The support a carer provides, seen as a contextual factor that affects disability in dementia, may have a potential role in facilitating or hindering ADL functioning. Undoubtedly, participation in ADLs as framed by the ICF model, depends on all these different components working together at the same time. The next section will introduce the reader to how these factors may be related to the gap between performance and ability to perform daily tasks in dementia.

2.6 Gap between the performance and the ability to perform ADLs in dementia

As mentioned in Section 2.2, in 2001, the WHO proposed and endorsed the ICF framework in an effort to recognise the importance of gathering individuals' information about their performance of activities and their potential abilities to carry them out, in order to make the necessary adjustments to promote people's participation in daily tasks and to reduce disability despite their health condition.

In dementia, a way to identify this gap has been through the investigation of the discrepancies between the carers' report of the PwD's performance of daily tasks and the observation of the PwD's ability to perform them. A body of evidence has emerged showing carers underestimating or overestimating the PwD's ability to complete ADLs (Bressan, 2007; DeBettignies, 1993; Doble, 1999a; Karagiozis, 1998, Loewenstein, 2001; Mioshi, 2009; Zanetti, 1999; Zimmerman, 1994). The evidence also showed that carers' wellbeing, such as depression and carer burden affected their appraisal of the PwD's ability to complete daily tasks (Argüelles, 2001; Loewenstein, 2001; Zanetti, 1999).

The role of extrinsic factors in the gap between performance and ability to perform ADLs has not been thoroughly investigated to date. Interestingly, agreement between performance and the person's ability to perform a task may be associated with the extrinsic factors that are present in ADL functioning in dementia: the environment and how it supports or undermines participation in ADLs, and the carer's level of understanding in relation to the support the PwD needs to participate in daily tasks.

Furthermore, there is a lack of investigation of the strategies and the type of assistance that carers use to support ADLs and how they could affect what the PwD does in their daily routine. In fact, the support that carers provide daily may contribute to increase the gap between performance and the ability to perform ADLs, and, to the best of my knowledge, no published studies in English have been identified to date about how the support (including use of strategies and types of assistance) provided by family carers affects ADL functioning in PwD.

An integrated investigation of how all these extrinsic factors, which are potentially modifiable, affect the performance and the ability to perform daily tasks, may lay the foundations for the development of novel non-pharmacological interventions to support ADL functioning in PwD. Following the ICF parameters and within the context of this thesis, a PwD may present with the ability to complete a task, but they do not perform it daily. By investigating the different factors associated with ADL functioning, potential adjustments could be made to reduce the gap between ability and performance.

2.7 Thesis aim and research questions

This thesis aims to understand the gap that exists between performance and the ability to perform ADLs among PwD by investigating different factors that are known to be involved when an individual carries out such activities.

The specific research questions are:

- What is the role of the physical environment on PwD's ability to perform daily tasks? How does the environmental clutter contribute to the ability to complete ADLs in PwD? (Chapter 4).

- What is the contribution of intrinsic and extrinsic factors to the changes in ADL performance in PwD? (Chapter 5).

- Is there a discrepancy between the carer's report of ADL performance and the PwD's ability to perform ADLs? What are the factors that contribute to that discrepancy? (Chapter 6).

- What are the different types of assistance provided by the carer when the PwD completes a task? Why carers assist the PwD and what are the consequences of using different types of assistance? (Chapter 7).

Chapter 3: Methodology and Study Design

3.1 Foreword

My PhD thesis was embedded in a larger research study called 'Interaction of intrinsic and extrinsic factors underpinning functional disability in dementia (TASKed)' which was sponsored by the University of East Anglia. TASKed was a four-year long study funded by the Alzheimer's Society in the UK, and led by Prof Eneida Mioshi, the primary supervisor of this thesis. My PhD was funded by the Faculty of Medicine and Health Sciences of the same University and benefited from some data collected from the TASKed study.

In this chapter, I will mention the research paradigm adopted and I will explain the rationale for using a mixed-methods approach with a description of each study design. I will then describe in detail ethical considerations, participants included in this thesis and procedures that were in place to complete recruitment and data collection. I will also mention the instruments used and data analyses carried out.

Each individual chapter explains in detail the sample size needed for each study, the treatment of missing data and the data analyses carried out.

3.2 Research paradigm and rationale for mixed-methods approach

To examine this topic, I adopted a pragmatic philosophical approach (Morgan, 2007), acknowledging the possibility of different truths (Creswell, 2003), and valuing the different types of knowledge generated through using quantitative and qualitative methods (Tashakkori and Teddlie, 1998). Mixed-methods research is a methodological approach where scientists combine both quantitative and qualitative research methods to extend the understanding of the topic being investigated (Johnson, 2007). The use of mixed-method approaches in research has gained recognition as they can address complex research problems (Creswell and Plano Clark, 2011).

The research questions proposed in this thesis to address the dynamic approach to disability suggested by the ICF classification (WHO, 2001) (Section 2.2) revealed the need for a varied range of approaches to allow for a successful analysis and interpretation of the role that the different intrinsic and extrinsic factors have on the PwD's performance of daily tasks. As such, the use of a mixed-methods approach, explanatory sequential design (Creswell, 2003) was thought to be the most suitable way to undertake the research studies. The explanatory design includes a two-phase model where a qualitative study is conducted to develop further knowledge that was built upon quantitative data (Creswell, 2003). This approach will allow me to synthesise the analysis of both phase one and phase two to build on the ICF's definition of disability (WHO, 2001) and apply it within the context of dementia care. Thus, the results from each study are analysed separately. The integration of both phases will be presented at the synthesis point (Section 8.3) using a narrative synthesis approach (Lisy and Porritt, 2016).

3.3 Study's Design

This thesis' research questions required a combination of different methodologies to be implemented in this thesis. Three main designs were then used along four chapters: experimental, cross-sectional and qualitative designs.

Chapter 4 is based on an experimental design where an independent variable (in this case, the environment) was decluttered. In addition, a within-subjects design (also known as repeated measure design) is used to compare the same participants' outcome measures between two different settings.

Chapters 5 and 6, are both based on a cross-sectional, exploratory design. This design was proposed to make inferences about possible relationships between the variables studied. The exploratory design was proposed due to the lack of evidence on a particular topic, which will be explained further in the corresponding chapters.

Chapter 7 uses a qualitative approach to explore and identify the types of assistance provided by carers during the performance of a daily task. This study used an interpretivist paradigm to conduct secondary analysis of video-recorded observations to examine participants’ experiences (Mertens, 2005). Its main aims were to interpret meaning from direct observations in order to describe and explore why carers of PwD support them during task performance. The criteria for rigor (credibility, transferability, dependability, confirmability and reflexivity) in qualitative research (Lincoln and Guba, 1985) has been applied during the research presented in this chapter as is explained in detail in Chapter 7.

An overview of the above-mentioned chapters is provided in Figure 3.1.

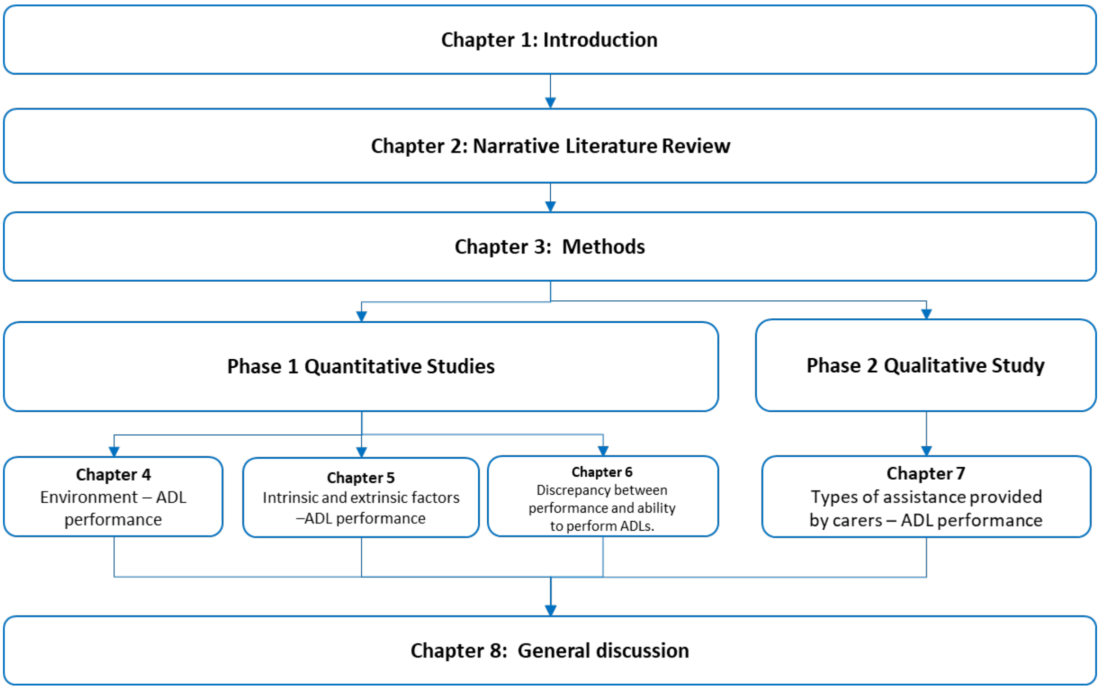


Figure 3.1 *General overview of the structure of the thesis and study’s design.*

3.4 Ethical Considerations

3.4.1 Ethics approval

Ethical approval for all the studies that were completed as part of this thesis, has been gained through the TASKed project which was approved by the National Health Service (NHS) Health Research Authority (HRA), Research Ethics Committee (REC) (IRAS ID 199002; 16/LO/0544). A copy of the Letter of Approval can be found as a supplementary file (see supplementary material, Chapter 3, Section 3.4.1, Ethical Approval Letter) in the Appendices.

3.4.2 Participant Consent

Information about the study was provided using the participant information sheets, which are included as a supplementary file (see supplementary material, Chapter 3, Section 3.4.2, Participant Information Sheets) in the Appendices. These pages explain in detail what the research activities were, the procedures involved and potential benefits or risks linked to them. Participants were free to withdraw at any time, without having to give a reason for doing so. Each dyad received a copy of the participant information sheets before the research visit, so the PwD and their carers had time to read detailed information beforehand.

In addition, during the home visit for data collection, additional time was given to discuss the research activities and to answer questions that may have arisen. Afterwards, both the PwD and their carers were asked to provide written consent, in order to be able to proceed with the assessments. A copy of the PwD’s consent form is included as a supplementary file (see supplementary material, Chapter 3, Section 3.4.3, Consent Forms) in the Appendices.

Considerations about the participants’ capacity to consent to the study were in place. Thus, the assessment of the individuals’ capacity to consent was completed before proceeding with the signing of the consent forms. In the case that a participant lacked the capacity to consent to the project, the family was consulted on what the participants' wishes would have been in regard to her/his participation on the study. These procedures are in line with the UK HRA guidelines on consent to research activities.

3.5 Participants

Participants included in this thesis were PwD living in the community and their carers. Carers were family members or friends who could provide with information about the PwD's personal characteristics, daily routine, ADL performance and behavioural changes. Each PwD and their carer formed one dyad.

3.5.1 Inclusion Criteria

Person with dementia

Participants had a clinical diagnosis of dementia and were living in the community. They had to be fluent in English and had to be willing to be video-recorded during some assessments. They had to be older than 40 years old and younger than 90. They also had to have a carer (either a family member or a friend) who provided unpaid support with ADLs for at least seven hours per week.

Dementia diagnosis was obtained through copies of letters of diagnosis made by consultant neurologists or psychiatrists. This process was consented to by the participant and approved by the HRA and the REC.

Carer

Carers were either family members or friends who provided unpaid support to the PwD for at least seven hours a week. They had to be able to give reliable information about the PwD's cognitive and behavioural changes as well as demographic information and ADLs. Carers had to be older than 18 years old, be fluent in English and they had to be willing to be video-recorded during one activity.

3.5.2 Exclusion Criteria

Person with dementia

PwD were not included if they had a history of additional major psychiatric disorder (e.g., schizophrenia, bipolar disorder) or had a dementia secondary to head trauma, alcohol misuse or brain tumour. They were also excluded if they had a significant medical illness that would have likely interfered with the research activities and were unable to respond to single step commands.

Carer

Carers were excluded if they did not provide any support or help to the PwD or received any formal payment for the support they provided.

3.5.3 Participant Recruitment

Participants included in my thesis were recruited via the TASKed study, which had several different sources of recruitment:

- Norfolk and Suffolk NHS Foundation Trust (NSFT)
- Cambridgeshire and Peterborough NHS Foundation Trust (CPFT)
- Join Dementia Research (JDR) website
- General Practitioner (GP) practices

The NHS is the UK National Health Service that provides British residents to free health access. Each NHS trust has a research and development department that support the development of research studies by connecting individuals to research teams across the UK. The TASKed team worked in close collaboration with the research and development department at the NSFT, located at the Hellesdon Hospital, in Norwich. This department helped identify potential participants and invited them to participate in TASKed, according to its inclusion and exclusion criteria.

Join Dementia Research (JDR) website is an initiative launched by the National Institute of Health Research (NIHR) where PwD and their carers are invited to sign up to support research studies across the United Kingdom. The website www.joindementiaresearch.nihr.ac.uk connects volunteers with studies on dementia across the UK, facilitating the recruitment of potential participants to different research projects. The TASKed study joined the JDR website and all the team members completed a training session before having access to the system. When a member of the TASKed study identified a candidate via JDR, the candidate was approached to discuss their suitability and interest in participating in the research project.

GP practices were also included as participant identification centres, and as such, they identified people who meet the TASKed eligibility criteria. When a participant was identified, their contact details were uploaded to a central mailing system (Docmail) that sent out invitations to the potential participants. They were asked to contact the TASKed team, using different methods, if they were interested in taking part in the research activities.

All these recruitment strategies were approved by the HRA and the REC.

3.6 Data collection

Three different methods of data collection were used in this thesis and were targeted at answering the different research questions that were proposed in Section 2.7. They included the use of a standardised performance-based assessment of ADLs (included in Chapters 4 and 6); a non-standardised observation of ADLs with carer support (included in Chapter 7) and the use of informant-based assessments and questionnaires that were included in different chapters of this thesis. All these instruments will be described later in this chapter.

I collected a very large proportion of the PwD’s assessments included in this thesis and the carer-related data, which were used in all the studies. Some of these data were collected with the help of the TASKed project team. I was solely responsible for the collection of all the performance-based assessments (Chapters 4 and 6; n=129) and the research activities conducted for Chapter 7 which included the non-standardised observation of a task completed by the PwD with carer support. Data collection methods, including settings and procedures, will be explained in detail in each corresponding chapter.

3.6.1 Procedures for data collection

All participants included in this thesis were initially contacted by a member of the TASKed team. During the TASKed project data collection, a first initial visit was carried out at the participants’ own home, where the consent process took place and where the studies included in this thesis were explained in detailed. During this visit, assessments that were part of the TASKed protocol were completed. Both carers and the PwD were interviewed alone in the majority of the visits. Some carers and PwD requested to be present during the research activities.

For those participants who expressed an interest in completing the additional studies that were part of my PhD, when consenting to the parent study, the TASKed team member leading the data collection informed me via email. I then contacted each participant on the phone to explain the projects further. If the participants were still happy to complete them, I arranged a visit within six months of the completion of the assessments (TASKed project data collection). More detailed information on the procedures is given in each corresponding chapter.

Figure 3.2 describes the procedures for data collection for the studies conducted as part of this thesis.

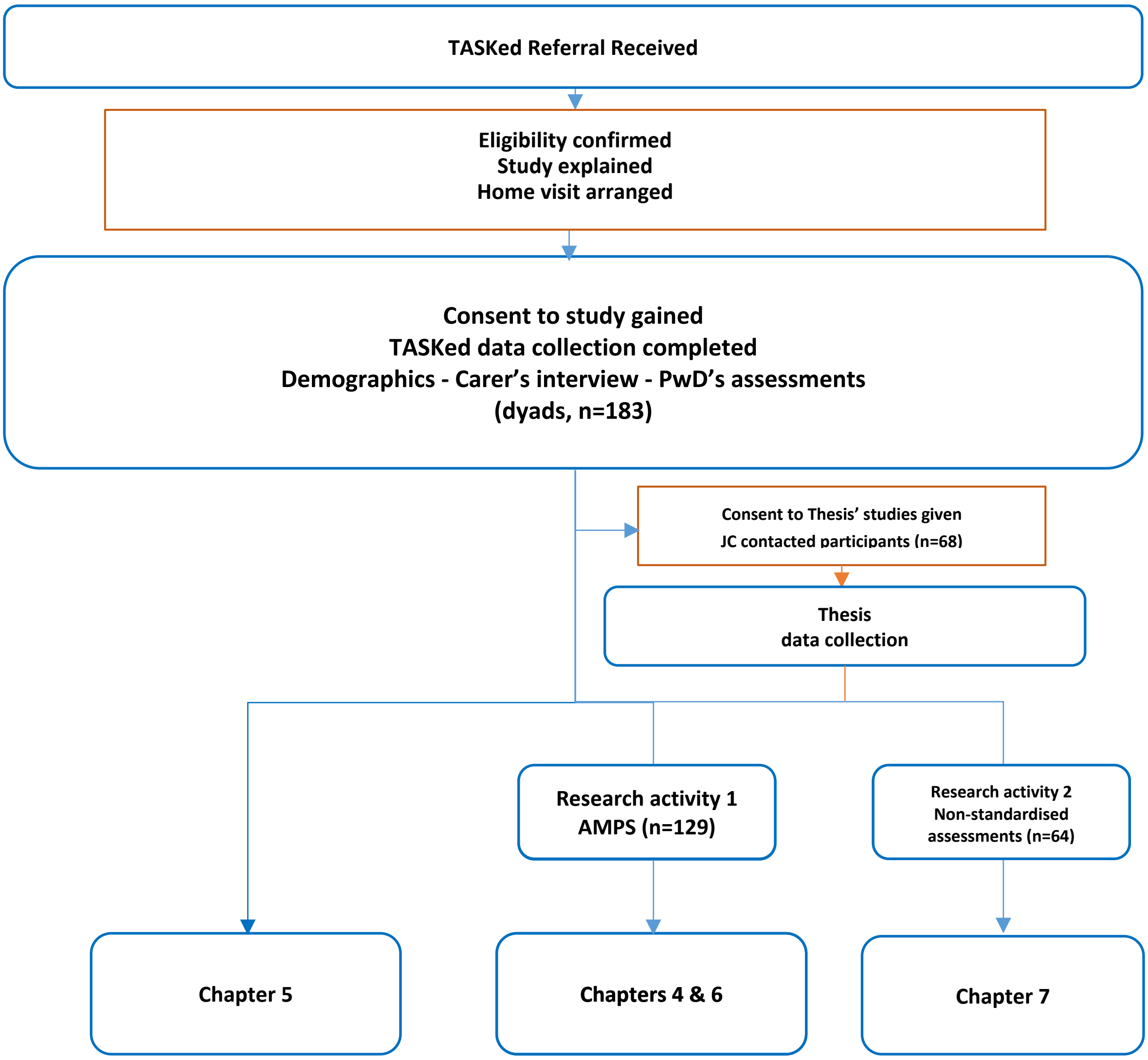


***Figure 3.2** Procedures for data collection*
AMPS (Assessment of Motor and Process Skills) is the performance-based ADL assessment used in this thesis. Orange boxes represent actions taken to ensure ethical procedures and participant eligibility criteria.

3.7 Instruments

The instruments used in this thesis assessed the PwD's characteristics and changes related to the disease – intrinsic dementia factors, as well as the carer and the physical setting – extrinsic factors. As such, they were categorised in different domains: ADLs, dementia stage, cognition, behaviour, environment, carer's management styles, carer's symptoms of depression and anxiety. Standardised questionnaires and assessments were used for all these categories (Table 3.1). All these instruments were originally selected by the primary supervisor, who developed and proposed the protocol as part of the TASKed study.

A value of Cronbach’s α, which is the most common measure of internal consistency used in health sciences and education (Tavakol and Dennick, 2011), is provided for each instrument, as well as a measure of its reliability. Internal consistency, or validity, expresses the capacity of the instrument to measure what it is intended to measure. Reliability refers to the ability of the questionnaire to consistently obtain the same results when repeatedly used (Bruton, 2000).

Table 3.1 summarises the list of instruments used in this thesis.

Table 3.1 Summary of the instruments used in this thesis.

Name of instrument	Assessment method	Domain Assessed	Included in chapter
Assessment of Motor and Process Skills (AMPS)	Performance-based	Ability to Perform ADLs	4 & 6
Disability Assessment for Dementia (DAD)	Informant-based Interview	Performance of ADLs	4, 5 & 6
Frontotemporal Dementia Rating Scale (FRS)	Informant-based Interview	Disease progression/ dementia Stage	All
Addenbrooke's Cognitive Examination-III (ACE-III)	Cognitive Screening Test	Global Cognition	4 & 5
Cambridge Behavioural Inventory-R (CBI-R)	Informant-based Self-complete	Behaviour	5
Home Environmental Assessment Protocol (HEAP)	Observation of the Home Environment	Environment	4
Dementia Management Strategies Scale (DMSS)	Informant-based Self-complete	Carer Management Styles	5 & 6
Patient Health Questionnaire (PHQ-9)	Informant-based Self-complete	Carer Depression	6
General Anxiety Disorder (GAD-7)	Informant-based Self-complete	Carer Anxiety	6

In addition to these questionnaires, demographic information was collected using carer's questionnaires including information about the PwD's age, gender, level of education, length of symptoms, marital status and living situation.

Information about the carer's age, gender, level of education and relationship with the PwD was also asked for.

Activities of Daily Living (ADLs)

To assess ADLs, two main instruments were used: a performance-based assessment and an informant-based interview:

Assessment of Motor and Process Skills (AMPS) (Fisher, 2012) was used to assess ability to perform ADLs.

The AMPS is an international and well-validated performance-based assessment. It consists of the observation of two ADL tasks that can be chosen from a pool of more than 100 cross-cultural standardised activities.

One important rule of the AMPS is that the PwD has to be familiarised with the activities that are going to be performed, and, therefore, assessed (Fisher, 2012). That is why, as part of this assessment, I had to have a brief interview with all the participants that were included in Chapter 4 and Chapter 6 before completing the assessment. During this interview, the dyad and I selected the tasks that the PwD normally completed in their daily routine and that matched the tasks options of the AMPS.

After the observation is completed, the scoring is transferred to a computer programme that converts the raw scores into linear measures using a Rasch model approach (Fisher, 2012). The AMPS software then returned two main results in logits that arise from the combination of the PwD's level of skills' performance (level of difficulty of the different skill items), task's level of difficulty and assessor leniency (Fisher, 2012). The software also takes into consideration the age and the diagnosis of the person assessed. For the purpose of this thesis, I have selected the option 'dementia unspecified' for all my participants.

The two main results are given by the software: the Motor and the Process Skills scores. Due to the nature of the dementia itself, the Process Skills scores have been used as the main outcome for the analyses run (Chapter 4 and Chapter 6). The

AMPS Process Skills' cut-off is 1.00, which indicates the lower limit of competent task performance in age-matched controls. In older adults with cognitive impairment, the AMPS has shown excellent test-retest reliability (Motor: r=0.88 – 0.9; Process: r=0.86 – 0.87) (Doble, 1999b). The AMPS has shown excellent internal consistency for both the Motor (Many-faceted Rasch equivalent of Cronbach's alpha was *R*=0.92) and the Process Skills scores (Many-faceted Rasch equivalent of Cronbach's alpha was *R*=0.91) (Fisher, 2012).

Only occupational therapists (OT) can conduct the AMPS and a five-day-course is needed in order to get AMPS calibration and the computer software that processes the information obtained during the assessment. Assessor leniency (Fisher, 2012) is obtained during the calibration process to determine the severity with which each OT assesses the individuals' performances. Even though this ensures inter-rater reliability of the AMPS assessments, 20% of the AMPS evaluations were also scored by a second OT Ana Paula Trucco (APT) (AMPS trained) to assess and confirm for inter-rater reliability of the assessments used in the thesis.

Disability Assessment for Dementia (DAD) (Gélinas, 1999) was used to assess performance of daily tasks.

The DAD is an informant-based interview assessment that was developed to use with people with AD living in the community, but it was also used with other dementias (Jang, 2012, Lima-Silva, 2015; Mioshi, 2007; Yassuda, 2018). The DAD includes both personal care tasks (BADLs=17 items) and more complex activities, such as meal preparation and going out (IADLs=23 items), including the ability to stay safely at home and pursue hobbies. Each item is assessed by considering different components of the performance of ADLs, such as initiation, planning and execution (or effective performance). Three answers are given: Yes (1), No (0) and Not Applicable (NA), so the scoring system does not consider those tasks that the individual has never performed in the past. These non-applicable questions will not affect the overall score. Total scores range from 0 to 100, where higher scores on the DAD denote better ADL performance. The DAD has been shown to have high degree of internal consistency (Cronbach’s α=0.96) and excellent inter-rater (ICC=0.95) and test-retest (ICC=0.96) reliability (Gélinas, 1999).

Dementia Stage

Frontotemporal Dementia Rating Scale (FRS) (Mioshi, 2010) was used to identify dementia stage.

The FRS is a 30-item questionnaire which assesses changes in behaviours and ADLs. Each item can be scored as 0 (happens sometimes and all the time) and 1 (never). The FRS rates the severity of the dementia as very mild, mild, moderate, severe, very severe and profound. For this thesis, I have grouped the sample in three stages only: Mild (very mild and mild), Moderate and Severe (severe, very severe and profound) and logit scores were used for the statistical analyses. The FRS has shown to be sensitive to disease progression in AD (Lima-Silva, 2020) and has shown excellent internal consistency (Cronbach’s α=0.93) and high inter-rater reliability (ICC=0.99) (Mioshi, 2010).

Cognition

Addenbrooke’s Cognitive Examination-III (ACE-III) (Hsieh, 2013) was used to measure global cognition.

The ACE-III is an internationally recognised dementia screening tool that measures global cognition and evaluates cognitive skills in five domains: language, attention, memory, verbal fluency and visuospatial abilities. The maximum score is 100, and higher scores indicate better cognitive functioning.

Behaviour

Cambridge Behavioural Inventory-Revised version (CBI-R) (Wear, 2008) was used to assess changes in behaviour.

The CBI-R evaluates behavioural symptoms in PwD, including motivation/apathy, sleep and changes in eating behaviour. These are assessed according to a frequency scale that goes from 0 (never), to 4 (constantly). Higher scores represent higher frequency of behavioural change. Only the motivation subscale of the CBI-R was used in this thesis to obtain the PwD's level of apathy. The CBI-R has shown to have a high degree of internal consistency for most of its subscales, except for the sleep one. The motivation subscale's Cronbach's α is 0.91 (Wear, 2008).

Environment

Home Environmental Protocol Assessment (HEAP) (Gitlin, 2002) was used to assess the environment.

The HEAP is an assessment used to evaluate the home environment of PwD. The items include a range of elements from quality of lighting and assistive technology equipment to structural modifications, of every room of the house. It also considers hazards and accessibility to the house. The HEAP also measures the clutter which is assessed through observation of each room separately and the score range is 1: <25% Low, 2: 26-50% Elevated, 3: 51-75% High and 4: >76% Severe. The extent to which surfaces are covered is determined by dividing the area into quadrants and estimating the percentage of the area covered. Some psychometric properties of the protocol were published for each item and each room assessed. Thus, slight to moderate strength of agreement was reported for home hazards, while substantial to almost perfect agreement was reported for adaptations, clutter and comfort items (Gitlin, 2002), when four independent raters used the HEAP in 22 homes of PwD.

Carer Management Styles

Dementia Management Strategies Scale (DMSS) (Hinrichsen, 1994) was used to identify carer management styles.

The DMSS is a 28-item questionnaire that characterises three different styles of management: criticism (11 items), active management (9 items) and encouragement (8 items). The items measure the frequency with which the carer uses each style, when managing dementia-related problems, on a scale that ranges from 1 (never) to 5 (most of the time). Each style is scored independently, giving a score for each one of them (criticism=up to 55; active management=45; encouragement=40). For this thesis, scores of each style were converted to a percentage to be able to make comparisons between styles. This percentage was obtained by dividing the score of each subscale by the sum scores of all items for each participant. Each style's internal consistency was reported separately, where criticism's Cronbach's α was 0.85, active management's Cronbach's α was 0.77 and encouragement's Cronbach's α was 0.80 (Hinrichsen, 1994).

Depression

Patient Health Questionnaire (PHQ-9) (Kroenke, 2001) was used to assess carer's symptoms of depression.

The PHQ-9 is a self-complete scale that measures symptoms of depression over the previous two weeks. The scale ranges from 0 (not at all) to 3 (nearly every day). Higher scores represent higher levels of depression, with scores higher than 15 considered moderately severe to severe depression, scores between 10-14 are considered moderate depression and scores between 5-9 are considered mild depression (Kroenke, 2001). The PHQ-9 has shown excellent internal consistency (Cronbach's α= 0.89) and excellent test-retest reliability (ICC=0.94) (Kroenke, 2001).

Anxiety

Generalised Anxiety Disorder scale (GAD-7) (Spitzer, 2006) was used to measure carer's symptoms of anxiety.

The GAD-7 is a self-complete questionnaire that assesses and measures the frequency and severity of anxiety symptoms. The scale contains seven items with options that range from 0 (not at all) to 3 (nearly every day). Higher scores denote higher levels of anxiety, with scores higher than 16 considered severe anxiety, scores between 11-15 considered moderate anxiety and scores between 6-10 considered mild anxiety (Spitzer, 2006). The GAD-7 has shown excellent internal consistency (Cronbach's α= 0.92) and good test-retest reliability (ICC=0.83) (Spitzer, 2006).

3.8 Sample Size

Sample size was calculated for each single study and will be explained in detail in the corresponding chapter. G*Power (version 3.1) was the software used along this thesis.

3.9 Missing Data

During data collection, data quality checks were completed to reduce the possibility of missing data. However, in those studies when missing data occurred, each situation was reported accordingly in each corresponding chapter.

3.10 Data Analyses

Statistical analyses were performed using the Statistical Package for the Social Sciences programme (SPSS version 25 for Chapters 4, 5 and 6 and SPSS version 28 for Chapter 7). The level of statistical significance was set at 5% ($p<0.05$).

Each chapter contains a dedicated section to explain the data analyses carried out. For completeness, this is a summary of the analyses that were used in this thesis:

- Descriptive statistics were used to describe the samples.

- Normality of the data was examined using either Shapiro-Wilk or Kolmogorov-Smirnoff tests alongside visual examination.

- Group comparisons for demographic data were made using independent samples *t*-tests (for continuous variables) and chi-square test (for categorical ones).

- Paired sample *t*-tests were conducted in Chapter 4.

- Intraclass Correlation Coefficient was applied in Chapters 4 and 6.

- Cohen’s Kappa was used in Chapter 6.

- Multiple regression analyses were conducted in Chapters 4, 5 and 6 and the assumptions of the regression were tested and reported accordingly.

- Thematic analysis was used in Chapter 7.

Chapter 4: Role of the environment in relation to the ability to perform daily activities among people with dementia

This chapter is based on the published paper:

Camino J, Kishita N, Trucco AP, Khondoker M, Mioshi E. (2021)
A new and tidier setting: how does environmental clutter affect people with dementia's ability to perform activities of daily living? *Alzheimer Dis Assoc Disord,* 35(4):335-341. https://doi.org/10.1097/WAD.0000000000000469

4.1 Introduction

As the majority of PwD live in their own home (Prince, 2014) and wish to remain doing so for as long as possible (Kelly, 2015), the living environment has become an essential aspect in the management of the dementia (Gitlin, 2003). However, the role of the home environment in supporting or hindering PwD's ability to perform ADLs is still controversial. The general assumption, for example on support websites for carers, is that PwD would benefit from a familiar and tidy home environment when performing daily tasks; however, the literature to date has shown contradictory results.

As dementia progresses, PwD gradually lose their ability to carry out daily activities (Brickman, 2002; Hsiao, 2015; Mioshi and Hodges, 2009) due to changes in their cognitive, motor and perceptual abilities (Mlinac and Feng, 2016). As such, one way in which participation in ADLs might be addressed is by adapting the person's physical environment (Gitlin, 2001; Linden, 2017; WHO, 2001). Consequently, environmental interventions have been proposed as a first–line treatment when dealing with dementia-related problems (van Hoof, 2010).

Different psychosocial interventions have been investigated in the past (Dooley and Hinojosa, 2004; Gitlin, 2001; Graff, 2006) to address the problems that

PwD encounter when performing ADLs. Such interventions primarily involved educational training for carers (Dooley and Hinojosa, 2004; Gitlin, 2001) or cognitive and behavioural interventions (Graff, 2006). These studies also seem to have addressed environmental changes. Although they have reported some promising results such as enhanced ADL performance (Gitlin, 2001; Graff, 2006) and improved PwD's quality of life (Dooley and Hinojosa, 2004), reduction of carer's upset (Gitlin, 2001) and burden (Graff, 2006), and improvement in carer's sense of competence (Graff, 2006), the specific changes made in the environment to improve ADL performance were not clearly stated (Woodbridge, 2018).

For example, an American study (Gitlin, 2001) trained dementia carers in the use of environmental simplification and task breakdown while another study (Doodley, 2004) recommended the use of visual cues and labelling drawers. However, information about the rationale or clinical reasoning for therapists to change the environment was not specified. On the other hand, a Dutch study (Graff, 2006) suggested that the OTs delivering the intervention should consider the possibility of making changes in the home environment; advice on such changes was, again, not provided. Interestingly, none of these studies has delved into any specific aspect of the environment, such as clutter management, lighting and colour contrast, in order to study the effect of this particular environmental intervention on PwD's task performance.

Turning to experimental research, only two studies to date have investigated how specific environments (home vs clinic) influenced PwD's task performance in dementia (Hoppes, 2003; Nygard, 1994). An older study (Nygard, 1994) found no differences in the performance of daily tasks between the PwD's own home and the dementia clinic, while a second study found differences in tasks that are designed to test motor skills only, such as putting on a shirt, transferring objects across room and walking through door (Hoppes, 2003).

Another experimental study has explored how different factors affected frail older adults' ability to do a meal preparation their own home and the clinic (Provencher, 2012). Although they included cognitive, psychological and physical factors in their analyses, participants were older adults without cognitive impairment, so their results could not be interpreted within the dementia context. At the moment, little is known about what factors are associated with better performance between different environments in PwD's task performance.

Environmental clutter has been defined as the presence of an excessive number of objects on a surface or the presence of items that are not required for a task (Gitlin, 2002). Some studies have suggested that the use of clutter management in environmental interventions may be beneficial for instrumental ADL independency (Gitlin, 2001) including the ability to perform meal tasks (Josephsson, 1995). However, the removal of clutter was primarily recommended as a strategy to approach behavioural problems, such as agitation and apathy (Gitlin, 2001). Studies investigating the effect of exclusively decluttering the environment while assessing the PwD's ability to perform ADLs have not been conducted to date. To the best of my knowledge, the effect of the environmental clutter on PwD's ability to perform ADLs is still unknown. If clutter plays a significant role in task performance, as suggested by other studies, this knowledge will provide evidence for families and clinicians to use decluttering methods as an approach to support PwD's daily tasks.

The objectives of this study were (1) to explore what role the environment plays in a PwD's ability to perform ADLs among the three different dementia stages (mild, moderate, severe), investigating the role of the environmental clutter; and (2) to investigate what factors predict better performance. The hypothesis is that if a simpler and less cluttered environment is provided, a PwD will encounter fewer difficulties when performing daily activities.

4.2 Methods

4.2.1 Study design

This was an experimental study that used a within-subjects design (repeated measure) to compare the same participants' outcome measures between two different settings. As such, participants completed a task twice but different conditions were used each time.

4.2.2 Participants

Participants were originally recruited to the TASKed project as explained in Section 3.5. One participant was recruited to the TRACC clinic (Dementia Research and Care Clinic) which was a study led by Prof Michael Hornberger and Prof Eneida Mioshi. The TRACC study's main aim was to assess and monitor PwD and their carers over the years and to identify changes in the participants' cognitive and behavioural profile using a wide range of assessments tools.

For this experimental project, 65 PwD and their carers (n=65 dyads) were included if they fulfilled the following criteria: PwD had been diagnosed with dementia, according to the DSM-V (American Psychiatric Association, 2013), being able to perform at least two tasks without help and willing to be video-recorded. In addition, PwD had to have a primary carer who could provide demographic information and who could also be interviewed about the PwD's task performance and behavioural changes.

4.2.3 Ethical considerations

All participants gave written consent before the study took place. Ethical approval for the study has been gained through the TASKed project and was provided by the HRA, REC (IRAS ID 199002; 16/LO/0544). The TRACC Clinic was also approved by the HRA, REC (IRAS ID 205788; 16/LO/1366).

4.2.4 Procedures

PwD and their carers had an initial interview with me to select tasks according to the performance-based ADL assessment's rules; this included the selection of tasks that the participants performed daily. Tasks ranged from very easy activities (i.e., washing and drying the hands) to more complex tasks (preparing and serving tea with biscuits). The tasks varied among the participants and were carried out mainly in two rooms: the kitchen and the bathroom.

Each participant's ADL ability and the environmental clutter were assessed (by me) at the participant's own home and at the research-lab NEAT (Norwich Electronic Assistive Technology Centre), at the University of East Anglia (UEA). The NEAT is a fully equipped research home located in the School of Health Sciences' building, where the different rooms (e.g., kitchen and bathroom) were decluttered to be used in this study.

Participants were assessed in one setting (own home), and, within two months, they were invited to complete the same tasks at the research-lab. To avoid practice effects, a counterbalanced design was utilised, where half of the participants were first assessed at their own home, and the other half were invited and evaluated to be assessed at the research-lab first. Random allocation was not possible due to the nature of data collection of the parent project, TASKed. As such, the first 34 participants completed the first assessment at home, followed by the research-lab assessment, while the next 34 participants were invited to do the first assessment at the research-lab, followed by the home assessment. Each ADL assessment in each environment was video-recorded to allow the researchers to score the assessment and check for inter-rater reliability. Other assessments below were completed as part of the parent studies, within six months of this experimental study.

Two samples were formed: *Sample 1*, which contained 61 participants that completed both the home and the research-lab assessments, and *Sample 2*, which had four additional participants who completed the home assessment only (Figure 4.1).

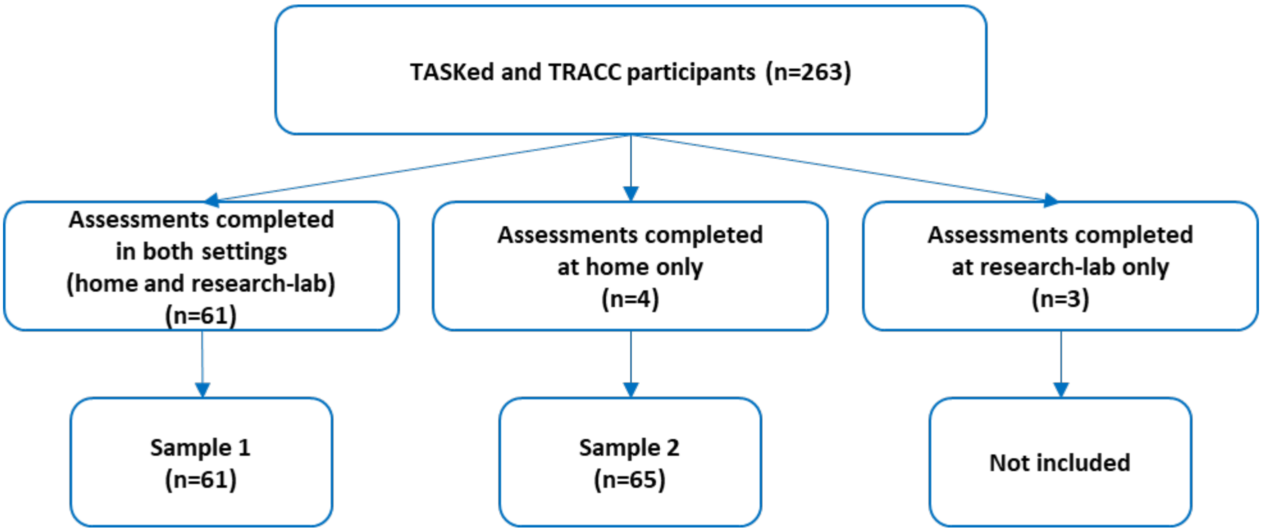


Figure 4.1 *Flow diagram showing how participants were included in each stage of this study.*

4.2.5 Instruments

Demographic information was collected on PwD's age, gender, level of education, living situation, marital status and length of symptoms, as part of the TASKed or TRACC projects, as explained in Section 3.7.

Instruments

Assessment of Motor and Process Skills (AMPS) (Fisher, 2012): performance-based assessment that evaluates the person's ability to complete ADLs using observation of two tasks. The scoring is transferred into a computer programme that gives two main logit scores: Motor and Process Skills scores. The Process Skills score was used for the analysis of this study because they include items belonging to cognitive skills. The AMPS Process Skills' cut-off is 1.00, which indicates the lower limit of competent task performance in age-matched controls. A proportion of the

AMPS (20%) tasks were re-scored by APT (AMPS trained) to check for inter-rater reliability.

Home Environmental Assessment Protocol (HEAP) (Gitlin, 2002): assessment of the home environment which was used in both the participants' home and the research-lab. The HEAP includes several different aspects of the environment, such as equipment, adaptations, use of external aids and assistive technology. The HEAP also assesses the clutter through observation of each room separately and the score range is 1: <25% Low, 2: 26-50% Elevated, 3: 51-75% High and 4: >76% Severe clutter. Only the clutter section of the HEAP was used in this study.

Frontotemporal Dementia Rating Scale (FRS) (Mioshi, 2010): informant-based interview questionnaire that was used to identify dementia stage. The FRS is a 30-item scale that includes different items, such as changes in behaviours, cognition, eating habits and ADLs. Each item can be scored as 0 (all the time and sometimes) and 1 (never). The FRS has shown to be sensitive to disease progression in AD (Lima-Silva, 2020).

Addenbrooke's Cognitive Examination-III (ACE-III) (Hsieh, 2013): a cognitive screening test that was used to measure global cognition. The ACE-III is a widely known screening test, that includes different cognitive skills, such as language, attention, memory, verbal fluency and visuospatial abilities. Higher scores indicate better cognitive functioning. The ACE-III's recommended cut-offs are 88 (sensitivity=1.0; specificity=0.96) and 82 (sensitivity=0.93; specificity=1.0) (Hsieh, 2013). The cut-off used in this study was 82.

More details of all these assessments and questionnaires are provided in Section 3.7.

4.2.6 Data Analyses

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

To characterise the sample, demographic and clinical measures (e.g., ACE-III and AMPS) were compared between moderate and severe stages of dementia, using independent samples *t*-tests for continuous variables, and chi-square test for categorical ones. People in the mild stage of dementia were excluded from this comparison, due to the small numbers in the sample.

Even though the assumption of normality were not met for the AMPS scores at home ($W_{(61)}=0.936$, $p=0.003$) and at the research-lab ($W_{(61)}=0.929$, $p=0.002$), parametric tests were used in the analysis (Elliott and Woodward, 2007), due to the sufficient sample size (Pallant, 2007).

To compare ability to perform ADLs and the level of clutter between home environment and research-lab, paired sample *t*-tests were undertaken (*Sample 1*).

To examine the effect of PwD's level of cognition, dementia stage, age and gender and the level of clutter on PwD's ability to perform tasks, a multiple regression analysis, enter method, was conducted (*Sample 2*), where all the independent variables were entered into the model at the same time

Residual analyses were performed to ensure that regression assumptions were met. Residual and scatter plots indicated that the assumptions of normality, linearity and homoscedasticity were all met. No independent variables were highly correlated thus, the data does not show multicollinearity or singularity. Tolerance and VIF's values were all within accepted limits. Mahalanobis distance scores (MD=20.39) were below its critical value of 20.52 for five independent variables (Pearson and Hartley, 1958), and Cook's distance value was below one ($D_i= 0.30$) thus, we can confirm that no outliers were found within the data.

To examine agreement between raters (APT and me) on the AMPS assessment, Intraclass Correlation Coefficient (ICC) (Koo and Li, 2016), two-way mixed models, absolute agreement, was run. Raters reached excellent agreement for AMPS Process Skills scores at home [(0.967 with a 95% CI from 0.895 to 0.990

($F_{(12,12)}$=29.272, *p*=<0.000)] and for AMPS Process Skills scores at the research-lab [(0.931 with a 95% CI from 0.773 to 0.979 ($F_{(12,12)}$=13,589, *p*=<0.000)].

4.2.7 Sample Size

The previous literature on PwD and their ability to perform tasks in different environments does not provide with convincing effect sizes for the outcome variable that it will be used in this project, the AMPS (Hoppes, 2003; Nygard, 1994; Park, 1994; Provencher, 2013). Therefore, a conventional medium size effect of 0.50 (Cohen, 1988) was chosen for the sample size calculation (G*Power, version 3.1). Cognition, dementia stage, age, gender and level of clutter were included as factors in the sample size calculation. Thus, the sample size required, in order to achieve a power level of 0.80 (two-tailed) a significance level of 0.05, and a medium effect size of 0.15 was 55. This power calculation used R-squared increase due to the inclusion of an independent variable of interest in the regression model as effect size (Cohen, 1988). Cohen's f^2 (Cohen, 1988) was used as the effect measure which is appropriate for calculating the effect size within the multiple regression model.

4.3 Results

Demographics

The demographics for all participants are shown in Table 4.1. The majority of the participants were more than 75 years old, male, married and lived with their carer. When grouped by dementia stage, it was found that there were only 9.2% PwD in the mild stage, 38.5% presented with moderate dementia, leaving the other 52.3% with severe dementia. Most participants were diagnosed with AD (69.3 %) followed by VD (18.5%). Other dementias (12.2%) included FTD and PCA.

Table 4.1. Information about demographic characteristics and clinical variables of the sample. All people with dementia (n=65) and grouped by dementia stage.

	All Sample (N= 65)	**Mild (n=6)**	**Moderate (N= 25)**	**Severe (N= 34)**	**Moderate vs Severe**
Age (in years)	77.94 (7.34)	76.83 (8.68)	77.28 (7.82)	78.62 (6.9)	ns
Gender (Male %)	61.5%	50%	60%	64.7%	ns
Education (in years)	11.83 (2.36)	11.33 (0.81)	12.08 (2.59)	11.74 (2.4)	ns
Length of Symptoms	4.21 (3.37)	3 (1.26)	2.78 (1.97)	5.42 (3.93)	*
Cognition (ACE-III)	63.35 (19.33)	73 (9.14)	69.52 (10.69)	57.12 (23.31)	*
ADLs (AMPS-Process Home)	0.55 (0.55)	0.9 (0.22)	0.72 (0.36)	0.37 (0.64)	*
Marital Status (%)					
Married	84.6	100	87.5	79.4	ns
Widowed	10.8	-	8.3	14.7	ns
Partner	3.1	-	4.2	2.9	ns
Other	1.5	-	-	2.9	ns
Living Situation (%)					
With Family	92.3	100	95.8	88.2	ns
Alone	7.7	-	4.2	11.8	ns

*Scores are means with SD in parentheses. Global cognition was assessed with the ACE-III (Addenbrooke's Cognitive Examination, third edition); ADLs (Activities of Daily Living) were measured with the AMPS (Assessment of Motor and Process Skills) Process Skills score. Independent samples t-test was used for continuous variables. Chi-square test was used for categorical variables. Statistically significant difference *p=<0.05.*

Is the ability to perform ADLs different between environments?

The ability to perform tasks was better at home (M=0.57, SD=0.56) than at the research-lab (M=0.45, SD=0.61) (AMPS Process Skills score: $t_{(60)}$=2.44, *p*=0.017, Cohen's *d*=0.29). It is worth noting that the majority of the participants (76.9%) scored below the AMPS Process Skills' cut-off, indicating that this sample' ability to perform ADLs was diminished or impaired, both at their own home and at the research-lab.

Is the environmental clutter different between environments?

The level of clutter was significantly lower in the research-lab (M=1.00, SD=0.00) than the participants' homes (M=1.22, SD=0.46) ($t_{(60)}$= 3.38, *p*=0.001, *d*=0.47). An example of a participant's own home and its level of clutter and how the research-lab was decluttered is offered as a supplementary file (see supplementary material, Chapter 4) in the Appendices.

What are the factors that best predict the ability to perform ADLs at home?

Five factors were included in the regression model: cognition, environmental clutter, age, dementia stage and gender. This combined model explained 54.4% (R^2=0.544, F=$13.14_{(5, 59)}$, *p*=<0.001) of the variance of the ability to perform ADLs at home, being cognition the only factor that made the largest and statistically significant contribution (*β*=0.65, $t_{(64)}$=6.52, *p*=0.001) (Table 4.2).

Table 4.2. Results of regression analysis.

Independent variables included in the multiple regression analysis. Dependent variable: Home AMPS Process Skills score (*Sample 2*: n=65).

Predictors	**HOME-AMPS-Process Skills score**			**95% CI of the β**	
	β	***T***	***P***	**Lower**	**Upper**
Cognition	0.657	6.519	**0.001**	0.255	0.482
Environmental Clutter	-0.003	-0.034	0.973	-0.105	0.102
Age	0.093	0.998	0.323	-0.052	0.155
Dementia Stage	-1.18	-1.178	0.244	-0.178	0.046
Gender	-1.23	-1.282	0.205	-0.177	0.039

Note. $F_{(5,59)}$=13.14; R^2=0.544, *p*=<0.001.

Is the ability to perform ADLs different between environments, when stratified by dementia stage?

PwD in the moderate stage of the disease had a better performance at home ($t_{(23)}$=2.980, 95%CI 0.048 to 0.268, *p*=0.007, *d*=0.60) than at the research-lab. However, for the mild (Home-Process M=0.90, *SD*=0.22; research-lab-Process M=1.00, *SD*=0.46; $t_{(5)}$=-0.866, 95% CI -0.396 to 0.196, *p*=0.426) and the severe (Home-Process M=0.38, *SD*=0.66; research-lab-Process M=0.25, *SD*=0.70; $t_{(30)}$=1.577, 95% CI -0.038 to 0.296, *p*=0.125) subgroups, no difference in the ability to perform ADLs was observed between the two environments (Figure 4.2).

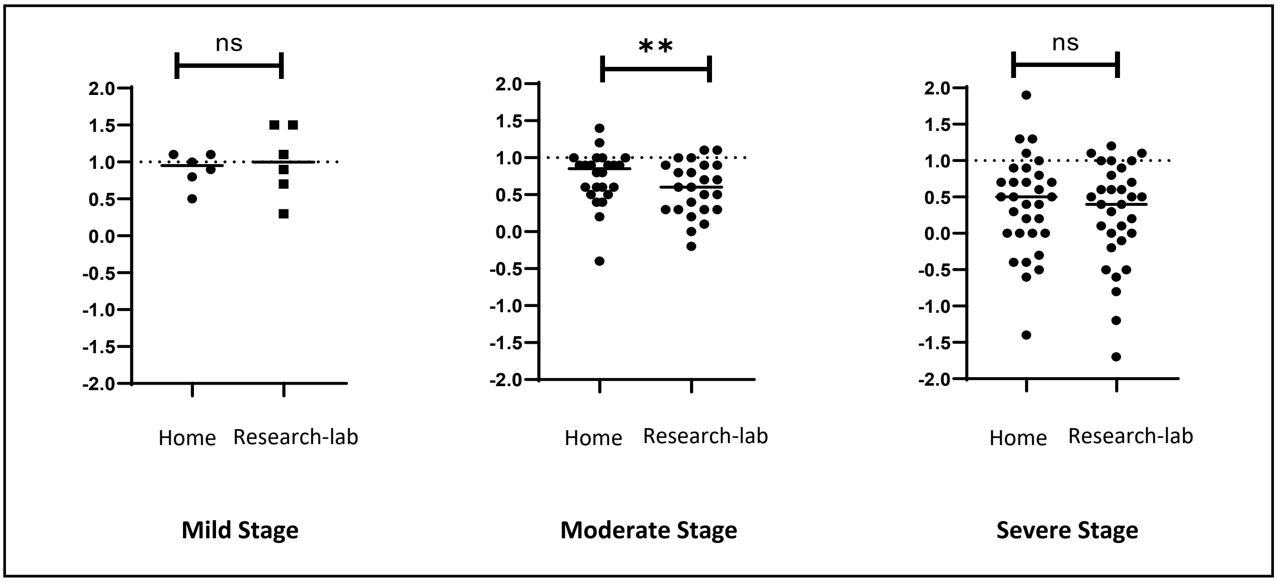


Figure 4.2 *Box plots showing results of comparison between groups. The scores of the AMPS (Assessment of Motor and Process Skills) Process Skills score (ADL Ability) between environments (Home vs research-lab) were compared. People with dementia (Sample 1: n=61) in the Mild (Panel A, n=6), Moderate (Panel B, n=24) and Severe (Panel C, n=31) stages of the disease according to the FRS (Frontotemporal Dementia Rating Scale). Paired samples t-tests. Statistically significant difference ** p=<0.01. Dotted line: AMPS Process Skills score's cut-off, age and gender-matched healthy adults.*

4.4 Discussion

This study examined differences in PwD's ability to perform everyday tasks in different environments, namely home and research-lab. Although previous studies compared PwD's ability to perform tasks in different settings (home vs clinic) (Hoppes, 2003; Nygard, 1994), to my knowledge, this is the first study that manipulated an environment to remove its clutter and examine the impact of this change on ADL functioning.

The results of this study indicated that PwD performed better at home rather than in the research-lab, despite the absence of clutter in the research-lab.

This suggests that decluttering an environment may not have a positive impact on PwD's ADL functioning. These results contradict a previous study where no differences in PwD's ability to perform tasks between home and the clinic were found (Nygard, 1994). However, this study's much larger sample (n=61) offers greater power when analysing the differences between settings. Another small study (n=12) comparing home and clinic (Hoppes, 2003) found that PwD performed better at home. This difference, however, was only significant in relation to motor skills, rather than cognitive and social skills. This finding was probably due to the use of a different type of assessment, where participants are assessed simulating (Bottari, 2006) different tasks instead of doing observation of real day-to-day activities.

When grouped by dementia stage, mixed results were found. The home environment offered benefits on ADL functioning for those people in the moderate stages of dementia. While PwD in the mild and severe stages presented with the same level of ability regardless of the environment. This could have been explained by the type of activities the participants performed. For example, PwD in the severe stages of dementia mostly completed very basic ADLs that consist of short and simple steps, such as brushing teeth and washing and drying the hands. In this case, the setting would probably not have contributed positively or negatively to the task performance. However, and notwithstanding, PwD in the mild stages also performed at the same level in both their homes and the research-lab, even when performing more complex ADLs. Nevertheless, the task level of challenge was taken into consideration by the assessment's software used in this study, so this does not explain why people in the mild and severe stages performed the tasks at the same level of ability. Future studies with larger number of participants with mild dementia may help in understanding how the environment may contribute to the PwD's ability to perform daily tasks.

A possible explanation of why PwD in the moderate stage of the disease performed better at home could be the use of compensation skills, which may have played a positive role in PwD's task performance, as these involve implementing strategies when existing abilities are lost (Baltes and Baltes, 1990). As such, the familiar home environment may have helped PwD compensate for some deficits that may not have been apparent during the assessment (Moore, 2007). However, this point has been refuted by Schmitter-Edgecombe *et al* [2014] when developing a compensation scale. The authors found that PwD did not use compensatory strategies when performing ADLs and neither did older adults without cognitive impairment (Schmitter-Edgecombe, 2014). Future experimental research addressing use of compensatory skills could help us understand their impact on PwD's ability to perform daily tasks.

The majority of participants in this study's sample had diminished ability to perform ADLs. This means that even though these participants performed better at home, they still showed problems completing the ADLs in both environments. This is in line with other studies using the same assessment tool, where PwD's AMPS Process Skills scores were below AMPS Process Skills' cut-off (Cooke, 2000; Nygard, 1994), indicating that PwD presents with ADL problems when comparing with healthy adults of the same age.

In relation to the factors that may have contributed to PwD's ADL functioning at home, we found that cognition was the only factor that predicted better performance in the current sample. This suggests that PwD relies greatly on cognitive abilities to complete daily tasks. However, this result has to be considered with caution, as cognition was measured using the ACE-III, a cognitive screening test, instead of an extensive neuropsychological battery. Procedural memory, which may be well preserved in PwD (Perani, 1993) could have contributed to PwD's better performance at home, as this specific memory function has been associated with greater ADL performance (Zanetti, 1997). Therefore, future studies could include other cognitive variables, such as procedural memory, executive functions and visuospatial abilities, to further investigate the role they play in PwD's ability to perform daily tasks.

An important finding of this study is that a decluttered environment may not have a positive impact on the PwD's ability to perform tasks. This has implications for OTs intending to use environmental interventions. Future studies could be carried out focusing in PwD's own home, where they could be assessed with and without clutter. In this way, more information can be obtained on how decluttering the environment may help or hinder PwD's task performance. Another implication for clinicians is where they should assess their patients. As the results of this study indicated that PwD in the moderate stage of dementia performed better at home, OTs should carry out their performance-based ADL assessments at the PwD's own home. However, for those PwD in the mild or severe stage, it seems that they could be assessed in either the home or the clinic, as no differences were found in the current sample.

There were limitations in this study. For example, information on the number of years a PwD resided in their own home was missing. This information would have helped us control for environmental familiarity as a factor to better understand how PwD benefit from a familiar home environment. Another limitation that was mentioned before was the small number of participants in the mild stage of dementia. Future studies with a large number of participants with mild dementia could help with the understanding of the factors that contribute to PwD's ADL functioning.

In summary, these results showed that PwD had better task performance in their own home rather than at the decluttered research-lab. This seems to suggest that decluttering the environment as a sole intervention may not be necessarily beneficial to improve ADL functioning. Future studies are required to elucidate the wider role of the environment in supporting engagement in daily activities in dementia.

4.5 Summary

Chapter 4 investigated the role of the environment, as an extrinsic factor, on the PwD's ability to perform ADLs. The next chapter will investigate how another extrinsic factor, namely the carer style when managing dementia-related problems, in combination with intrinsic factors, affects ADL performance in PwD.

Chapter 5: Daily tasks in dementia: does carer management style influence the people with dementia's task performance?

This chapter is based on the published paper:

Camino J, Kishita N, Bregola A, Rubinsztein J, Khondoker M, Mioshi E. (2021) How does carer management style influence the performance of activities of daily living in people with dementia? *Int J Geriatr Psychiatric,* 36(12):1891-1898.

http://doi.org/10.1002/gps.5607

5.1 Introduction

PwD present with gradual deterioration in the performance of ADLs (Reisberg, 1982). Several intrinsic dementia factors have been associated with decline in daily tasks in several dementia subtypes (Jang, 2012; O'Connor, 2016; You, 2015). Factors include decline in specific cognitive domains such as memory and executive function (Martyr and Clare, 2012; Razani, 2011) and behavioural symptoms (O'Connor, 2016; You, 2015), for example apathy, the most common behavioural symptom reported in dementia (Mega, 1996). However, intrinsic factors alone do not seem to fully explain the variance of ADL scores and some studies have found no association between PwD's level of cognition and ADL performance (Jang, 2012; Mioshi, 2007).

Extrinsic factors, such as carer-related characteristics (Dassel and Schmitt, 2008), have also been associated with the PwD's performance of daily tasks. For example, female carers tend to report poorer ADL performance when compared with male family members (Conde-Sala, 2013). Carers' mental health factors, such as carer depression and burden (Conde-Sala, 2013) have also been shown to have a negative impact on the PwD's performance of ADLs. Thus, carers who are depressed and burdened tend to report more deficits in the PwD's daily tasks (Conde-Sala, 2013).

Another less investigated extrinsic factor that could affect the PwD's performance of daily tasks is the style that carers use when managing dementia-related problems. These management styles refer to the specific ways in which a family carer approaches dementia-related issues. Three carer's styles have been described in the literature, based on the strategies used by carers: *criticism*, which describes efforts to manage the patient by actions such as yelling, criticising, threatening and related behaviours. *Active management* includes actions to assist, engage, stimulate and associated behaviours primarily directed toward modifying the environment or daily routine. *Encouragement* includes efforts to praise the individual, get them to discuss feelings or look on the bright side of things (Hinrichsen, 1994). Studies on the use of carer management styles in dementia have found correlations between the carer's use of criticism style and higher carer burden (Hinrichsen, 1994; Leggett, 2019; Lim, 2011) while the use of encouragement style has been associated with carer's greater feelings of gain, which denotes a positive caring experience (Leggett, 2019; Lim, 2011).

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

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

5.2 Methods

5.2.1 Study design

A secondary analysis was conducted using data collected for the TASKed project to complete this exploratory, cross-sectional and observational study.

5.2.2 Participants

Participants included in this study were originally recruited to the parent project, TASKed, as explained in Section 3.5. Out of 183 dyads from this project, 143 PwD were included in this study if they had a diagnosis of AD (McKhann, 2011), mixed or VD (Roman, 1993). Inclusion criteria for the PwD also included living at home and be >40 years old and <90 years old. Exclusion criteria for PwD included having a history of additional major psychiatric disorder, being unable to respond to single-step commands and diagnosis of dementia secondary to head trauma, alcohol misuse or brain tumour.

Carers (n=143) needed to be fluent in English, be over 18 years old and have had to provide at least seven hours of unpaid support each week. The primary carer was then defined by these criteria. All participants and their carers were assessed at their own home.

5.2.3 Ethical Considerations

Both the PwD and their carers provided written consent at the home visit. If the PwD lacked the capacity to consent to the study, appropriate measures were in place so that the carer could state what they thought the PwD's wishes would have been regarding their participation in this study. Ethical approval for the study has been gained through the TASKed project and was provided by the HRA, REC (IRAS ID 199002; 16/LO/0544).

5.2.4 Instruments

As already mentioned in Section 3.7, carers completed demographic questionnaires for both the carer and the PwD, which included information about their gender, age, education, length of symptoms, relationship with the PwD, marital status and living situation.

Instruments

Disability Assessment for Dementia (DAD) (Gélinas, 1999): carers were interviewed with the DAD to measure PwD's performance of ADLs. The DAD is an informant-based interview assessment that includes both personal care (showering and getting dressed) and IADLs, such as medication management and meal preparation. For each task, three answers are given: Yes (1), No (0) and Not Applicable (NA). These not applicable questions do not affect the final score. Higher scores on the DAD denote better ADL performance.

Addenbrooke's Cognitive Examination-III (ACE-III) (Hsieh, 2013): PwD were assessed with the aim of obtaining information about their cognitive function. The ACE-III measures global cognition and assesses cognitive skills in five domains: language, attention, memory, verbal fluency and visuospatial abilities. The maximum score is 100, and higher scores indicate better cognitive functioning. The ACE-III's proposed cut-offs are 88 (sensitivity=1.0; specificity=0.96) and 82 (sensitivity=0.93; specificity=1.0) (Hsieh, 2013). The cut-off used in this study was 82.

Cambridge Behavioural Inventory-Revised version (CBI-R) (Wear, 2008): was used to assess PwD's level of apathy. The CBI-R assesses different behavioural changes, including motivation/apathy and changes in eating behaviour. Higher scores represent higher frequency of behavioural change. The motivation subscale of the CBI-R was used in this study to obtain the PwD's level of apathy.

Frontotemporal Dementia Rating Scale (FRS) (Mioshi, 2010): was used to identify dementia stage. This is an interview scale that categorises dementia in six stages from 'very mild' to 'profound' dementia. For this study, three main stages were grouped and used: mild, moderate and severe. As mentioned already, the FRS has also been shown to detect changes in other dementias, including AD (Lima-Silva, 2020), confirming suitability for use in this study.

Dementia Management Strategies Scale (DMSS) (Hinrichsen, 1994): was used to identify carers' management styles. This is a 28-item self-complete scale that identifies three different styles of management: criticism, active management and encouragement. Carers are asked to respond the frequency with which they use different strategies on a scale that ranges from never to most of the time. Scores of each style were converted to a percentage to enable comparison between them.

Patient Health Questionnaire (PHQ-9) (Kroenke, 2001): carers also filled in a self-complete questionnaire, which was used to measure carer's symptoms of depression. The scale includes items that assess symptoms of depression using a scale that ranges from 0 (not at all) to 3 (nearly every day). Higher scores represent higher levels of depression, with scores higher than 15 considered moderately severe to severe depression, scores between 10-14 considered moderate depression and scores between 5-9 considered mild depression (Kroenke, 2001).

More details of these questionnaires and assessments can be found in Section 3.7.

5.2.5 Sample Size

Sample size was calculated using G*Power (version 3.1) based on a multiple linear regression analysis allowing for five predictors (cognition, apathy and the three-carer management styles variables) in the model. In order to detect a medium effect size (Cohen’s $f^2=0.15$) (Cohen, 1988) with 95% power at 5% significance level, the minimum sample size required was estimated to be n=138.

5.2.6 Data Analyses

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

To characterise the sample, descriptive statistics were performed for demographics and clinical variables. To investigate possible differences between dementia stages, data was compared using independent samples *t*-test (continuous data) or chi-square test (categorical data) for the clinical variables (cognition, apathy and ADLs). Tests of normality (Shapiro-Wilk) were conducted to define the type of statistical tests that were going to be used when describing the data.

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

Preliminary analyses were performed to ensure that assumptions of normality, multicollinearity, linearity and homoscedasticity were met. Outliers were also checked using Mahalanobis and Cook’s distances. No independent variables were highly correlated, thus, the data did not show multicollinearity or singularity. This was also confirmed with Tolerance and VIF, as these values were all within accepted limits. For this sample, Mahalanobis distance scores (MD=20.43) were just below its critical value of 20.52 for five independent variables (Pearson and Hartley, 1958), and Cook’s distance value were below one (D_i= 0.13). Thus, we can conclude that no outliers were found within the data. Residual and scatter plots indicated that the assumptions of normality, linearity and homoscedasticity were all met.

5.3 Results

Demographics

The descriptive statistics of demographic and clinical variables for all participants are shown in Table 5.1. Parametric tests were used in the analysis of demographic data, due to the normal distribution of the variables.

The majority of PwD were male (62.9%), lived with their family and were married. Their average age was 78 years (M=78.73, SD=7.33). The majority had a diagnosis of AD (76.6%) followed by VD (18.9%) and MD (4.9%). Figure 5.1 compares the PwD's level of cognition, apathy and ADL performance, by dementia stage.

Table 5.1. Information about demographic characteristics and clinical variables of the sample. All people with dementia (n=143) and their carers (n=143) and grouped by dementia stage. Mild group not included in the comparison of demographic variables due to its small sample size.

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

Scores are means with SD in parentheses. Global cognition was assessed with the ACE-III (Addenbrooke's Cognitive Examination, third edition); ADLs (Activities of Daily Living) were measured with the DAD (Disability Assessment for Dementia). Apathy was measured with the motivation subscale of the CBI-R (Cambridge Behavioural Inventory-Revised) (Frequency score: 0-100%;). Carer depression was assessed using the PHQ-9 (Patient Health Questionnaire-9). Carer management styles were identified using the DMSS (Dementia Management Strategies Scale).

*Independent samples t-test was used for continuous variables. Chi-square test was used for categorical variables. Statistically significant difference *p=<0.05; **p=<0.01. † Missing data for both the length of symptoms (n=128/143) and carers' age (n=142/143).*

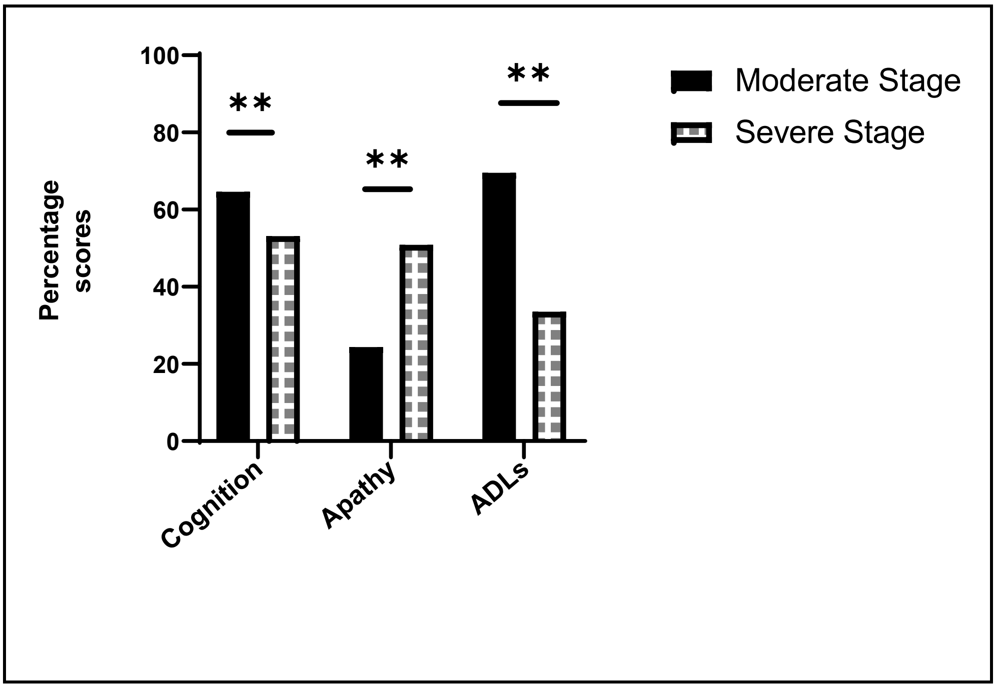
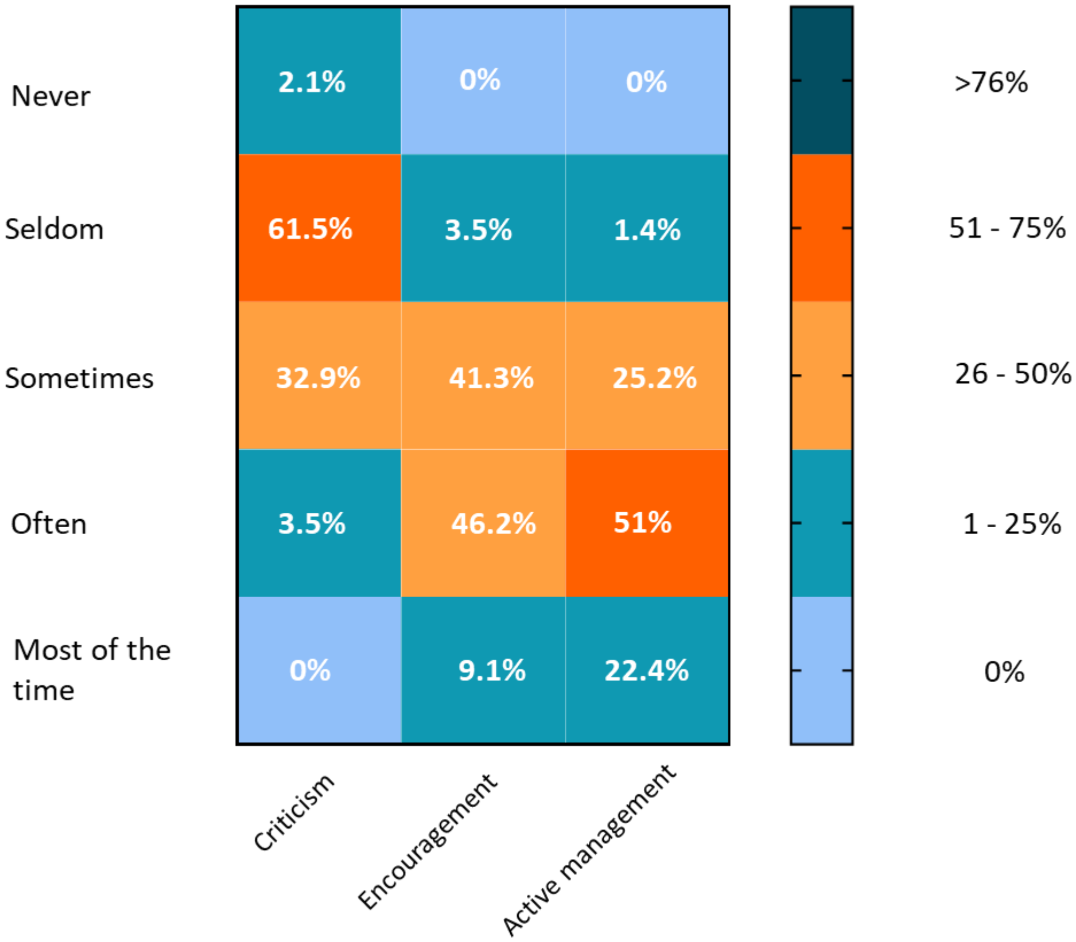


Figure 5.1 *Bar graphs comparing clinical variables between dementia stage.*
*The scores for level of cognition, apathy and ADL performance of people with dementia, grouped by dementia stage [moderate (n=56) vs severe (n=77)] were compared using independent samples t-test. People in the mild stage of dementia were excluded from this comparison, due to the small numbers in the sample (n=10). Cognition was assessed with the ACE-III (Addenbrooke's Cognitive Examination, third edition) (Scores 0-100, higher scores denote more preserved cognitive abilities). Apathy was measured with the CBI-R (Cambridge Behavioural Inventory-Revised) (0-100%, higher scores denote higher levels of apathy). ADLs (Activities of daily living) were measured with the DAD (Disability Assessment for Dementia) (0-100%, higher scores denote better ADL performance). Statistically significant difference **p=<0.01.*

Carers were mostly female and were 73 years old on average (M=73.08, SD=10.57). The majority of carers were spouses reporting mild depressive symptoms (Table 5.1). Carers reported using an active management style more often (51%) than encouragement style (46.2%) and they reported seldom-use of criticism strategies (61.5%) (Figure 5.2).



	Criticism	Encouragement	Active management
Never	2.1%	0%	0%
Seldom	61.5%	3.5%	1.4%
Sometimes	32.9%	41.3%	25.2%
Often	3.5%	46.2%	51%
Most of the time	0%	9.1%	22.4%

Figure 5.2 *Heat map reporting carers selected styles.*

The frequency with which carers reported the use of different strategies while managing dementia-related problems, as described by the three-carer management styles based on the DMSS: criticism, active management and encouragement, was reported. Carer management styles were assessed using the DMSS (Dementia Management Strategies Scale). The scale ranges each strategy using this graduation: 1 (never used the strategy), 2 (seldom), 3 (sometimes) 4 (often) and 5 (most of the time).

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

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

The best model that explained the highest variance on the DAD included PwD's level of cognition (β =0.413, $t_{(142)}$=4.463, *p*=0.001), PwD's apathy levels (β =-0.365, $t_{(142)}$=-5.556, *p*=0.001), carer's use of criticism style (β =-0.326, $t_{(142)}$=-2.479, *p*=0.014) and carer's use of encouragement style (β =0.402, $t_{(142)}$=2.941, *p*=0.004). This model explained 40% of the variance of the ADL performance (R^2=0.40, F=18.359$_{(5,137)}$, *p*=<0.001). Active management was the only factor that did not significantly contribute to the variance in ADL performance. Results of the regression analysis are displayed in Table 5.2.

Table 5.2. Results of regression analysis.
Independent variables (carer or person with dementia) included in the multiple regression analysis. Dependent variable: ADL Performance (n=143).

Predictors	DAD (ADL performance)				**95% CI of the β**	
	β	**SE**	***T***	***P***	**Lower**	**Upper**
PwD Cognition (ACE-III)	0.413	0.092	4.463	**0.001**	0.228	0.594
PwD Apathy (CBI-R)	-0.365	0.066	-5.556	**0.001**	-0.493	-0.231
Carer Criticism (DMSS)	-0.326	0.134	-2.479	**0.014**	-0.602	-0.071
Carer Encouragement (DMSS)	0.402	0.137	2.941	**0.004**	0.134	0.676
Carer Active Management (DMSS)	-0.083	0.136	-0.612	0.541	-0.359	0.181

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

The contribution of each of the variables to the ADL performance model varied. For each point that the PwD scored on the CBI-R apathy subscale, which denotes increase level of apathy, their ADL performance (DAD) decreased by 3%. PwD's performance of ADLs also decreased by 3% for each point that the carer scored on the criticism subscale (DMSS). On the other hand, for each point that the PwD scored for better cognition (ACE-III) their ADL performance increased by 4%, and for each point that the carer scored on the encouragement subscale (DMSS), the PwD's performance of ADLs increased by 4%.

5.4 Discussion

This is a novel study investigating how the combination of intrinsic and extrinsic dementia factors can affect PwD's performance of ADLs. Carer's use of criticism style decreased ADL performance while encouragement style improved task performance, confirming the key role that carers have when supporting PwD in the performance of daily tasks. In addition, better global cognition contributed to better ADL performance while apathy had the opposite effect, confirming previous studies (Boyle, 2003; Delgado, 2019; O'Connor, 2016; Yassuda, 2018; You, 2015).

The use of encouragement style was associated with increased ADL performance. Encouragement strategies are based on an emotional support approach, since they include ways of encouraging the PwD to have a positive attitude in relation to their circumstances such as, for example, motivating the PwD to discuss their emotions and feelings, showing the PwD physical affection and keep up with friends. The fact that the more encouraging the carer was improved ADL performance suggests that a positive atmosphere, where the PwD is listened to and prompted to express themselves, provides a more favourable environment that supports ADL performance. Using this style was also associated with positive carer outcomes in the past. For example, a study that looked at the relationship between the carer management styles and carer-related measures found that the use of encouragement predicted perception of positive gain in Asian carers (Lim, 2011), increasing the carer's positive feelings of the caring experience. As such, this study also contributes to the knowledge that implementing positive strategies when caring for someone with dementia will influence the carer's wellbeing while having an effect on the PwD's performance of ADLs.

Criticism style was the least chosen style among this study's carers, with the majority of them reporting that they seldom used it. Still, this style negatively affected PwD's performance of ADLs. The criticism style is based on strategies where the carer, for example, blames the PwD for having created difficulties and asks the PwD to stop doing things that cause worry, and also the use of yelling and threatening. Even though these carers reported that they were rarely critical towards the PwD, the fact that these strategies still affected ADL performance shows that a critical environment is not conducive to the task performance of the PwD. On the other hand, the use of criticism was found to be associated with increased carer's use of home and social services in a previous study (Leggett, 2019). This supports the current findings by linking the use of criticism strategies, which leads to poor PwD's performance of ADLs and may result in the need for greater external help. In addition, in previous studies, the use of criticism style has been linked to higher carer burden (Hinrichsen, 1994; Leggett, 2019; Lim, 2011), and carer burden has been associated with poor ADL outcomes (Conde-Sala, 2013). Future studies could include both measures of carer burden and carer management style, to further understand how these extrinsic carer-related factors may further influence PwD's performance of ADLs.

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

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

PwD's increased level of apathy had a detrimental effect on PwD's performance of daily tasks, which is in agreement with previous research into apathy in AD (Boyle, 2003; Delgado, 2019; You, 2015). For example, an American study (Boyle, 2003) found that apathy uniquely contributed to the PwD's performance of ADLs, while apathy and PwD's sleep disorders were found to contribute to ADL performance more recently (You, 2015). In relation to cognition, previous studies had varied results in relation to its contribution to ADL performance. In this study, PwD's higher level of cognition improved ADL performance. A review of the cognitive contributions to everyday performance (Royall, 2007) found that greater global cognition was positively associated with better everyday function in people with AD (Royall, 2007). Other studies (Jang, 2012; Mioshi, 2007), however, did not demonstrate such an association between cognition and ADL performance, possibly because they focused on rarer forms of dementia such as frontotemporal lobar degeneration phenotypes, with smaller samples.

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

This study has several implications. Firstly, it showed how the use of different carer styles contributed to the PwD's performance of ADLs. Clinicians may need to consider the identification of the carer's style when using informant-based questionnaires to evaluate performance of ADLs. This could help clinicians identify possible effects of carer styles on the PwD's performance of daily tasks, allowing them to offer appropriate support to their clients and families. In addition, this study suggests that the use of encouragement style should be advised to carers when supporting PwD in their daily tasks and other dementia-related issues. A relevant implication for researchers is the opportunity to develop and test non-pharmacological multicomponent intervention programmes that focus on the style that carers adopt when dealing with dementia-related problems and apathy management. By targeting these strategies, novel carer-based interventions could maintain function and so delay the dementia's progression, while also having a positive effect on carer wellbeing.

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

5.5 Summary

This chapter revealed how the combination of both intrinsic and extrinsic factors, including the carer's use of different strategies, can affect the PwD's ADL performance.

In order to explore this topic further, I decided to go a step forward to investigate if the carer's report of ADL performance is consistent with the PwD's ability to perform specific tasks. I did this by testing whether there was a discrepancy between the carers' appraisal of task performance and the observed ADL performance, using a standardised performance-based ADL assessment. In addition, I wanted to study how different carer-related factors, including the strategies that carers use to support ADL performance, affected this discrepancy.

Chapter 6: Discrepancy between the performance and the ability to perform ADLs

This chapter is based on the paper:

Camino J, Khondoker M, Trucco AP, Backhouse T, Kishita N, Mioshi E. (2022) Contributions of carer management styles to the discrepancy between reported and observed ADL performance in people with dementia. *J Alzheimers Dis*, 88(4):1605-1614. http://doi.org/10.3233/JAD-220155

6.1 Introduction

The assessment of performance of ADLs for people living with dementia relies mostly on the carer's report through widely used informant-based questionnaires (Desai, 2004). As a result, decisions about the type and amount of support the carer provides to the PwD are mainly based on the carer's appraisal of the PwD's ADL performance (Zimmerman, 1994). Although informant-based assessments are affordable and easy to administer (Desai, 2004), certain carer-related factors (Conde-Sala, 2013) have been shown to affect their appraisal of the PwD's everyday functioning. Performance-based ADL assessments, on the other hand, require that the PwD performs day-to-day activities during the assessment, thus allowing clinicians and researchers to objectively observe and evaluate the individual's task performance, but they are costly (Camino and Mioshi, 2017).

As already mentioned in Section 2.2, the WHO launched The ICF (WHO, 2001) recognising the importance of gathering an individual's information about performance of activities and their potential abilities to carry them out. Identifying the discrepancy between reported and observed ADL performance could be the first step in recognising the type of support the PwD may need to perform a task, and which type of guidance carers may require. As such, several studies have identified discrepancies between the ADL performances (Argüelles, 2001; Loewenstein, 2001; Mioshi, 2009); however, gaps in knowledge remain. It is not known how extrinsic potentially modifiable factors affect this discrepancy in ADL functioning and, importantly, the type of support the PwD may need when performing daily tasks.

Research into the discrepancy between ADL performances, as reported by the carer, and a standardised observed performance, has shown contradictory results. On one hand, some studies found that carers underestimate the PwD's performance of ADLs (Bressan, 2007; Mioshi, 2009), while others reported that carers overestimate what the PwD could do (Doble, 1999a; Loewenstein, 2001). Among factors associated with the carers' appraisal of ADL performance, PwD's higher level of cognition – an intrinsic factor, seemed to contribute to carers' overestimation of ADL performance (Doble, 1999a; Loewenstein, 2001).

Certain carer variables have also been associated with the discrepancy in ADL performances, such as carer burden (Mangone, 1993; Zanetti, 1999) and carer depression (Argüelles, 2001). For example, carers who present with higher levels of burden tend to underestimate ADL performance (Zanetti, 1999). Studies examining carer depression have shown varied results: a study found that carers with clinical depression underestimated ADL performance (Argüelles, 2001) while another found no associations between the carer's appraisal of ADL performance and the carer's level of depression (Loewenstein, 2001). In addition, even though carers' level of anxiety is a prevalent problem experienced by carers of PwD (Kaddour and Kishita, 2020), little is known about the role it plays in the way carers report ADL performance.

Another possible factor that could influence the way caregivers report ADL performance is the management style that caregivers use daily, when dealing with dementia-related issues. Different styles have been identified, including criticism, active management and encouragement styles (Hinrichsen, 1994). Criticism describes a caregiver who yells, criticises and threatens the PwD. Active management includes engaging the PwD, stimulating and assisting them while encouragement refers to a caregiver who would praise the PwD using an emotionally-based approach to solve problems. A recent study showed how the caregiver's use of criticism and encouragement styles affected PwD's ADL performance (Camino, 2021a). However, it is still unclear how caregiver management styles may influence the discrepancy between reported and observed ADL performance. Investigating the role of caregiver management styles would contribute to our understanding of the type of support the PwD needs when completing daily activities.

The main goals of this study were to determine if (1) there is a discrepancy between PwD's ADL performance as reported by their carers and a standardised observed performance. In addition, the study explored whether (2) carer management styles and the carers' level of depression and anxiety have an effect on this ADL performance discrepancy.

6.2 Methods

6.2.1 Study design

This was a cross-sectional exploratory study that followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) recommendations (von Elm, 2007) to design and report the results of this study.

6.2.2 Participants and procedures

Participants included in this study were originally recruited to the parent project, TASKed, as explained in Section 3.5. Inclusion criteria comprised a diagnosis of dementia, according to the DSM-V (American Psychiatry Association, 2013) and the PwD had to be able to perform at least two daily tasks without help, such as washing their hands, brushing their teeth or making a hot drink and had to be willing to be video-recorded while performing certain tasks. Carers had to be a family member or friends of the PwD, be older than 18 and be fluent in English and be providing more than seven hours of care per week.

PwD and their carers (dyads) were initially visited at home as part of the TASKed study and completed several questionnaires and assessments, including an informant-based interview on PwD's performance of ADLs. All PwD were invited to complete a performance-based ADL assessment and, if they agreed to it, the assessment was carried out within six months of the first TASKed visit. Performance-based assessments were video-recorded to enable scoring by two independently trained raters (APT and me). Only PwD and carers who completed both the ADL informant-based interview (DAD) and the performance-based ADL assessment (AMPS) were included in the study. Sixty-eight PwD and their carers (n=68 dyads) were eligible for inclusion. From these, four dyads were excluded because no comparable data across assessments was available (e.g., meal preparation tasks evaluated in the AMPS had not been evaluated with the DAD), leaving a total sample of 64 dyads for the analyses. All of these participants were included in Sample 1. A smaller sample was used (Sample 2) for the second research question, as there was some missing data for the carer's depression and anxiety measures (n=61).

6.2.3 Ethical considerations

Ethics approval was obtained through the TASKed study and was provided by the HRA, REC (IRAS 199002; 16/LO/0544). Participation was voluntary and both PwD and carers' consent was gained before the assessments were conducted.

6.2.4 Instruments

Demographic information for both the PwD and the carers was documented and included: PwD's age, gender, level of education, length of symptoms, marital status and living situation. Carer's age, gender, education and relationship with the PwD were also documented. This was also explained in Section 3.7.

Instruments

Assessment of Motor and Process Skills (*AMPS)* (Fisher, 2012) was used to assess ADL performance using direct observation of daily activities, or ability to perform ADLs. The AMPS is a performance-based assessment of two tasks that can be selected from a list of more than 100 cross-cultural standardised activities. After the observation is completed, the performance of the participant is scored using 35 items. The raw scores are then entered into a computer programme that converts them into linear measures using a Rasch model approach. Two main logit scores are given: Process Skills and Motor Skills. The Process Skills score was used for the analyses due to the cognitive nature of its items. To check for inter-rater reliability, 20% of the AMPS evaluations were scored by a second trained OT (APT), blind to the first set of scores (myself). In this study, the AMPS Process Skills score was used to refer to observed ADL performance and was called 'AMPS performance score', which refers to the ability to perform activities.

Disability Assessment for Dementia (DAD) (Gélinas, 1999) was used to assess ADL performance as reported by the carer. The DAD is an informant-based assessment which provides information about both personal care tasks and more advanced tasks, such as meal preparation, medication management and going out. The DAD consists of 10 subdomains, including hygiene, dressing, continence, eating, meal preparation, telephoning, going out, finances and corresponding, medication and leisure and housework. Each subdomain contains different steps or components of the task. The items of the form are presented as questions and the scoring system offers three answers: Yes (1), No (0) and Not Applicable (NA) (these exclude tasks that had never been performed by the person before the onset of dementia). The subdomain scores were converted to an individual percentage according to the number of subtasks of the subdomain the PwD still completes (yes=1) or does not (no=0). Higher scores on the DAD indicate better ADL performance. In this study, DAD subdomain scores were used to refer to the ADL performance as reported by the caregiver and called ‘DAD performance score’, which refers to the performance of activities.

Frontotemporal Dementia Rating Scale (FRS) (Mioshi, 2010) was used to categorise PwD in regard to dementia severity. The FRS is an interview questionnaire which comprises 30 items related to everyday functioning and behavioural symptoms. Items are scored as 0 (all the time and sometimes) and 1 (never). The FRS has been shown to detect disease progression also in other dementias (Lima-Silva, 2020), confirming suitability for use in this study. The FRS categories ‘very mild’ and ‘mild’ were combined, and so were the categories ‘severe’, ‘very severe’ and ‘profound’, resulting in three main categories of interest for this study: mild, moderate and severe.

Dementia Management Strategies Scale (DMSS) (Hinrichsen, 1994) was used to identify carers’ management styles. This self-complete questionnaire contains 28 items that characterise three different styles of management when dealing with dementia-related problems: criticism, active management and encouragement. Items are scored on a frequency scale that ranges from never to most of the time. Each style can be assessed independently. For this study, scores of each style were converted to a percentage to enable comparison between styles.

Patient Health Questionnaire (PHQ-9) (Kroenke, 2001) was used to measure carers’ symptoms of depression. The scale comprises nine items that evaluate symptoms of depression over the previous two weeks. The items range from 0 (not at all) to 3 (nearly every day). Lower scores represent lower levels of depression, with scores between 5-9 considered mild depression, scores between 10-14 considered moderate depression and scores higher than 15 considered moderately severe to severe depression (Kroenke, 2001).

Generalised Anxiety Disorder scale (GAD-7) (Spitzer, 2006) was used to assess and measure the frequency and severity of the carers’ anxiety symptoms. The scale contains seven items with options that range from 0 (not at all) to 3 (nearly every day). Higher scores denote higher levels of anxiety, with scores higher than 16 considered severe anxiety, scores between 11-15 considered moderate anxiety and scores between 6-10 considered mild anxiety (Spitzer, 2006).

6.2.5 Sample Size

The sample size calculation (G*Power, version 3.1) for a regression analysis included three carer management styles, carer depression and carer anxiety as independent factors. The power calculation used R-squared increase (Cohen, 1988). The minimum sample size required, in order to achieve a power level of 0.80, a significance level of 0.05, and a medium effect size of 0.15 was 55.

6.2.6 Data Analyses

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

To characterise the sample, descriptive statistics were performed on demographic and clinical measures. Independent samples *t*-test was used for comparison of continuous variables, while chi-square test was used for categorical variables.

To investigate if there was a discrepancy between the informant-based ADL assessment (DAD), which records ADL performance as reported by the carer, and the performance-based (AMPS) assessment, which entails the observation of ADL performance, a new continuous variable was created, named *comparative ADL score*. In this first step, each individual *comparative ADL score* created was a result from the comparison and subtraction between the AMPS and the DAD performance scores (see Table 6.1). Thus, the AMPS performance score, which comprises the observation of the performance of two tasks, was compared to the subdomain score of the DAD, which is equivalent to the two tasks that were observed with the AMPS. For example, when the PwD performed two kitchen-based tasks for the AMPS, the subdomain 'meal preparation' of the DAD was used in the generation of the *comparative ADL score*. Table 6.1 describes the score comparison used between both the AMPS and the DAD performance scores, to generate the *comparative ADL score* for each participant. Both these instruments measure two different constructs of activities of daily living. For the purpose of this study, and following the ICF classification (WHO, 2001), the DAD is used to record what a person does in their daily routine, while the AMPS is used to measure potential ability to complete activities.

Table 6.1. Stratification used to analyse score comparison between performance and ability to perform tasks.

Table with stratification of impairment on ADL performance and score comparison used to analyse consistency between performance as reported by the carer (DAD) and performance scored using direct observation of tasks (AMPS).

Level of ADL impairment	DAD	AMPS*
No change in ADL performance (0)	100%	> 1.0
Marginal to mild ADL impairment (1)	70 - 99%	0.9 / 0
Moderate to severe ADL impairment (2)	30 - 69%	-0.1 / -0.9
Severe to very severe ADL impairment (3)	0 - 29%	< -1.0

ADL (activities of daily living); DAD (Disability Assessment for Dementia) informant-based assessment; AMPS (Assessment of Motor and Process Skills) performance-based assessment.
**AMPS Process Skills' cut-off: 1.0 (Fisher, 2012).*

It was then established whether there was overestimation, underestimation or perfect agreement between the informant-based and the performance-based assessments. Overestimation was determined when the ADL performance score reported by the carer was better than the ADL performance observed. For example, if the participant scored 100% in the DAD (no change in ADL performance) and obtained a score between 0 to 0.9 in the AMPS (marginal to mild ADL impairment) their *comparative ADL score* was 1 (Table 6.2). Agreement was determined when the same level of ADL impairment was reported by the carer and during the observation of the same tasks. As such, when a participant obtained the same ADL score in both the AMPS and the DAD performance scores, the *comparative ADL score* was zero (0). Underestimation was determined when the ADL performance reported by the carer was poorer than the observed ADL performance (Table 6.2). For instance, if a participant scored between 70 to 99% in the DAD (marginal to mild ADL impairment) and scored more than 1.0 in the AMPS (no change in ADL performance) their *comparative ADL score* was -1. The range of scores in the *comparative ADL score* goes from +3 to -3. See Table 6.2 for more details. To determine the level of agreement, overestimation and underestimation of this cohort, Cohen's Kappa was used (agreement vs disagreement).

Table 6.2. Description of how each comparative ADL scores (overestimation, agreement and underestimation of ADL performance) were computed and clinical interpretation.

Comparative ADL score	**Clinical interpretation**	**DAD Score**	**AMPS Score**
Overestimation (=3)	DAD score higher than AMPS	**100%**	**0.9 to 0**
Overestimation (=2)		**100%**	**-0.1 to -0.9**
Overestimation (=1)		**100%**	**<-1.0**
Agreement (=0)	DAD and AMPS scores: same ADL level	**100%**	**> 1.0**
		70 – 99%	**0.9 to 0**
		30 – 69%	**-0.1 to -0.9**
		0 – 29%	**< -1.0**
Underestimation (=-1)	DAD score lower than AMPS	**70 – 99%**	**> 1.0**
Underestimation (=-2)		**30 – 69%**	**0.9 to 0**
Underestimation (=-3)		**0 – 29%**	**-0.1 to -0.9**

ADL (activities of daily living); DAD (Disability Assessment for Dementia): informant-based assessment. AMPS (Assessment of Motor and Process Skills): performance-based assessment. Table 6.1 describes the score interpretation for the DAD and AMPS performance scores.

To investigate if there was a relationship between the severity of dementia and the *comparative ADL score*, Spearman's rank order correlation was applied.

Thereafter, multiple linear regression analysis, enter method, was used to investigate which factors may influence the discrepancy between observed and reported ADL performance. The new *comparative ADL score* was used as the dependent variable and carer management styles (criticism, active management and encouragement), carers' level of depression and anxiety, were used as independent variables in the regression model.

Preliminary analyses were conducted to ensure that assumption of normality, linearity and homoscedasticity were met. Visualisation of the Normal P-P Plot and the scatterplot of the standard residuals, suggest that these assumptions were not violated. Tolerance and VIF's values were all within accepted limits, confirming that multicollinearity was not a concern. Outliers were also checked using Mahalanobis and Cook's distances. Mahalanobis distance scores (MD=17.42) were below its critical value of 20.52 for five independent variables (Pearson and Hartley, 1958) and Cook's distance value was below one (D_i= 0.25). Thus, we can conclude that no outliers were found within this data.

To examine agreement between raters (APT and me) on the AMPS assessment, Intraclass Correlation Coefficient (ICC) (Koo and Li, 2016), two-way mixed models, absolute agreement, was determined. Raters reached excellent agreement for AMPS Process Skills scores [0.967 with a 95% CI from 0.895 to 0.990 ($F_{(12,12)}$=29.272, *p*=<0.000)].

6.3 Results

Demographics

PwD were on average 77 years old, mostly male, married and lived with their family. They had a diagnosis of AD (64.1%), VD (15.6%), MD (7.8%) and other dementias (12.5%). PwD were mostly in the severe stage of the disease (53.1%), followed by those in the moderate stage (37.5%); they had an average of four years of disease duration (Table 6.3).

Table 6.3. Information about demographic characteristics and clinical variables of the sample.

All the sample and grouped (n=64) by dementia stage. Comparisons were done between moderate and severe stages; mild group not included due to small sample size.

	PwD (n= 64)	**Mild (n=6)**	**Moderate (n=24)**	**Severe (n=34)**	**Moderate vs severe**
Age (in years)	77.61 (7.32)	76.83 (8.68)	77.25 (7.99)	78 (6.78)	ns
Gender (Male %)	62.5	50	58.3	41.7	ns
Education (in years)	11.89 (2.43)	11.33 (0.81)	12.04 (2.64)	11.88 (2.51)	ns
Length of Symptoms	4.28 (3.43)†	3.00 (1.26)	2.77 (2.02)	5.56 (3.96)	**
ADLs (DAD)	38.37 (40.31)†	89.17 (18.23)	69.63 (14.71)	33.59 (18.12)	**
ADLs (AMPS)	0.50 (0.58)	0.90 (0.22)	0.71 (0.36)	0.29 (0.67)	**

*Scores are means with SD in parentheses. ADLs (Activities of Daily Living) were measured with the DAD (Disability Assessment for Dementia) and the AMPS (Assessment of Motor and Process Skills). Independent samples t-test was used for continuous variables. Chi-square test was used for categorical variables. Statistically significant difference **p=<0.01. † Missing data for the length of symptoms (n=60/64) and ADLs (DAD) (n=63/64).*

Carers were 72 years old on average, mostly female and were spouses of PwD. As a group, their average anxiety score fell under the category of 'no anxiety'. Carers reported mild symptoms of depression (Table 6.4). In addition, carers' responses showed that they used an active management style (71.4%) more frequently than encouragement (66.7%). None of them selected criticism style as their main approach when managing dementia-related problems (Figure 6.1).

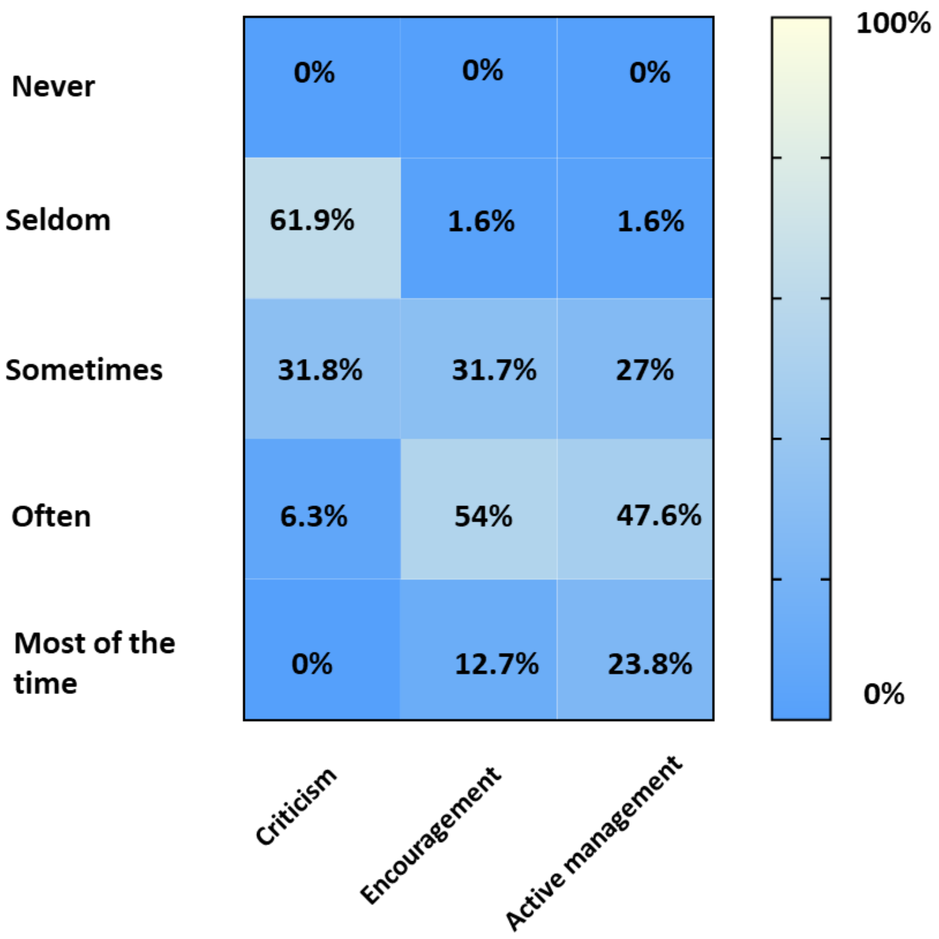


Figure 6.1 *Heat map reporting carers selected styles.*

The frequency with which carers reported the use of different strategies characterised by the DMSS: criticism, active management and encouragement style, was reported. Carer management styles were assessed using the DMSS (Dementia Management Strategies Scale). The scale ranges each strategy using this graduation: 1 (never used the strategy), 2 (seldom), 3 (sometimes) 4 (often) and 5 (most of the time).

Do carers overestimate or underestimate the person with dementia's ADL performance?

The majority of carers underestimated PwD's performance of ADLs, as they reported poorer performance when compared with the score obtained during the observation of the same tasks (71.9%). Less than a quarter of carers overestimated PwD's performance of ADLs (17.2%), i.e., reporting better ADL performance than the one actually observed. Finally, only 10.9% of carers reached perfect agreement between ADL performance scores, where carers' report of ADL performance (DAD) was at the same level as the one obtained during the observation of the tasks (AMPS). As such, Cohen's kappa [*k*= -0.025 (95%CI -0.123 – 0.073)] indicated a poor level of agreement between DAD and AMPS performance scores (Cohen, 1960).

Overall, carers from the agreement, overestimation or underestimation groups were similar. There were no significant differences between the *comparative ADL score* on the age of the carer, relationship with the PwD, carer's level of depression and anxiety. Table 6.4 describes demographics and clinical variables of PwD and their carers, grouped by overestimation, agreement or underestimation of ADL performance. In addition, there was no significant association between the *comparative ADL score* and the dementia severity ($R_{s(62]}$=0.216, p=0.089).

Table 6.4. Information about demographic characteristics and clinical variables of the sample grouped by their comparative ADL score. Information about demographic and clinical variables of carers included.

	Carers (n=64)	Overestimation (n=11)	Agreement (n=7)	Underestimation (n=46)
Length of symptoms	N/A	4.6 (5.77)†	4.5 (4.8)†	4.18 (2.53)†
Relationship	-	-	-	-
Spouse	84.4	90.9%	85.7%	82.6%
Children	9.4	-	14.3%	10.8%
Other	6.2	9.1%	-	6.6%
Dementia Stage	-	-	-	-
Mild	N/A	33%	16.7%	50%
Moderate	N/A	20.8%	16.7%	62.5%
Severe	N/A	11.8%	5.9%	82.4%
Carer Age	72.61 (9.20)†	-	-	-
Carer Gender (male)	31.2	-	-	-
Carer Education	12.88 (3.04)	-	-	-
Carer Depression	5.20 (4.60)†	-	-	-
Carer Anxiety	4.56 (4.96)†	-	-	-

Scores are means with SD in parentheses.
Comparative ADL score: overestimation occurred when the ADL performance reported by the carer (DAD) was better than the one observed (AMPS). Agreement was reached when the participant obtained the same ADL performance as reported by the carer (DAD) and the observed (AMPS). Underestimation occurred when the performance reported by the carer (DAD) was poorer than the one observed (AMPS).
Dementia stage was classified using the FRS (Frontotemporal Dementia Rating Scale). Carer depression was assessed using the PHQ-9 (Patient Health Questionnaire) and carer anxiety was measured with the GAD-7 (Generalised Anxiety Disorder scale).
† Missing data for PwD's length of symptoms (Overestimation n=10/11; agreement n=6/7; underestimation n=44/46); carer's depression (n=45/46) and carer's anxiety (n=44/46).

What are the factors that affect the comparative ADL score?

Five factors were included in the regression model: the three carer management styles, carer depression and carer anxiety. The *comparative ADL score* was used as the dependent variable.

This overall model comprising the three carer styles, carer depression and carer anxiety, explained 18% (R^2=0.18, $F_{(5, 55)}$=2.52, *p*=<0.05) of the variance of the *comparative ADL score*. Active management (β=-0.037, $t_{(60)}$=-3.363, p=0.001) and encouragement (β=0.025, $t_{(60)}$=2.018, p=0.05) styles were the two factors that made the largest and statistically significant contribution to the model (Table 6.5).

Table 6.5. Results of regression analysis.

Independent variables included in the multiple regression analysis. Dependent variable: *comparative ADL score* (Sample 2: n=61).

Predictors	Comparative ADL Score			**95% CI of the β**	
	β	***T***	***P***	**Lower**	**Upper**
Anxiety (GAD-7)	-0.034	-0.684	0.497	-0.664	0.326
Depression (PHQ-9)	-0.042	-0.821	0.415	-0.665	0.279
Criticism (DMSS)	0.007	0.677	0.501	-0.210	0.424
Active management (DMSS)	-0.037	-3.363	**0.001**	-1.040	-0.263
Encouragement (DMSS)	0.025	2.018	**0.048**	0.003	0.782

Note. $F_{(5,55)}$=2.52, p=<0.05, R^2=0.18.

For each point that the carers scored on the active management subscale, the *comparative ADL score* decreased by 0.4%. This indicates that the use of active management strategies may decrease the *comparative ADL score* along the scale. For each point that the carers scored on the encouragement subscale, the *comparative ADL score* increased by 0.25%. This means that the more the carer uses encouragement style, the more the comparative ADL score increases along the scale.

To facilitate clinical interpretation of the findings, Figure 6.2 was created and examples are described next. For instance, if a carer's *comparative ADL score* was -3 (underestimation, bottom of y axis), this carer could use more *encouragement* strategies in order to get closer to ADL agreement, and to reduce the gap between reported and observed ADL performance. If the carer's *comparative ADL score* was +3 (overestimation, top of y axis), this carer could use more *active management* strategies to reduce the *comparative ADL score* and move closer to zero, i.e., ADL agreement.

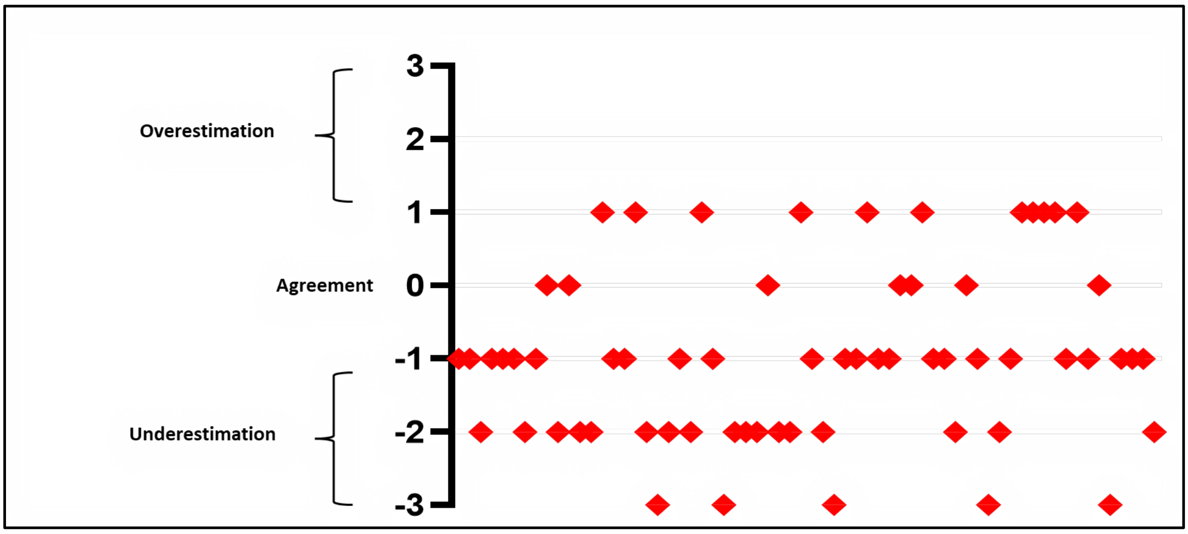


***Figure 6.2**. Distribution of carers according to their comparative ADL score.*
Each carer is represented as a red diamond on the figure above (n=64). Y axis represent the comparative ADL score. X axis represent the carers. Overestimation occurred when the ADL performance reported by the carer was better than the one observed. Agreement was reached when the participant obtained the same ADL performance as reported by the carer and the one observed. Underestimation occurred when the performance reported by the carer was poorer than the one observed.

6.4 Discussion

This original study investigated the discrepancy between PwD's ADL performance as reported by the carer and the observed ADL performance, while introducing novel carer-related factors to investigate what influences this discrepancy. Two main findings arose: the level of agreement between the carer's appraisal of ADL performance and the observation of the same tasks was low; and the strategies that carers use daily when dealing with dementia-related problems, namely the encouragement and active management styles, affected the identified discrepancy in ADL performance.

The majority of the carers in this study underestimated PwD’s ADL performance, reporting lower performance than the one observed during the completion of the same tasks. This is in accordance with other studies (Bressan, 2007; Mioshi, 2009; Zanetti, 1999) that used both informant and performance-based assessments and found that carers mostly underestimated PwD’s ADL performance. A possible explanation would be that family carers might require specific training to appropriately appraise PwD’s remaining abilities to perform ADLs. These difficulties progress slowly over time in dementia (Reisberg, 1982) and carers may be adapting to a situation without having enough information on how to enable the PwD to engage in activities of daily living for longer. As such, carers may report PwD’s ADL performance based on the help they provide instead of the real assistance that the PwD requires. This study suggests that the optimal support provided to the PwD could be identified if the caregiver is offered training on how to recognise the level of assistance a person needs.

The number of carers in this study who reached perfect agreement between reported and observed performance was quite small, i.e., carers reported the same level of ADL performance as the one that was formally observed during assessment. A possible reason why the agreement was low in this group of carers may have been related to the methodological differences between the performance-based assessment and informant-based questionnaire used in this study. For example, the PwD may be able to prepare a sandwich when observed but they may present with other difficulties when preparing a full cooked meal. Thus, the scores on the DAD may have been lower than the AMPS results due to the scoring system of the informant-based assessment. In future, studies comparing single tasks would contribute further to the understanding of the discrepancy of ADL performances. An important factor that could also affect the agreement between reported and the observed performance may lie in the fact that carers may need to provide constant motivation to the PwD for them to complete certain tasks. Future studies could target the dynamics that underpin the relationship between PwD and their carers.

Similarly, the proportion of carers who overestimated PwD's ADL performance was also low in the current study. These carers reported that the PwD had a higher performance that the one observed during the completion of the same tasks. One possible reason may be that these carers minimised the difficulties the PwD had when carrying out daily tasks, or they may not have been present when the PwD performs tasks and are unable to identify difficulties. Another possible interpretation is that carers may think that the PwD's everyday problems are not caused by the dementia-related decline and they may accept changes in day-to-day activities as part of other circumstances, including ageing itself.

Another important finding was that there were no differences among those carers who underestimated, reached an agreement or overestimated ADL performance, in terms of their age and relationship with the PwD. This contrasts with other studies where it was found that discrepancy was higher if the informant was a spouse of the PwD (Zanetti, 1999). In addition, dementia severity was not associated with the *comparative ADL score*. This is in agreement with other studies, where dementia severity did not affect the difference between observed and reported performance (Karagiozis, 1998). This finding suggests that potential interventions to promote independence in dementia could be applied in all stages of dementia.

The use of the carer styles affected the *comparative ADL score* in different directions (i.e., overestimation or underestimation) and this may be explained by the type of strategies these styles comprise. Carers using *active management* strategies take an active role stimulating and prompting their family member through the adaptation of the environment, repetition and anticipating problems and thus may underestimate PwD's ADL performance. The strategies belonging to *encouragement* style, on the other hand, are based on an approach where carers praise the PwD and motivate them to discuss their feelings and to do activities for themselves, so perhaps overestimating PwD's ADL performance. Therefore, the *active management* places the carer in an active and practical role, perhaps resolving all issues for the PwD before they have had a chance to try resolving them, while the *encouragement* style characterises a carer who focuses on an approach where the PwD is encouraged to resolve the issues by themselves, before support is provided.

The criticism style did not affect the discrepancy between reported and observed ADL performance. This was a surprising finding given that the use of criticism style was found to negatively affect PwD's performance of daily tasks (Camino, 2021a). One way to explain this finding may be that criticism strategies are based on communication-related interactions, rather than providing actual support, and therefore its use had no effect on the *comparative ADL score*. Another reason could be the fact that this sample of carers reported seldomly used criticism, which can explain why it did not affect the discrepancy between reported and observed performance.

Carers' level of depression and anxiety had no effect on the *comparative ADL score* either. This can be attributed to the nature of the PwD's performance of daily tasks which is based on how their skills are affected by intrinsic dementia factors (Camino, 2021a) and extrinsic factors such as the environment (Camino, 2021b), rather than on the way the carers feel. Other studies have published contradictory results on the way depression affected carers' reports of ADL performance (Argüelles, 2001; Loewenstein, 2001; Zanetti, 1999) and, to date, none of those studies measured the effect of carer level of anxiety on the discrepancy between informant and performance-based measures. Furthermore, the low incidence of depression and anxiety in this cohort of carers may explain the lack of effect on the discrepancy between reported and observed ADL performance. Future studies could be conducted with carers with a different range of symptoms of depression or anxiety to investigate whether these affect the discrepancy between ADL performances.

One limitation of this study was the composition of the sample, which was comprised of PwD in the more severe stages of the disease. The investigation of everyday functioning in older adults in the mild stages of dementia and how their carers appraise ADL performance is an important area requiring further research.

Investigating ADL changes early in the post-diagnostic phase may enable identification of the type of support the PwD needs, reducing underestimation or overestimation of carers when appraising ADL performance. It is also important to mention the methodological complexity of comparing two different elements of ADLs, namely performance (DAD) and ability (AMPS). It is only possible to conduct this comparison by using two different types of ADL assessments, i.e., an interview-based questionnaire and a performance-based assessment. Finally, it needs to be acknowledged that this model explained 18% of the variance of the *comparative ADL score*, so future studies could investigate the role of other variables that may influence the discrepancy between reported and observed ADL performance in PwD.

These results are promising for those working in the dementia field, as they highlight the prominent role of the styles that carers use when dealing with dementia-related problems on PwD's ADL performance, and provide knowledge on how to improve carers' skills to support independence for the PwD. Novel carer-based interventions and clinical advice should take into account the type of strategies carers use to enable optimal support for activity participation in dementia.

6.5 Summary

This chapter showed a high discrepancy between reported and observed ADL performance and identified how the strategies that carers use affect this discrepancy. The next chapter will explore the specific types of assistance that carers implement when supporting the PwD during the performance of daily tasks.

Chapter 7: Assistance provided by carers to people with dementia during the performance of ADLs

This chapter is based on the manuscript:

Camino J, Trucco AP, Kishita N, Mioshi E, Backhouse T. (2021)

What type of assistance do carers provide to people with dementia during the performance of ADLs?

This manuscript is currently under review.

7.1 Introduction

PwD present with progressive difficulties when performing routine ADLs (Desai, 2004; Green, 1993). As a consequence, the individual gradually loses their ability to remain independent and will, at some point, require assistance to complete daily tasks. Typically, assistance will be mostly provided by family members who become informal carers (Freedman and Spillman, 2014; Prince and Jackson, 2009) who usually do not receive any training or specific information to gain the skills they need to appropriately support their family members (Georges, 2008).

Training interventions for carers of PwD, are usually targeted to increase the carer's abilities to improve communication with the PwD (Ripich, 1998), and behavioural management (Chenoweth, 2009). In these types of interventions, carers are trained in how best to communicate with the PwD, by learning to use specific words or using a certain tone of voice (Chenoweth, 2009; Eggenberger, 2013). Research has identified the usefulness of certain strategies that nurses employ when assisting residents with moderate to severe dementia (Wilson, 2012) and how verbal assistance can be provided to people with brain injury during an assessment of ADLs (Gagnon-Roy, 2021). In dementia care, several verbal strategies were identified, such as greeting, complimenting, using repetition and negotiating.

However, the data were obtained from the report of health specialists and it may have been influenced by their professional conduct (Dalpai, 2016; Wilson, 2012). Communicating with the PwD is important in order to sustain a long and healthy interaction between both the carer and their family loved one (Ripich, 2000) and has been proven to reduce the carer's level of distress (Done and Thomas, 2001). However, it is not clear that the communication strategies that a carer uses will lead to a successful provision of assistance when the PwD requires support to complete ADLs.

When it comes to the assistance provided by family carers of PwD during the performance of daily tasks, fewer studies have been done, and those have mainly focused on the amount of assistance carers tend to provide (Amato, 2021; Riffin, 2017) rather than how carers assist a PwD to complete a task. As such, studies on the types of assistance the carer offers to the PwD when performing ADLs are rare, and the ones found investigated the assistance provided by formal carers rather than family members. Using an observational, qualitative content analysis approach, one study observed support workers and nurses assisting PwD during the performance of a personal care task (Wilson, 2013). Three different dimensions were identified from their data, including social communication, task-focused communication and miscellaneous, which included physical assistance and redirection. Carers were qualified health assistants whose approach could have been influenced by their professionalism and expertise when assisting the PwD. In addition, the task chosen for the study was a basic ADL (brushing teeth) which may have influenced the type of interactions the authors found. Studies with people with different abilities and doing different activities are needed to elucidate the types of assistance carers use when supporting ADL performance. This would contribute to the understanding of how specific actions could be targeted in future interventions to better support PwD during the performance of ADLs and could be useful to develop carer-based interventions to sustain ADL performance for longer.

This study's main objective was to explore the types of assistance that family members employ to support the PwD during the performance of daily tasks. In addition, this study aimed to gain understanding about why carers assisted and the consequences of carers using different types of assistance during task performance.

7.2 Methods

7.2.1 Study design

A secondary analysis was conducted using data collected for the TASKed project to complete this exploratory qualitative study, which followed the Standards for Reporting Qualitative Research (SRQR) recommendations (O'Brien, 2014) to report its findings.

7.2.2 Ethical considerations

Ethical approval for the study had been gained through the TASKed project and was provided by the HRA, REC (IRAS ID 199002; 16/LO/0544).

7.2.3 Participants, procedures and sampling

Participants included in this study were PwD and their family carers who consented to the TASKed project, as explained in Section 3.5. The diagnosis of dementia was based on the DSM-V (American Psychiatric Association, 2013). Eligibility criteria for the participants with dementia included their ability to perform a task by themselves, such as washing their hands, making a sandwich or making a hot drink. Inclusion criteria for the carers were being family members of the PwD and they had to be fluent in English. They also had to be older than 18 years old and provide at least seven hours a week of unpaid support. In addition, both the PwD and the carer had to be willing to be video-recorded when completing a task together.

During the consent process, TASKed participants (both PwD and their carers) were invited to complete a second research activity. This research activity consisted in the completion of a non-standardised observation of a real task by the PwD, while the carer was asked to provide assistance if the PwD needed help. Some of the tasks included making a fruit salad, making a cheese sandwich, making a hot drink and doing a personal care task. This activity was video-recorded to allow for the analysis of the data. In total, 128 participants (64 dyads) completed this activity.

Next, to answer the research question proposed for this study, I purposely sampled from these recordings (n=64) to conduct a secondary data analysis (Heaton, 2004). This purposive sampling technique was used to identify and include individuals with different characteristics (Luborsky and Rubinstein, 1995) in order to gain a wide understanding of the types of assistance a PwD receives when they perform certain tasks. Purposive sampling in qualitative research has been shown to be more effective than random sampling (van Rijnsoever, 2017). Different factors have been shown to affect the PwD's performance of ADLs in the past, including the PwD's age (Tabira, 2020) the carer's gender and relationship with the PwD (Conde-Sala, 2013), and stage of dementia (Liu, 2007). Therefore, these variables were taken into consideration to select the study's sample. For example, I made sure to select individuals with different stages of dementia but mainly in severe and moderate stages as these tend to define the PwD's difficulties in ADLs (Liu, 2007), and with different ages (younger than 70, between 71 and 80 and older than 80 years old). I also selected cases where carers were either male or female and included cases where the carer was either a husband or wife, a daughter or a son.

7.2.4 Data collection

All activities were completed in the participants' own home. Carers completed questionnaires that included demographic information for both participants, as part of the TASKed project. In order to identify the PwD's stage of dementia, the Frontotemporal Dementia Rating Scale (FRS) (Mioshi, 2010) was used. This interview-based questionnaire classifies dementia in six different stages, that were grouped in Mild, Moderate and Severe stages, as explained in Section 3.7.

Data collection was based on a non-participant, direct observation procedure (Busetto, 2020) where I observed and recorded the participants when they completed a task. These interactions were video-recorded to enable revisiting of data and a thorough analysis employing more than one person. I stayed in the room a small distance away from the participants but with a clear view of the activity being undertaken. On occasion, I had to follow participants around, to capture every step and interaction during the task. Occasionally, due to the location of the setting and the participants in relation to the video camera, some aspects of the task were missing from the video, such as the recording of specific steps. Permission to record was obtained from all participants during the consenting process to the TASKed project. In addition, before the recording took place, all participants were asked verbally if they re-confirmed consent for the activity to be recorded.

All the participants were given the same instruction, which was to complete a daily task; their carers were asked to assist the PwD if they needed support or assistance. I informed all the dyads that I was not going to interact with them while the PwD was completing the task (non-participant). However, some individuals interacted with me and I had to remind them of the instructions previously given. Some carers also interacted with me mainly to ask questions about the assistance that was being provided.

Tasks included making a fruit salad, a green salad, preparing a hot drink, making a cheese/ham sandwich, serving a glass of a cold drink and a personal care task, such as washing their hands. The tasks were grouped according to a hierarchical level of difficulty, where making a salad (either green or fruit) was the most difficult task, followed by making a sandwich or a hot drink and finally by serving a drink or the completion of personal care tasks. As such, the selection of the task completed was made after a discussion between the participants (both the PwD and their carers) and me. The decision on what task was the most suitable to perform was based on the number of steps the carer thought the PwD could complete, and in some cases, it was based on the PwD's familiarity with the task. For example, although some PwD said they never made a fruit salad, they said they felt capable of doing so. When the PwD could not decide which task they were going to do, the carer expressed their opinion based on the type of activities the PwD could complete during an ordinary week. There were no cases where the task had to be changed once selected.

I attempted to record all pairs for at least 10 minutes to obtain rich information about the types of assistance the carer provided when the PwD completed the task. However, the duration of the interaction was determined by different factors, including the PwD's abilities to perform the task, the carer's involvement in the process and the nature of the task itself. Some carers showed less engagement with the activity, finishing the interaction before all the steps of the task were completed. On other occasions, the PwD requested to stop the task before completing it, due to feeling fatigued.

7.2.5 Data processing and analysis

The video-recordings were safely stored in the University of East Anglia's secure file storage system, which is physically located on campus based on IBM enterprise hardware housed in secure and environmentally controlled and monitored data centres. All the researchers who participated in the analysis of the data had expressed permission through the delegation of duty log used for the TASKed project to access to the video-recordings.

A secondary data analysis was implemented on the TASKed data. Secondary analyses offer an opportunity to re analyse existing data that was primarily collected to answer other research questions (Heaton, 2004).

Data saturation (Glaser and Strauss, 1967) was employed during the analysis, to determine the sample size for this study, as it is the most frequently used process in qualitative research to determine sample sizes (Guest, 2020). Data saturation is a process in which either the data collection or the data analysis is discontinued because no new or additional information is identified (Saunders, 2018). For this study, inductive thematic saturation (Saunders, 2018) was conducted, due to the type of analysis carried out.

The data were analysed using an inductive reflexive thematic analysis (Braun, 2018) approach, based on Braun and Clarke's six-phases model (Braun and Clarke, 2006). This model proposes an accessible and flexible approach that enables the examination of patterns across the dataset. The inductive approach is a 'bottom-up' approach that is determined by observations and patterns produced from the data. The patterns were identified following the six-phase approach: 1) familiarising yourself with the data (data familiarisation), 2) generating initial codes (data coding), 3) searching for themes (theme development), 4) reviewing potential themes (revision), 5) defining and naming themes (definition of themes) and 6) producing the report (reporting findings) (Braun and Clarke, 2006). Even though this is a rigorous process, and the phases follow a sequential pattern, the analysis is flexible in regard to the order of the phases, as the researcher may need to come back to step 4 (reviewing themes) after naming them (step 5).

Four researchers participated in the data analysis to increase validity and trustworthiness (Patton, 2015). I am an OT who has extensive clinical experience working with PwD and their carers. Tamara Backhouse (TB), who is an experienced care-home worker and post-doctoral research fellow who has published several articles using qualitative approaches in dementia care. Ana Paula Trucco (APT), an OT with substantial clinical experience and PhD candidate, and Eneida Mioshi (EM), also an OT and Professor of Dementia Care Research and the primary supervisor of this thesis, with vast experience in both clinical and research areas. Collaborative and reflexive analysis using other researchers also allows the development of a richer understanding of the data (Braun and Clarke, 2019).

Stage 1: Familiarisation

I observed and recorded all interactions (n=64) and made notes of some cases to familiarise myself with the data and wrote down initial thoughts. I then selected two videos to work on stage 2.

Stage 2: Generating initial codes

Two researchers (TB and me) observed these two video-recordings independently and inductively made detailed notes of the observations, including all the different actions that carers used when providing assistance to the PwD, to generate initial codes. We made sure to code interesting, repetitive and unusual codes. We met afterwards to examine and compare the initial codes and to assess the level of consensus between the researchers. We then independently observed the same interactions using the newly agreed codes and used two new videos to see if the codes resonated with those observations. After another meeting between the two researchers, the codes were refined. A third researcher (APT) was asked to closely observe the second pair of interactions and she checked the existing codes making new inductive notes. She contributed to the identification and development of further codes.

I subsequently observed and transcribed 13 new videos. Eighty-one different codes (which included observations about the verbal and physical actions taken by carers) were found to be used during the performance of the tasks. These were transferred into a list, which was used for all the researchers (TB, EM, APT and me) to check if they resonated with their understanding of the data. Further interactions (4) were then observed and analysed (APT and me) in order to consolidate the development of the codes. Data saturation was finally gained when no new codes were found in the data (Saunders, 2018), making a total sample of 21 cases.

Stage 3: Searching for themes

I considered all codes and generated initial themes critically reflecting on what the codes meant, aiming to collapse and/or cluster codes into themes and sub-themes that could explain the types of assistance that carer used to support PwD during task performance.

Stage 4: Reviewing potential themes

Several meetings were held between researchers (EM and me) and a group meeting was held with (EM, TB and me) where all researchers engaged with the data, codes and initial themes and sub-themes and they reflected on their meanings and scope. Interpretations were discussed and themes and sub-themes were further developed and refined.

Stage 5: Defining and naming themes

Two further group meetings were held to define and name the themes and sub-themes. In the first meeting all researchers (EM, TB, APT and me) agreed on the proposed themes and sub-themes of types of assistance that carers used to support PwD during the performance of daily tasks. Names and definitions for each theme and sub-themes were discussed. In the second meeting, names and definitions for themes and sub-themes were revisited, revised and agreed.

Stage 6: Producing the report

During the analysis of the recordings, I made comprehensive notes about the interactions observed that contributed to the development of the themes. These notes helped with the development of the study in all the different stages and contributed to my understanding of how carers used different types of assistance when the PwD completes a task. This process has enabled a clear story when writing up the results.

7.3 Findings

A total of 21 video-recordings of a PwD and their carer were included in this study. Average recording length was eight minutes and 31 seconds (range 1.25 – 17.16 minutes). PwD were mostly male (61.7%), presented with a diagnosis of Alzheimer’s disease (80.8%) and lived with their family (95.2%). Most carers were female (66.7%) and were spouses of the PwD (85.7%). Demographic of the sample are presented in Table 7.1.

Table 7.1. Information about demographic characteristics of the sample. Demographic characteristics of participants with dementia (PwD) and carers of PwD (n=21).

PwD's characteristics	Total sample (n=21)
Age, mean *(SD)* (range)	78.57 *(8.14)* (61-93)
Gender, male % (n)	61.9 (13)
Education, years, mean *(SD)* (range)	12.57 *(2.95)* (6-20)
Length of symptoms, years, mean *(SD)* (range)	4.48 *(3.43)* (1-14)
Dementia diagnosis % (n)	
Alzheimer's disease	80.8 (17)
Vascular dementia	4.8 (1)
Mixed dementia	4.8 (1)
Other	9.6 (2)
Marital Status % (n)	
Married	85.7 (18)
Widowed	14.3 (3)
Living Situation % (n)	
With family	95.2 (20)
Alone	4.8 (1)
Dementia Stage % (n)	
Moderate	66.7 (14)
Severe	33.3 (7)
Carer's characteristics	**Total sample (n=21)**
Age, mean *(SD)* (range)	72.86 *(8.66)* (59-84)
Gender, female % (n)	66.7 (14)
Education, years, mean *(SD)* (range)	12.38 *(3.42)* (6-20)
Dementia-related training, completed yes % (n)	19 (4)
Relationship with the PwD % (n)	
Wife	57.1 (12)
Husband	28.6 (6)
Daughter	9.5 (2)
Son	4.8 (1)

Five main themes of types of assistance used by carers to support PwD during the performance of daily tasks were identified: 1) Person-enabled assistance, 2) Goal-directed assistance, 3) Carer-led assistance, 4) Partnership-oriented assistance and 5) Bystander (Figure 7.1).

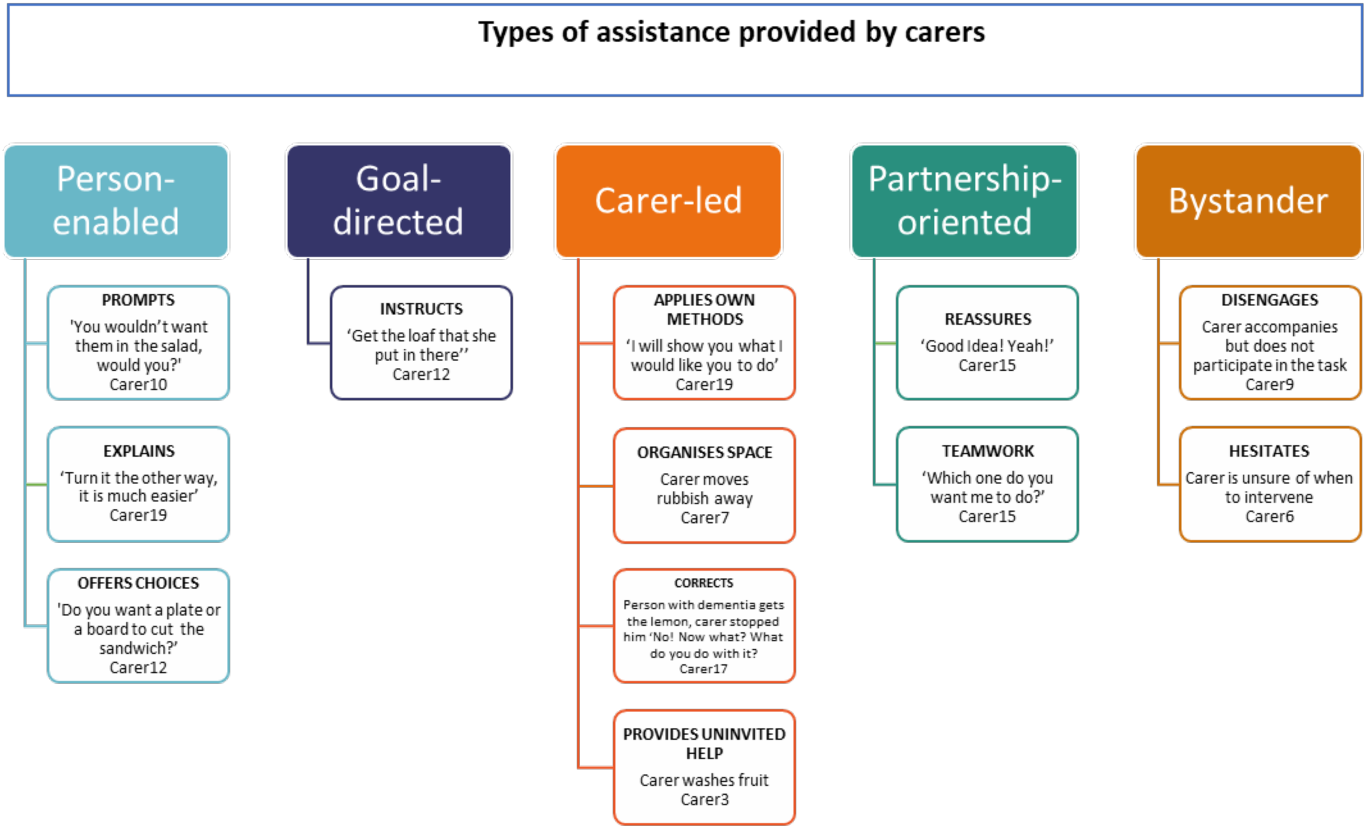


Figure 7.1 *Themes and sub-themes (with brief examples) identified and generated from the data.*

Each dyad was identified by giving them the same number. As such, Carer1 is the carer that supports PwD1; Carer2 is the carer that supports PwD2 and so on.

Analysis showed that some carers clearly used one type of the assistance identified, where others tended to move between two or more different types (identified themes) while supporting the PwD during the performance of the task.

Person-enabled assistance

The Person-enabled assistance theme contained the following sub-themes: prompts, explains and offers choices. When using this approach, carers adopted a guiding attitude when assisting the PwD and their interventions were mainly directed to promote the individual's participation. For example, a carer prompted their family member:

The person with dementia (male, father) is working at the kitchen island to make a fruit salad. The carer (male, son) stands one metre away, leaning towards the island while attentively observes what the person with dementia does. The person with dementia gets the orange, looks at it with a confused look:

Carer: ***'How would you do the orange?'*** *responsively using a gentle tone of voice.*
Person with dementia: ***'I don't know, I don't put oranges in the fruit salad.'***
Carer: ***'Well, do you want to do the pear?'***
Person with dementia gets the pear and the peeler.
Carer: ***'That should work!'***
Person with dementia peels the pear and starts cutting it.
(Person with dementia13, male, father and Carer13, male, son).

The carer used prompts to help the PwD solve a problem or overcome a barrier without making them feel like they had failed. Well-timed intervention from the carer offering stimuli or a possible solution in the form of questions enabled the PwD to maintain the pace of the task and a sense of control of the activity, since the ultimate decision was left to them.

When using person-enabled assistance, carers often provided context of what was happening:

The person with dementia (male, husband) is making a fruit salad on the kitchen table. They are cutting apples, the carer (female, wife) brings a bottle of lemon:

Carer: ***'If you sprinkle lemon on them, so that stops them from going brown'*** *using a gentle voice while giving the person with dementia the lemon juice.*
Person with dementia pours lemon into the salad.
Carer: ***'OK, if you give them a stir, so they are all coated'*** *giving the person with dementia a spoon.*
Person with dementia stirs the fruit salad.
(Person with dementia3, male, husband and Carer3, female, wife).

By using explanations, the carers allowed the PwD to know what to do and why they were using different ingredients or materials emphasising the meaning of that part of the task, while allowing the PwD to take the time needed to complete steps and engage with the development of the task.

Person-enabled assistance enabled the PwD to make decisions about the carer's interventions, and to have the space to decide how the task was completed, while the carer encouraged them in a supportive way:

The person with dementia (male, husband) is sitting on a perching stool in front of the kitchen sink. The participant is asked to wash their hands. The carer (female, wife) is standing beside the person with dementia and while grabbing their arm, points at the sink:

Carer: ***'OK, where is the bowl of water for the hands? Where is your bowl of water?'*** *using a gentle but clear tone of voice and guiding the person with dementia's arms to the sink, the person with dementia sighs.*

*Carer: **'Do you want to stand a little bit? Do you want to stand?'** supporting the person with dementia's back, person with dementia makes an unintelligible comment.*
*Carer: **'Or would you like to stay there?'** using a casual but caring tone of voice.*
The person with dementia decides to stand.
(Person with dementia18, male, husband and Carer18, female, wife).

This interaction illustrates how offering choices allowed the PwD to keep their autonomy, while also being actively guided through the task. Carers using this type of assistance demonstrated the ability to empower the PwD.

Person-enabled assistance seemed to involve a harmonised combination of different elements, such as timing prompts, explanations and offering options, according to PwD's abilities to complete the task. Carers' actions encouraged PwD to assume an active role during task performance.

Goal-directed assistance

The Goal-directed assistance theme was mainly characterised by giving instructions. Some carers took the role of 'director of the scene', providing verbal instructions and directions, but without taking the time to glance at the bigger picture of what was happening. Carers using this type of assistance did not notice if direction or instruction was required or even wanted by the PwD, and the possibility of offering options to the PwD was not sought by carers when using this approach:

The person with dementia (female, wife) is asked to serve a glass of orange juice, which was left in the fridge of their kitchen. The carer (male, husband) walks around accompanying the person with dementia:

*Carer: **'Get the orange juice from there'** using a neutral but direct tone of voice.*

Person with dementia: ***'Uhm'*** *looks at the carer's eyes and places their hand in the fridge's door handle.*
Carer: ***'Open the fridge, get the orange juice out'.***
Person with dementia: ***'Yes, we'll soon find that'*** *opening the door.*
Carer: ***'Can you see the orange juice?'***
Person with dementia: ***'Is this, is this one?'*** *getting one bottle of orange juice.*
Carer: ***'Lovely, shut the fridge door up'*** *using a gentle tone of voice.*
(Person with dementia8 female, wife and Carer8, male, husband).

This observation demonstrates how each action of the PwD was directed by the carer. Step-by step instructions were provided which shows the carer was predominantly committed to the completion of the task rather than to actively involving the PwD in deciding the next steps. This type of assistance could have been influenced by the PwD's skills to complete the task. However, there was no time or space given to the person to display their current abilities.

Goal-directed assistance seemed to be focused on the successful completion of the task rather than the participation of the PwD. Carers were highly concentrated on the consecutive achievement of each small step instead of focusing on actively promoting and involving the PwD with the task.

Carer-led assistance

The Carer-led assistance theme contained four sub-themes, namely: applies own methods, organises space, corrects and provides uninvited help. Most carers using this type of assistance tended to use a hands-on approach, which included moving items around the task area, selecting and getting materials and deciding how to complete steps:

The person with dementia (male, husband) is asked to make a fruit salad and is working in front of the kitchen's counter. The carer (female, wife) stands beside them, leaning in towards the person with dementia's space and has been *monopolising the task. The carer gets the orange and the knife, cuts the orange in a half:*

Carer: ***'I will show you what I would like you to do'*** *cuts one end of the orange.*
Carer: ***'You see like that'*** *cuts the other end of the orange.*
Carer: ***'And then like that'*** *cuts the peel of one side of the orange.*
Person with dementia makes an unintelligible sound.
Carer: ***'Yeah, please'*** *taking rubbish away and comes back to the scene.*
Carer: ***'Try not to cut too much of the flesh off if you could curve it around'*** *making a gesture with their hands running their hand down the side of the orange.*
(Person with dementia19, male, husband and Carer19, female, wife).

This observation shows how carers using carer-led assistance were deeply engaged and involved with the development of the task, adopting a central role. Here, the carer explicitly stated and demonstrated how they wanted the step to be completed. They showed the PwD how to do things according to their own personal views without providing space for the person to decide on the way they wanted to do things.

Carers using this approach also organised the space by bringing in materials or instruments or by removing the rubbish away. On occasion, they provided help that was not required:

The person with dementia (female, wife) is asked to make a fruit salad. All the ingredients are on the counter surface, the person starts by looking for the materials they will need. The carer (male, husband) stays one step away from the person, following them around the kitchen. A couple of minutes later while the person with dementia is peeling an orange, the carer gets the berries and opens the box. Once the person with dementia puts them into the bowl of fruit, the carer takes the box away.
(Person with dementia7, female, wife and Carer7, male, husband).

Although their goal may have been to help the PwD, the carer repeatedly stepped in without consulting the PwD. Therefore, the carer controlled aspects of the task that should have been completed by the PwD by either organising the space, getting materials or taking the initiative to complete steps when the person did not ask for help.

Other carers imposed their way by correcting the PwD:

The person with dementia (male, husband) is asked to make a fruit salad. They are working at the kitchen counter and the carer (female, wife) is standing behind them, two steps away. The carer directs the person with dementia to get a dish out of the cupboard:

Carer: ***'You want the chopping board, for fruit. No, in the same cupboard I said! The white one'*** *using an authoritative tone of voice and the person with dementia gets the chopping board.*
Person with dementia peels and cuts an orange.
Person with dementia: ***'Right, I've done that'*** *stepping back from the kitchen counter to face the carer, leaves the knife on the side of the chopping board and gets the lemon.*
Carer: ***'No! Now what?'*** *using an authoritative tone of voice to correct the person who immediately steps forward and leaves the lemon on the counter.*
Person with dementia: ***'Well, I just peeled the orange'*** *using a hesitant tone of voice and looking at the carer.*
Carer: ***'What do you do with it?'***
The dialogue continues and the person with dementia completes steps following the carer's instructions.
(Person with dementia17, male, husband and Carer17, female, wife).

Here, the carer used corrections to impose their way of doing a specific task. There was evident tension between the couple but the person with dementia did not look too uncomfortable, suggesting that these roles may have been established in their relationship, with the carer taking control over certain tasks and the PwD following. Correcting had the effect of making the PwD hesitant and unsure, and although the carer's intention may have been to stop them making mistakes, this could have a potential drawback by disempowering the PwD further.

Carer-led assistance appeared to be defined by how the carer interpreted their role in supporting the PwD and linked to their perception of their family member's abilities to complete the task. Some carers may have used these actions as they usually completed tasks themselves without the PwD being involved. Regardless, the PwD seemed to have little autonomy when completing the task in their own way.

Partnership-oriented assistance

Partnership-oriented assistance comprised two sub-themes: reassures and teamwork. Some dyads worked together throughout the task as if they were working as a team:

The person with dementia (female, wife) is asked to make a fruit salad in the kitchen. The carer (male, husband) stands near the person with dementia. The person with dementia gets the chopping board from the cupboard:

Person with dementia: ***'Follow me over there'*** *looks at the carer, nods pointing at the counter and brings the chopping board using a humorous tone of voice.*
Person with dementia: ***'So, I am doing, and you are assisting'.***
Carer: ***'I am assisting'*** *takes things out of the counter.*
Person with dementia: ***'As necessary?'*** *looks around.*
Carer nods.
Person with dementia: ***'Right, fruit salad'*** *transporting the ingredients from the table to the counter.*
The carer organises the space by moving objects away and the person with dementia gets the orange.

Person with dementia: ***'I struggle with oranges so you can start with the orange please'*** *using a kind tone of voice.*
Carer: ***'Right, I'll peel the orange'*** *gets a knife.*
Carer: ***'It's like a silent movie, isn't it?'*** *while peeling the orange.*
Person with dementia: ***'You couldn't help yourself!'*** *they both laugh.*
(Person with dementia11 female, wife and Carer11, male husband).

This example shows teamwork and demonstrates how the existing trusting relationship the dyad has facilitates the completion of different steps of the task in constant harmony. There seemed to be mutual respect and affection between pairs, and reassurance about what they were doing, which resulted in a positive and genuine encouragement that led to efficient and smooth task completion. The PwD was able to take the lead and delegate to the carer, while also having the opportunity to thrive.

In this theme, the PwD was independent and did not need physical assistance, however, when they seemed confused about the task, partnership-oriented assistance supported them without the need of instructions or prompts, while reassuring the PwD:

The person with dementia (female, wife) is asked to make a fruit salad and all ingredients are left on the kitchen's counter. The person with dementia gets a chopping board for the carer (male, husband) and one for themselves. They stand in front of the counter and decide what they are going to do:

Person with dementia: ***'I'm going to do the lemon, that's what I'm going to do'****.*
The carer moves away to get a knife.
Person with dementia: ***'Sorry, what are you going to do?'*** *continues looking at all the different fruits displayed in front of them.*
Carer: ***'Should I start with the strawberries?'*** *using a cheerful tone of voice while looking at their wife.*

*Person with dementia: **'No pinches! I would do the apple then!'** using a joyful and enthusiastic tone of voice the person with dementia gets an apple and starts peeling it.*
The person finishes cutting the apple and takes the rubbish away
*Person with dementia: **'I was going to put some orange juice in there'** and looks at the carer who is working on their chopping board.*
*Carer: **'Yes'** and looks at them.*
*Person with dementia: **'Or liquid?'***
*Carer: **'Good idea!'** using a gentle and positive tone of voice.*
*Person with dementia: **'Good idea?'***
*Carer: **'Yeah'** and the person with dementia smiles while getting the juice out of the fridge.*
(Person with dementia15, female, wife and Carer15, male husband).

This case illustrates how the carer's initiative to work along the PwD pulled her back into the task when the PwD appeared confused. The proposed action as a question, empowered the PwD to focus on the activity without the need of getting direct support. The use of reassuring words provided a positive environment where the decisions made by the PwD were celebrated and welcomed.

In Partnership-oriented assistance, carers offered support and were ready to monitor and follow how the PwD wished to complete the task. This theme depicted a person with dementia-led approach, where the person took the initiative to ask the carer to complete certain steps and prompt them to engage. These participants showed greater abilities to solve and achieve the task indicating that this type of support relied on the PwD having some ability to complete tasks, but also relying on carers providing the space for this in the interaction.

Bystander

The bystander theme was characterised by two sub-themes: hesitates and disengages. In very few occasions, the carer did not respond to the situation and did not intervene even when it was clearly needed:

The person with dementia (male, husband) is asked to serve a glass of a cold drink. The tonic water has been placed on the kitchen's counter where they are standing. The carer (female, wife) is standing a metre away, behind them. The person with dementia opens the cupboard, gets a glass and puts it on the counter:

*Person with dementia: **'It's all your fault, isn't it?'** points in a direction where there is no one present, then closes the cupboard.*
*Person with dementia: **'Do I have to put this in there?'** grabs the tonic water and points at the glass and looks away in the direction where there is no one. The carer does not intervene and stays standing in their initial position.*
*Person with dementia: **'Eh?'** opens the tonic water and looks at the researcher.*
*Person with dementia: **'That's what I have to do?'** the carer looks at the researcher.*
*Researcher (JC): **'Your wife is going to help you if you need help'** the carer approaches the person with dementia but stays away from them, holding their hands and leaning forward as if trying to observe what the person with dementia was doing.*
*Carer: **'You are going to pour a glass of tonic, or just half a glass'** using a low tone of voice.*
(Person with dementia6, male, husband and Carer6, female, wife).

This observation depicts a carer who does not respond to the situation and even when the PwD clearly shows a need for support. The carer is distanced and appeared confused, and no assistance is given until the carer is actually prompted. This approach left the PwD uncertain about what they were doing as there was no confirmation or response. The carer may have interpreted the researcher's instructions incorrectly particularly since the carer assisted the PwD after they were prompted to do so. However, it shows the PwD faltering with the task due to receiving no support. This observation revealed that carers may fail to identify the correct moment to assist the PwD during daily tasks.

The next observation showed a carer who became disengaged from the task:

The person with dementia (female, wife) is asked to make a fruit salad. The carer (male, husband) is standing behind the person, one metre away. While the person with dementia makes the salad, the carer looks around for approximately 12 seconds, then looks at the person and finally moves to the kitchen sink where they look through the window and start washing the dishes.
(Person with dementia9, female, wife and Carer9, male, husband).

Here, the carer was not engaged with what the PwD was doing.

Bystander was the least observed type of assistance. Carers using this approach appeared unsure of how and when support was needed, and even though they may have attempted to allow the PwD to apply and use all their skills to perform the task, there was a sense of disconnection between the carer and the PwD that sometimes resulted in difficulties completing the activity.

7.4 Discussion

This study explored the types of assistance that carers employ to support PwD during the performance of daily tasks. Five main themes were identified during the analysis of observations of PwD and carers when they performed a task together: person-enabled assistance; goal-directed assistance; carer-led assistance; partnership-oriented assistance and bystander.

These five themes provide rich in-depth understanding of the different ways in which carers assist PwD with daily tasks. The themes included subtle carer actions which, on most occasions, were targeted at the PwD's response to the task. Future research could examine the impact each approach has on the task performance of PwD to enable an understanding of what works well and what could be changed to facilitate the person's participation in ADLs. This could potentially optimise the PwD's independence.

Several factors could have been related to the types of assistance identified by this study. For example, the type of assistance provided by carers was shaped by the PwD's abilities to complete the task. This was demonstrated when carers were attuned to the person, adjusting their actions and the setting at the right time to provide prompts, explanations or options, when they perceived these were needed by the PwD. This is surprising as most carers (81%) in this study had not completed any training as part of their role as carers. A possible explanation is that they have progressively learnt from their own experiences how to assist their family member and that they are following their intuition and own perception when providing daily support.

Carers' perception of the needs of the PwD was another factor that played an important role when using different types of assistance, and this was also evidenced when carers provided room for errors or offered choices so that the PwD could try and then decide on how to continue with the task. Future research is needed in order to determine the benefits of allowing PwD to make their own choices.

Previous roles, components and mechanisms that formed the relationship between the carer and the PwD were also seen to define the types of assistance provided. Some carers were strong on suggesting and even imposing their own ideas for the task while the PwD accepted them, following what seemed like a pre-established dynamic in the relationship of these dyads. This was also confirmed in the past, where gender has been found to be associated with the amount of assistance provided in day-to-day tasks (Spector and Fleishman, 1998) showing that older male adults received more support than women. The fact that the carers using partnership-oriented assistance were all husbands (males) highlights the specific role that gender may have when providing types of assistance to PwD.

Previous studies have measured the amount of assistance carers provide and showed that specific daily tasks required the highest level of support, such as showering, dressing and home maintenance (Amato, 2021). However, the specific type of help that carers provided was not acknowledged. Formal carers' communication strategies used during personal care tasks with people in the severe stages of dementia have been investigated in the past (Wilson, 2012), but these carers were qualified nurses. After many years of disease progression, the strategies used by care providers may be directed to compensate for missing abilities, rather than to improve participation. In addition, as family carers are the main providers of support (Prince and Jackson, 2009), gaining insight of how they assist the PwD from the early days is an important first step to develop knowledge on how to assist ADL performance in this population. The findings of this study could form a coding strategy that could be used in future studies to identify assistance types, the factors that affect the use of these, and how they promote or hinder ADL functioning in PwD.

The identification of these types of assistance also allows for the recognition of possible motives and goals for which the carers adopted different ways to support ADL performance, such as promoting active participation, completion of the task and teaching own methods. More research would be needed to explore why carers provide support during task performance to understand the types of assistance they daily use.

An important finding of this study was the fact that carers had a key role in facilitating the PwD to thrive or to become hesitant and unsure during task performance. When carers gave space for the PwD to execute the task and make their own decisions, a door was open for them to succeed. On the other hand, when carers corrected the PwD imposing steps or disengaged, a sense of disconnection from the task arose. Carers had a crucial and meaningful role in maintaining or enabling PwD's sense of autonomy that allowed them to feel more confident when doing a task.

This study had some limitations. This was a secondary analysis, so information on the ethnicity of the participants was not collected, so the sample used in the study may lack the heterogeneity needed to get a richer and wider understanding of how culture shapes carers' actions. In addition, information about the number of years that carers had supported the PwD with ADL performance was missing. This information may have helped to understand how the experience these carers had may have contributed to the development of the different types of assistance identified by this study.

Strengths of the study involved following the criteria for rigor suggested for qualitative studies (Lincoln and Guba, 1985), included its credibility and trustworthiness, which was demonstrated by conducting a consistent, precise and systematic analysis, that included analyst triangulation (Patton, 1999). This enhanced the quality of the analysis by reducing selective perception and blind interpretive bias. Debriefing sessions before data collection and peer scrutiny were also implemented, which increased the credibility of the study (Shenton, 2004) and reinforced reflexivity (Lincoln and Guba, 1985). Dependability and confirmability were reached by providing with a clear account of the steps taken to accomplish the study following the Standards for Reporting Qualitative Research (SRQR) recommendations (O'Brien, 2014). A clear description of these steps and the participants included in this study also guaranteed a potential transferability of this findings to other settings (Lincoln and Guba, 1985).

Clear implications arise from these findings, including the possible development of clinical non-pharmacological interventions to train carers in the different types of assistance they can use when supporting ADL performance. Healthcare professionals can also incorporate these results when educating family members on how best to approach and facilitate care.

These findings provide robust information to further elaborate on how different types of actions carried out by carers can affect the maintenance of the person's abilities to complete daily tasks. Exploring and observing how carers provided support during daily tasks has also highlighted and revealed important gaps in the literature about PwD's performance of daily tasks. The first insight was that several PwD were clearly able to request help, by asking where ingredients were or what was next, while others did not attempt to seek advice or support and this appeared to be linked to carer assistance type. The second insight provided by this study, was the number of times carers over-assisted the PwD, particularly before the need for help was clearly observed. As such, for carers, finding a balance between the assistance provided and the assistance needed was consistently a challenge. A clear question then arises: when should carers step in to provide assistance to the PwD when they are performing daily tasks? Future research could be conducted to determine how to identify the right moment of need for assisting a PwD during task performance.

In summary, these findings provide a rich source of information on the different types of actions carried out by carers and suggests that these can affect the maintenance of the person's abilities to complete ADLs by either facilitating or hindering task performance of PwD. Carer assistance types were defined by the PwD's abilities to complete the task, which revealed the relationship that exists between PwD's skills and the assistance the carer provides.

7.5 Summary

This chapter was dedicated to the identification of different types of assistance used by carers when providing daily support to the PwD. It also found that carers' actions are shaped by the PwD's abilities to complete tasks. In order to integrate all the findings reported in this thesis, the next and final chapter, will provide a summary of findings, including implications, limitations and future directions.

Chapter 8: General Discussion

8.1 Foreword

The main aim of this thesis was to investigate the role that different factors play in regard to PwD's activities of daily living to better understand the gap between ability and performance of daily tasks. The ICF framework was selected as the theoretical model within which to conduct the studies that formed this thesis. The main ICF components included were the Contextual factors, Body functions, Activity and Participation. The Contextual factors studied were the physical (represented by two different settings) and human environment (represented by family carers), while the factors included as part of the Body functions were cognition and apathy levels. Activity and Participation were referred as ADLs. The figure below includes the factors studied in this thesis and how they mapped the ICF model (introduced as Figure 2.2 in the literature review, Chapter 2, Section 2.5).

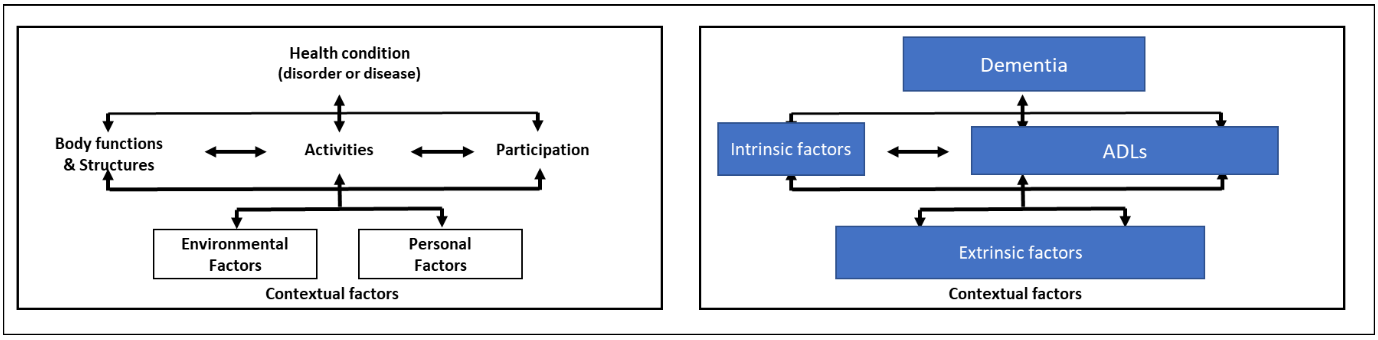


Figure 2.2 (Chapter 2, Section 2.5) *Thesis factors mapped on to the International Classification of Functioning, Disability and Health (ICF) framework. On the left, the ICF's diagram, while the figure on the right includes examples of the factors that will be studied in this thesis and how they fit the ICF model. Dementia is the health condition which is the focus of this thesis that produces intrinsic factors, such as cognitive and behavioural changes. ADLs refer to the ICF components 'Activity and Participation' as explained in Section 2.2. The ICF so-called Environmental factors' component are considered the extrinsic factors (both the physical and the human environment) proposed for this thesis.*

Different methods were used to investigate how the physical and the human environment, which includes the strategies applied by carers and the types of assistance used by them affects the performance of daily activities in PwD. The ICF model proposed that these components are non-static and interact dynamically. The use of a mixed methods design, which included both quantitative and qualitative approaches, appeared to be the best way to investigate both the effect of intrinsic and extrinsic factors and how they can affect PwD's daily activities.

This chapter will include a summary of the findings of the studies conducted as part of this thesis, followed by a narrative synthesis to integrate findings within the discussion of the theoretical and clinical implications that arise from them. A conclusion will be provided but not before mentioning the limitations and future research recommendations and directions that derive from this thesis.

8.2 Summary of findings

Chapter 4: The role of the environment in relation to the ability to perform daily activities among people with dementia.

In this chapter, an experimental design (repeated measures) was used to investigate the role the physical environment plays in the PwD's abilities to perform daily tasks. The physical setting, where an individual completes activities, is one of the extrinsic factors that can determine how successful their performance could be, as framed by the ICF model.

The study assessed participants using a well-known performance-based assessment in two different settings: the home environment and the research-lab, a fully equipped research setting located at UEA. The use of an experimental approach provided an extra advantage, as one of the settings was manipulated to reduce the level of clutter. As such, the study tested the hypothesis that the PwD will show a better performance in a tidier environment.

Results of this study showed that PwD performed better in their own home, even when the research-lab's level of clutter was significantly lower than the participants' homes. When investigating the possible factors associated with this increased performance at home, only cognition was found to contribute significantly to the PwD's abilities to complete activities at home. In addition, and when grouped by dementia stage, PwD in the moderate stages of the disease had a better performance at their own home, while PwD in the mild and severe stages of the disease showed the same level of performance in both environments.

Chapter 5: Daily tasks in dementia: does carer management style influence the people with dementia's task performance?

In this chapter, an exploratory cross-sectional approach was applied to investigate how the combination of intrinsic and extrinsic factors contributed to the problems that PwD have when performing daily tasks. This study incorporated two different aspects of the ICF model, namely the changes at the body level (i.e., cognitive function and apathy levels) and the external human environment, represented as the primary carer. Incorporating both intrinsic and extrinsic factors was a novel approach in dementia studies, as traditional investigation of impairment of ADLs originally focused on how intrinsic dementia factors, such as cognitive problems and behavioural changes, affected the PwD's abilities to complete activities (Bennett, 2002; Farias, 2013; Martyr and Clare, 2012; Razani, 2011). A multiple regression analysis was used to investigate how the PwD's level of cognitive function, apathy and the carers' use of criticism, active management and encouragement strategies (three carers' styles) contributed to the changes in ADL performance. Results showed that better cognition and carer's use of encouragement contributed to better performance of daily tasks and the PwD's level of apathy and the carer's use of criticism style contributed to worse ADL performance. These findings corroborated the important role the human environment, such as family carers, have on ADL performance in PwD and confirmed that task performance, where its impairment is framed as disability in the ICF framework, depends on both intrinsic and extrinsic factors.

Chapter 6: Discrepancy between the performance and the ability to perform ADLs

This chapter aimed to further explore the ICF framework by investigating the gap that exists between qualifiers of ADL functioning, namely ability to perform activities and the current performance of daily tasks. As such, another exploratory cross-sectional design was used to examine the agreement that existed between the report of the carer of what the PwD does in their current routine, and what they could potentially do. In this way, the PwD was asked to perform a real task, using a performance-based assessment, while carers completed an interview-based ADL assessment. The agreement in this sample was low, with the majority of the carers underestimating the PwD's abilities to perform tasks. I then conducted a regression analysis to investigate how the human environment, through the use of the carers' strategies to manage dementia-related problems, affected the discrepancy between performance and ability to perform activities. This was another novel study and the results showed that active management and encouragement styles made the largest and significant contribution to the discrepancy, showing that a way to find agreement between what a PwD does and could do, can be gained by making adjustments to the human environment, in this case, the primary carer's use of strategies.

Chapter 7: Assistance provided by carers during the performance of ADLs

Finally, and in order to gain a deeper understanding of how carers provide hands-on support to PwD during task performance, I used a qualitative approach to observe families assisting the PwD when they complete an activity. Although the ICF framework provides a structure classification to assess components of disability, the model lacks detailed information on how particular aspects of certain domains, such as the human environment or Support and Relationships domain of the Environmental factors' components, can act as facilitators of, or barriers to, PwD's abilities to perform daily tasks. A lack of literature on the specific actions' family carers use during daily tasks was identified, which in turn led to the conducting of this secondary analysis. Five main themes of types of assistance used by carers were identified: Person-enabled assistance; Goal-directed assistance; Carer-led assistance; Partnership-oriented assistance and Bystander. They encompass different actions that carers used, and findings showed that the types of assistance used by carers either facilitated or hindered task performance. The study also demonstrated that the types of assistance used by carers were closely linked with the PwD's abilities to complete the task and the previous roles adopted by the dyad.

8.3 Implications

The findings of the studies conducted as part of this thesis have revealed several theoretical and clinical implications relating to how extrinsic factors contribute to ADL functioning, by investigating the role of the physical and the human environment in PwD's abilities to perform daily tasks.

Theoretical Implications

This thesis aimed to investigate the different components that can affect a PwD's activities of daily living in order to further understand the gap between performance and the ability to perform activities in this population. The theoretical framework used was the International Classification of Functioning, Disability and Health (WHO, 2001).

The ICF classification was originally proposed to recognise disability as a result of interacting features of the person's health condition and the context in which they live, while also including the identification of facilitators of and barriers to individuals' participation. This model was launched to widen the approach to defining disability and identifying the consequences of chronic health diseases' to the individual's life, and as a response to the unsuccessful approach to treating long-term conditions using the biomedical model (Rocca and Anjum, 2020). By showing that both the physical and human environment (both environmental factors of the ICF model) hindered or facilitated disability, this thesis confirmed the suitability of the ICF components in understanding and investigating ADL functioning in dementia. This thesis also confirmed the important role that extrinsic factors, such as the human environment, play in reducing potential disability, as proposed by the ICF and confirmed that disability does not depend exclusively on illness-related factors, as the biomedical model assumed (Ludwig, 1975).

A novel and unique element of the ICF framework are the so-called qualifiers, which are used to record the presence and severity of a problem at the body, person, activities, participation and environmental levels (WHO, 2001). The qualifiers investigated in this thesis, namely the performance and ability to perform ADLs, allow for the identification of the gap between what a person does in their daily routine and what their potential abilities are, which is essential to promote changes needed to improve an individual's participation in daily tasks. By investigating both qualifiers (in the study conducted in Chapter 6) this thesis also strongly supported the ICF model by showing how the human environment plays a central role in estimating and shaping disability of the PwD.

An important aspect of disability is determining how to modify or remove external obstacles and how to facilitate ADL functioning. The results of this thesis have confirmed one of the core applications of the ICF model at the individual level, by showing how the physical environment could help reduce or increase disability. However, specific changes made to the environment, as seen in the study about decluttering (Chapter 4), were not sufficient to improve ADL functioning. There seem to be additional elements that are involved in removing possible barriers to the environment to facilitate participation in daily tasks. On a similar theme, this thesis also confirmed that the human environment could be an important aspect of reducing or increasing disability, as family carers can either prevent or enable ADL performance of the PwD when using daily strategies and actions, as seen in the studies conducted in Chapters 5, 6 and 7. This is actually endorsed by the ICF framework, as it states that the same extrinsic component can work in both directions: barrier to or facilitator of ADL functioning.

This section has described how the findings of this thesis support the dynamic model the ICF framework proposes to assess and define disability and its applicability in PwD. How they translate into practice and the clinical scope of the variables investigated will be discussed next.

Clinical implications

Several clinical implications were uncovered in the studies of this thesis, which showed that ADL performance depends on both intrinsic and extrinsic factors. Thus, the identification and use of the physical and certain other aspects of the human environment by healthcare professionals, could aid to the development of better care plans for both the PwD and their family carers.

Regarding the physical environment, the first clinical implication that arises from this thesis is that PwD's ability to perform daily tasks should be assessed at home, as results showed that the home environment benefited task performance. However, PwD in the early as well as the severe stages of dementia, could complete activities in a new environment, which suggests that OTs discharging PwD from their acute services, for example, could assess ADL functioning in the hospital setting according to the severity of the dementia of the individual involved. This information could be also included in their discharge plans. Cognition was the only variable that seems to predict better performance at home, which is in agreement with several studies that have found associations between cognitive function and ADL performance (Farias, 2013; Martyr and Clare, 2012; Miller, 2013; Razani, 2011). When discharging PwD from hospital or moving them into residential care homes, the PwD's level of cognition and confusion (Inouye, 1990) should be considered to facilitate participation in daily tasks in the new setting.

Environmental clutter did not predict worse ability to complete ADLs, which suggests that reducing cluttering as a possible clinical intervention is unlikely to influence the PwD's ADL functioning. This finding indicates that clutter may act neither as a barrier to or a facilitator of ADLs. However, clutter removal was shown to prevent falls and was an effective strategy to reduce risks of PwD living at home in the past (van Hoof, 2010). This has potential implications not only for OTs, but other community healthcare professionals who are also involved in the delivery of home services (Carnemolla and Bridge, 2020). An observational assessment of ADLs could be carried out before and after decluttering an environment, to determine if this specific element of the environment acts as a barrier or a facilitator and to ensure a person-centred approach is promoted to support PwD's participation in daily tasks. These types of assessments could be time-consuming and require training (Sikkes and Rotrou, 2014). However, considering the lack of clear evidence that decluttering an environment could have an impact on the PwD's ADL performance, the benefits of carrying out an observational assessment outweigh the costs and time required to complete such assessments.

The study conducted in Chapter 5 showed that disability in dementia is shaped by both intrinsic and extrinsic factors. In this case, the carers' use of strategies was found to facilitate or hinder PwD's ADL performance. Practical strategies included in the criticism carer management style should not be advised in clinical practice, while encouragement strategies, such as praising the PwD and discussing feelings and ideas, could be recommended. Cognition, once again, and apathy, both dementia intrinsic factors, were found to improve or reduce activity performance in the same study, confirming previous research (Bennett, 2002; Boyle, 2003; Farias, 2013; Martyr and Clare, 2012; Razani, 2011; You, 2015). This lack of motivation of the PwD may also define the types of strategies carers use, something similarly seen in the study conducted as part of Chapter 7. This study showed how carers constantly motivated the PwD to complete daily tasks, which could be explained by their level of apathy. In addition, practical strategies could be an important first step in facilitating ADL performance, while improving carer's wellbeing, which will be positively affected by the use of encouraging strategies

(Lim, 2011). While clinical trials are being conducted to delay disease progression by focusing on improving cognitive function, family carers can be taught specific procedures which they can apply to reduce disability. This is in line with the NICE guidelines on supporting carers to get training to provide care (NICE, 2018). NICE guidelines are clinical, evidence-based recommendations, made by the National Institute for Health and Care Excellence (NICE) in England, for healthcare and social care professionals, commissioners and providers of care, housing associations and service users. The role of the human environment in ADL functioning has been highlighted by this thesis and the NICE guidelines could tailor their recommendations to improve the skills of primary carers of PwD's when providing support.

ADL functioning is a complex construct that involves the PwD performing daily tasks and having the potential ability to complete them during their daily routine, as also framed by the ICF. This was confirmed by the high discrepancy shown between the reported and observed ADL performance in the study conducted in Chapter 6 and could be taken into consideration by healthcare professionals working in dementia services when determining the type of support the person needs, by alternating both report and observation of ADL performance of the PwD. Some specific factors were not associated with this discrepancy, such as dementia severity and carer's age and relationship with the PwD. This was also found in the qualitative study (Chapter 7) where either spouses or children of the PwD used different types of assistance to support task performance, confirming the suitability of employing strategies and types of assistance by any family member in any disease stage. Thereby, healthcare professionals could then use an integrated approach to recommend carers who underestimate performance to employ encouragement strategies, before support is provided. In the opposite case, for those carers overestimating ability to perform activities, the recommendation would be to use active management strategies to adjust the support and the environment to promote task participation.

Carer's types of assistance, such as prompting and giving explanations and choices to the PwD, led to active participation and promoting autonomy, as identified by the qualitative study (Chapter 7). Offering choices to the PwD has been found to reinforce personal control (Taft, 1997), a subsequent important aspect of the caring role, which was also highlighted by the carer's ability to empower the PwD to succeed. While family carers receive little information on how to give appropriate assistance (Georges, 2008), this thesis also showed that carers gradually learn how to provide support. However, some carers were found to still be unsure about what to do or when to intervene, which could have been due to their uncertainties about when to offer support. The rising costs of informal care in dementia has been linked to the type of support family carers provide (Prince, 2015), which supports the need to have a comprehensive approach to deal with how the carers are taught about the types of assistance they can provide during daily tasks. Dementia services could then offer training to carers on how to provide support for PwD to maintain ADL functioning and reduce dementia costs.

The findings of this thesis highlight the important role of extrinsic factors have and reinforce the need of the application of an environmental approach, that integrates both the physical and the human aspects of those living with dementia, to promote participation of daily tasks that will affect both the PwD and their primary carers. In future, this approach could be applied as a non-pharmacological, multicomponent intervention programme, that focuses on the style carers adopt, the specific actions they employ, apathy management and reinforcement of cognitive function, to maintain function and delay disease progression. In the meantime, those running or planning new dementia services should consider an assessment of the environment and the different elements that can affect the individual's performance in particular the role of the human environment, specifically, the strategies and types of assistance carers use to support ADL performance in PwD.

8.4 Strengths, limitations and future directions

One of the strengths of this thesis was the use of a mixed methods approach that combined quantitative and qualitative studies. This enabled an integrated approach to both intrinsic and extrinsic factors in order to investigate the many aspects that are involved when a PwD performs a task. Another strength was the number of PwD and carers included in the thesis, that allowed for an appropriately powered sample in each reported study. One hundred and ninety-seven standardised and non-standardised tasks have been conducted and included in the analyses.

Each individual chapter addressed the specific limitations that were identified in the process of developing the research methods of each study. However, there are general limitations of the thesis that will be discussed in detail in this section, not to mention the potential research directions that arise from the findings of this thesis and that remain to be investigated in future studies.

It would have been important to understand the relationship between ADL functioning at home and the familiarity with the environment, so that additional data could have been collected from participants, i.e., the number of years residing at home. More specific information related to the physical environment could have been collected in order to investigate its effects on ADL functioning, such as use of visual adaptations, equipment or modifications made to the home environment.

The physical environment is made of many different elements that can promote or hinder ADL functioning, such as lighting, noise, temperature, furnishing, objects and design (Woodbridge, 2018). In dementia, the premise is that, as individuals present with progressive difficulties to adapt to new circumstances, the surroundings could be changed to suit the PwD's needs (Desai and Grossberg, 2001). Although OT-based environmental interventions for PwD were proposed and tested in the past (Dooley and Hinojosa, 2004; Gitlin, 2001; Graff, 2006), and environmental adaptations being the most common OT intervention for PwD in the UK (Swinson, 2016), the modifications made to the environment were not specifically mentioned (Swinson, 2016; Woodbridge, 2018). In this thesis, a repeated measures design was used to understand the influence of the environment on PwD's ADL performance, and limitations on the use of such design should be mentioned. In this case, the two chosen outcomes (ADL assessment) could not be strictly compared, as changes in the dependent variable could be attributable to other unrelated factors. In addition, the design included the removal of the clutter in the new environment. Considering the many different aspects of the environment that could potentially affect the performance of daily activities, the findings of this thesis confirm the need for new experimental studies that test specific changes in the environment in order to assess their effectiveness in supporting ADL performance in PwD. One way that future research could further investigate the role of clutter is by removing the clutter in the PwD's own environment, before and after completing a task, to reduce the influence of other variables in the analysis. It would also be interesting to understand how people with different dementia subtypes, in particular those with PCA, benefits from the removal of clutter, as they present with visuospatial difficulties.

Information on the primary carer, such as length of years spent in the caring role, and formal use of paid carers for specific activities, would have contributed to the understanding of how carers learn to support PwD during daily tasks. Information on their level of education and knowledge about dementia would have also contributed to the understanding of the type of strategies or actions they use during ADL performance. In future, studies could include these valuable factors in the analysis to further explore the role of the human environment in reducing or increasing disability

Two important demographic features that were missing from the analysis were information about the dyads' ethnicity and their socio-economic status. These two variables could have influenced the strategies employed by carers and the types of assistance they used as part of this thesis.

Some considerations regarding the methodological problems that arose in Chapter 6 are worth mentioning. The two different assessments used to compare performance and ability to perform tasks may differ in terms of the components of activity performance they measure. While the AMPS focuses on the planning and execution of a specific and well-delimited task, each subdomain of the DAD includes different components such as initiative, planning and execution of the chosen activity. Future studies could consider targeting particular tasks including assessments that would evaluate the same components of task performance, such as the IADL Profile (Bottari, 2010) and including specific strategies that carers use during ADLs such as use of praising the PwD or stimulating them, to further understand the effect they have on PwD's abilities to complete daily activities.

The human environment also includes those elements related to the carer wellbeing or mental health factors, that have been largely investigated in the literature, namely carer's level of burden and depression (Argüelles, 2001; Conde-Sala, 2013). Even though the study conducted in Chapter 6 included carers' symptoms of anxiety and depression to investigate their effect on the discrepancy of ADL performances, the main focus of this thesis was the investigation of extrinsic elements of the human environment that can be practically modifiable with, for example, non-pharmacological carer-based interventions. Future research could be conducted to investigate the relationship between the use of strategies and specific actions during ADL performance and the carers' symptoms of anxiety and depression.

An imbalance between the ICF Environmental factors' components can be noted in the thesis, where the physical environment may appear as a less important factor than the human environment, represented by the primary carer. Even though environmental adaptations are one of the first-line approaches on dementia care (van Hoof, 2010), PwD will need support for daily activities from either a formal or informal carer (Prince and Jackson, 2009), so there is a clear need to identify what is the best way that carers can approach PwD to maintain function for longer. In addition, the physical environment could be targeted and manipulated with technological devices, as recent research has shown the direction this area is taking to support participation in daily tasks (Ishii, 2016). The use of assistive technology in dementia also demands a further and detailed analysis of the ICF classification, as the framework contains a specific chapter called Products and Technologies, which is part of the Environmental factors' components. Research has shown how the classification does not include all the different and newer options of assistive technologies (Bauer, 2011), which could be included in future studies to investigate the role of technological devices, as qualifiers of the physical environment, to reduce disability in PwD.

The qualitative study that consisted in the observation of carers and PwD during the performance of daily tasks has revealed how little is known about the PwD's ability to ask for help and how carers respond to this request. In addition, it was notable that most carers did not seem to know the right moment to offer support, meaning that in many situations the carer may have offered assistance when it was not needed. Future studies could consider the comparison between performance with and without carer support to determine if the assistance provided by carers was needed during ADL performance.

8.5 Concluding remarks

This thesis has confirmed that both intrinsic and extrinsic factors, including the physical and the human environment, in the context of a person living with dementia, affect their performance of ADLs. The human environment, seen as extrinsic factors that could affect ADL functioning in PwD, include the strategies that carers employ when supporting ADL performance and the types of assistance they use when the PwD performs a task. The gap between performance and ability to perform activities can be obtained by measuring the two different qualifiers of ADL performance and is also shaped by the strategies that carers used to support ADL performance. Carers employ different types of assistance, and there is a relationship between the PwD's ability to perform tasks and the actions carers use during ADL performance.

The results of this thesis increase the understanding of how the combination of different elements, including dementia intrinsic factors and extrinsic ones, contribute to the changes in ADL functioning of PwD. This thesis has also revealed the central role that the human environment, represented by the primary carer, has on the performance of daily tasks in PwD. The findings provide clear evidence that can be used to further develop non-pharmacological interventions to reduce the gap between performance and ability to perform activities in PwD.

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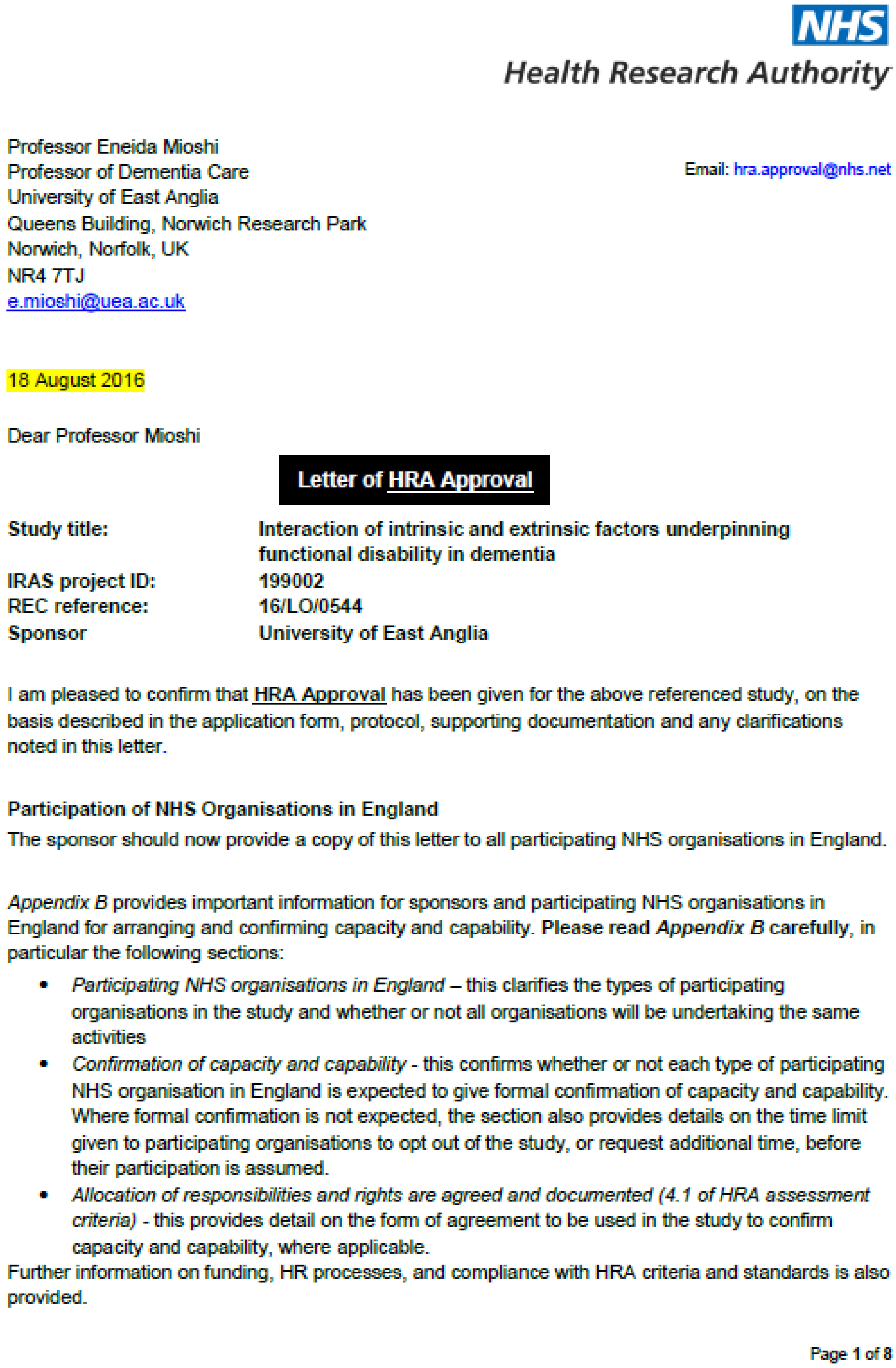
Appendices

Supplementary material, Chapter 3, Section 3.4.1, Ethical Approval Letter:
TASKed’s Ethical approval letter.



NHS
Health Research Authority

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University of East Anglia
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Email: hra.approval@nhs.net

18 August 2016

Dear Professor Mioshi

Letter of HRA Approval

Study title:	**Interaction of intrinsic and extrinsic factors underpinning functional disability in dementia**
IRAS project ID:	**199002**
REC reference:	**16/LO/0544**
Sponsor	**University of East Anglia**

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

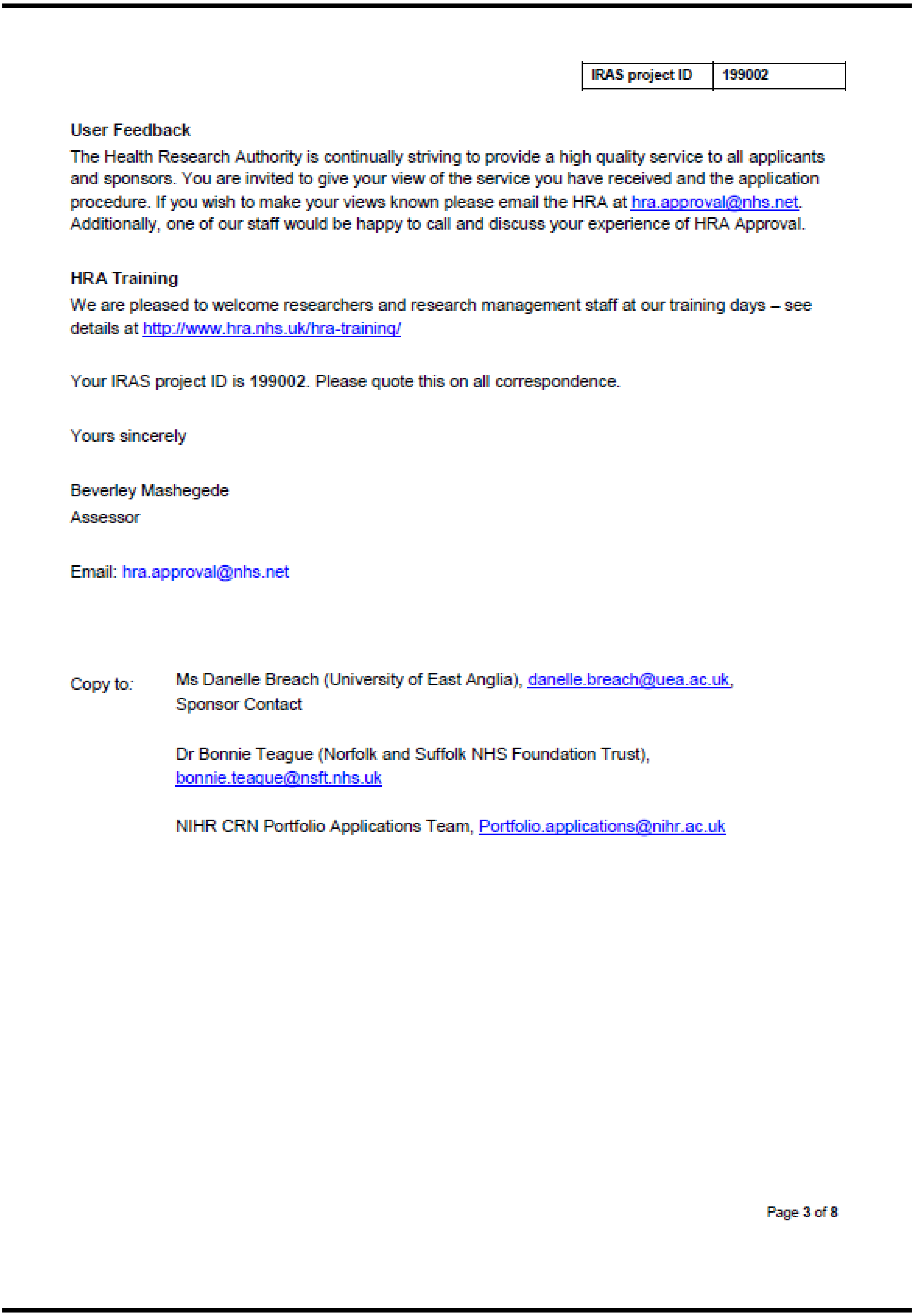
- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.



User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **199002**. Please quote this on all correspondence.

Yours sincerely

Beverley Mashegede
Assessor

Email: hra.approval@nhs.net

Copy to: Ms Danelle Breach (University of East Anglia), danelle.breach@uea.ac.uk, Sponsor Contact

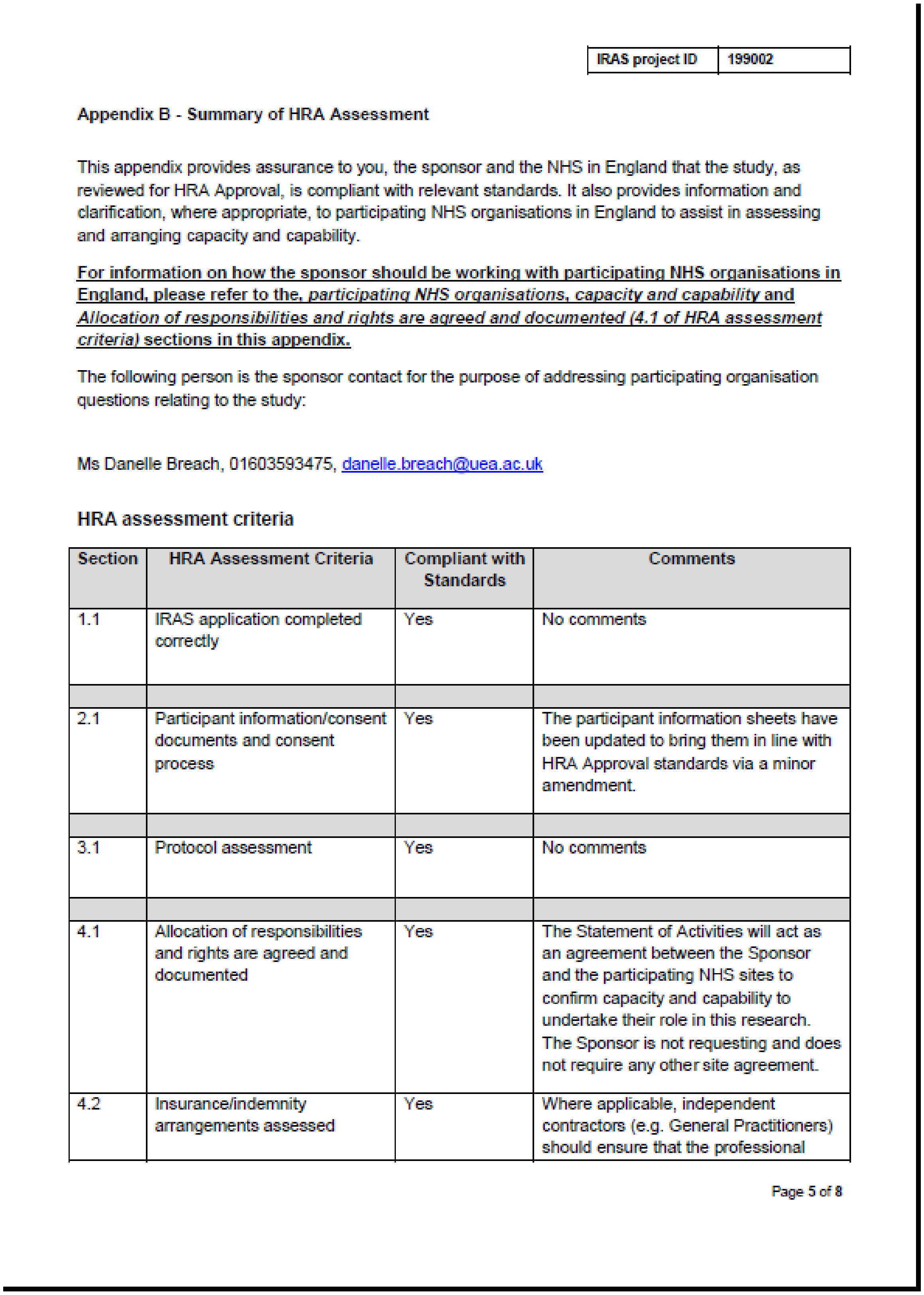
Dr Bonnie Teague (Norfolk and Suffolk NHS Foundation Trust), bonnie.teague@nsft.nhs.uk

NIHR CRN Portfolio Applications Team, Portfolio.applications@nihr.ac.uk

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Patient leaflet]	1	14 January 2016
Covering letter on headed paper		08 March 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		08 March 2016
GP/consultant information sheets or letters [GP letter]	1	08 November 2015
IRAS Application Form [IRAS_Form_09032016]		09 March 2016
IRAS Application Form XML file [IRAS_Form_09032016]		09 March 2016
IRAS Checklist XML [Checklist_21032016]		21 March 2016
IRAS Checklist XML [Checklist_04052016]		04 May 2016
Letter from funder [Letter from Alzheimer's Society]		29 September 2015
Other [HRA statement of activities (NSFT)]	1	
Other [HRA schedule of events (NSFT)]	1	
Other [Response to validation query]		21 March 2016
Participant consent form [Consultee declaration]	3	21 March 2016
Participant consent form [Consent to contact]	1.1	03 May 2016
Participant consent form [Participant consent form (carer)]	3.2	May 2016
Participant consent form [Participant consent form (patient)]	3.2	May 2016
Participant information sheet (PIS) [Participant information sheet (carer)]	3.2	August 2016
Participant information sheet (PIS) [Participant information sheet (patient)]	3.2	August 2016
Participant information sheet (PIS) [Consultee information sheet]	3.2	August 2016
Research protocol or project proposal	1	08 March 2016
Summary CV for Chief Investigator (CI)		09 March 2016
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Lay summary]	1	08 March 2016
Validated questionnaire [Disability assessment for dementia]		



IRAS project ID	**199002**

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

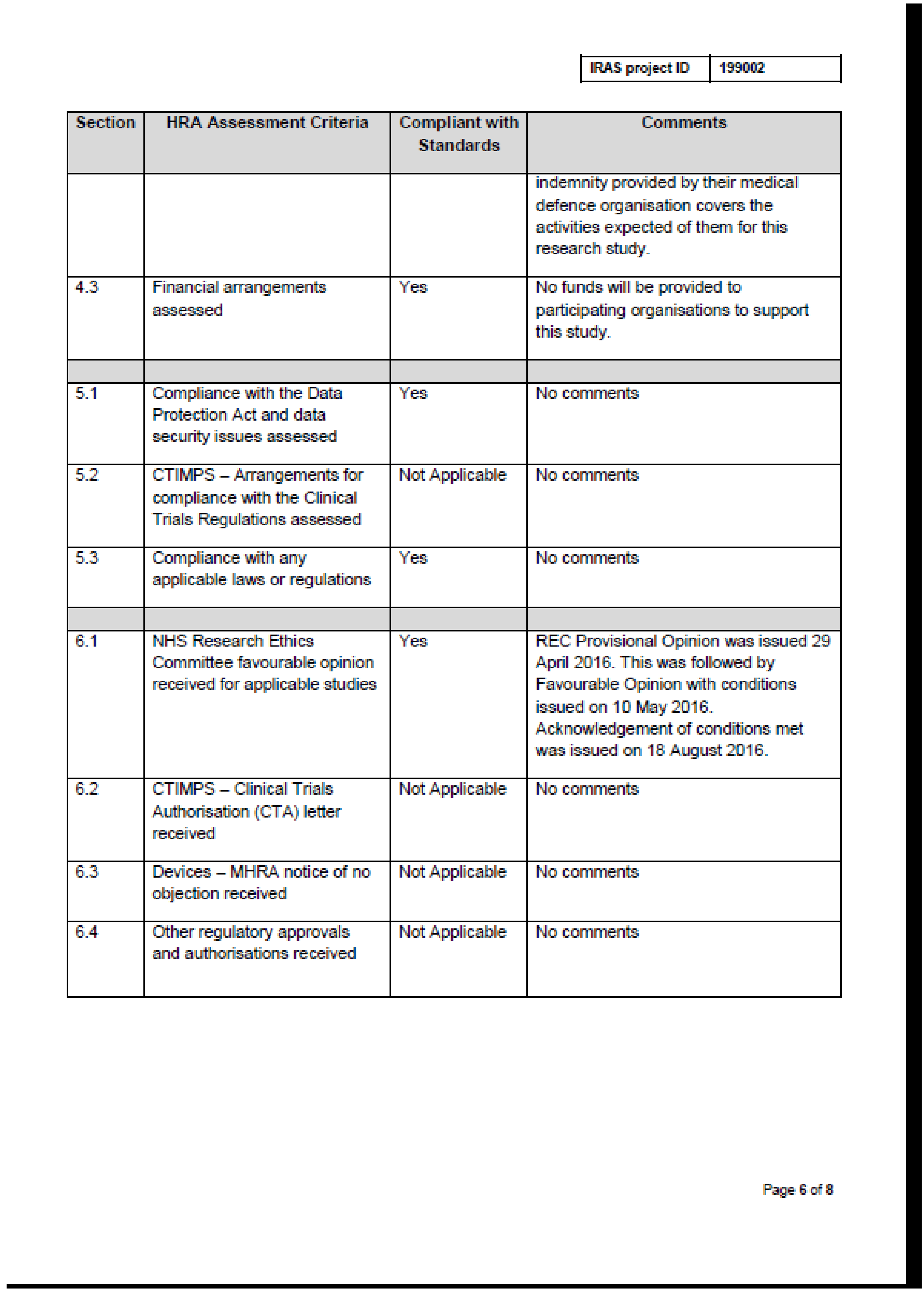
For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

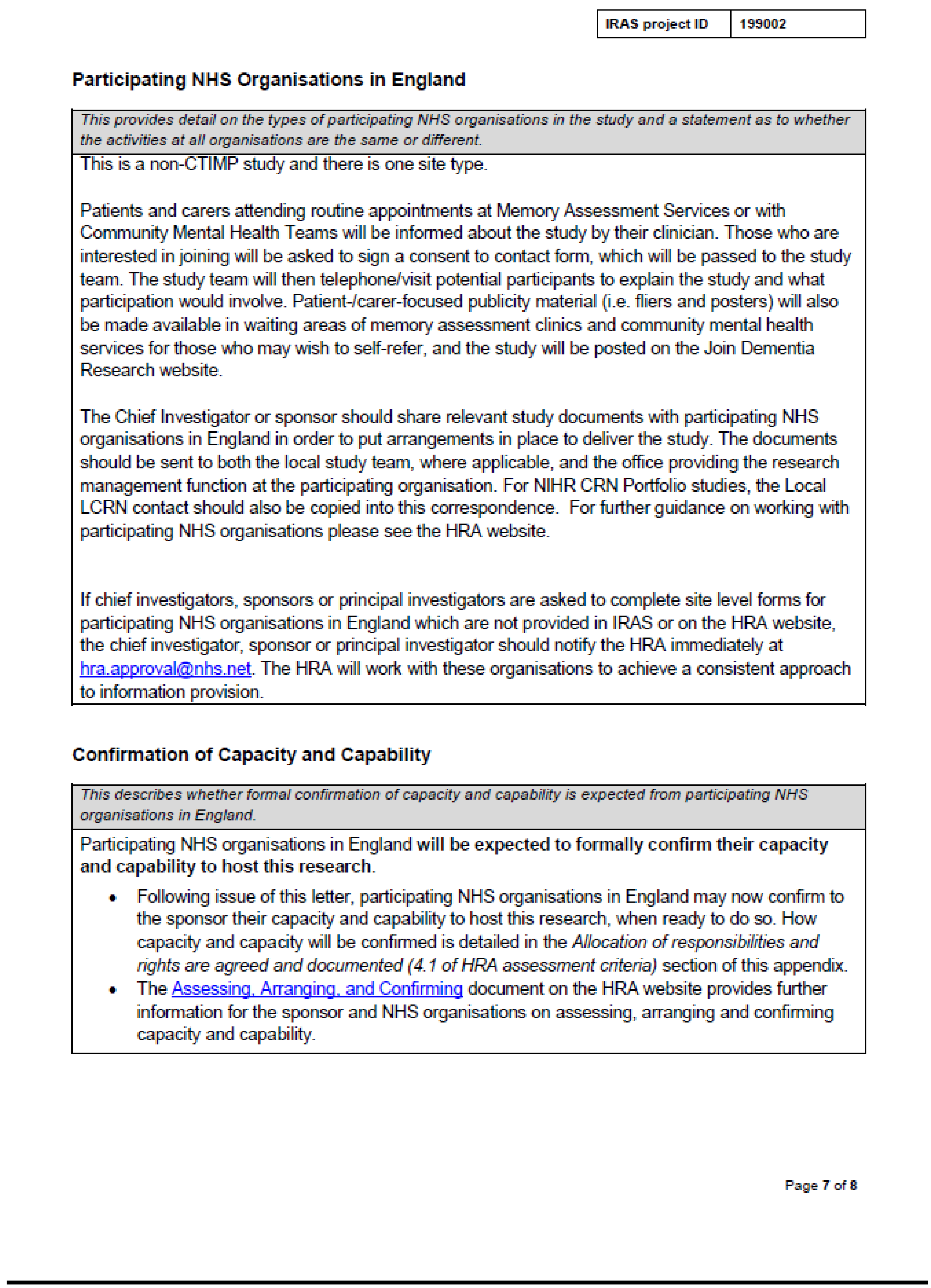
Ms Danelle Breach, 01603593475, danelle.breach@uea.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	The participant information sheets have been updated to bring them in line with HRA Approval standards via a minor amendment.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The Statement of Activities will act as an agreement between the Sponsor and the participating NHS sites to confirm capacity and capability to undertake their role in this research. The Sponsor is not requesting and does not require any other site agreement.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional



Section	HRA Assessment Criteria	Compliant with Standards	Comments
			indemnity provided by their medical defence organisation covers the activities expected of them for this research study.
4.3	Financial arrangements assessed	Yes	No funds will be provided to participating organisations to support this study.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC Provisional Opinion was issued 29 April 2016. This was followed by Favourable Opinion with conditions issued on 10 May 2016. Acknowledgement of conditions met was issued on 18 August 2016.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments



IRAS project ID	**199002**

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

This is a non-CTIMP study and there is one site type.

Patients and carers attending routine appointments at Memory Assessment Services or with Community Mental Health Teams will be informed about the study by their clinician. Those who are interested in joining will be asked to sign a consent to contact form, which will be passed to the study team. The study team will then telephone/visit potential participants to explain the study and what participation would involve. Patient-/carer-focused publicity material (i.e. fliers and posters) will also be made available in waiting areas of memory assessment clinics and community mental health services for those who may wish to self-refer, and the study will be posted on the Join Dementia Research website.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

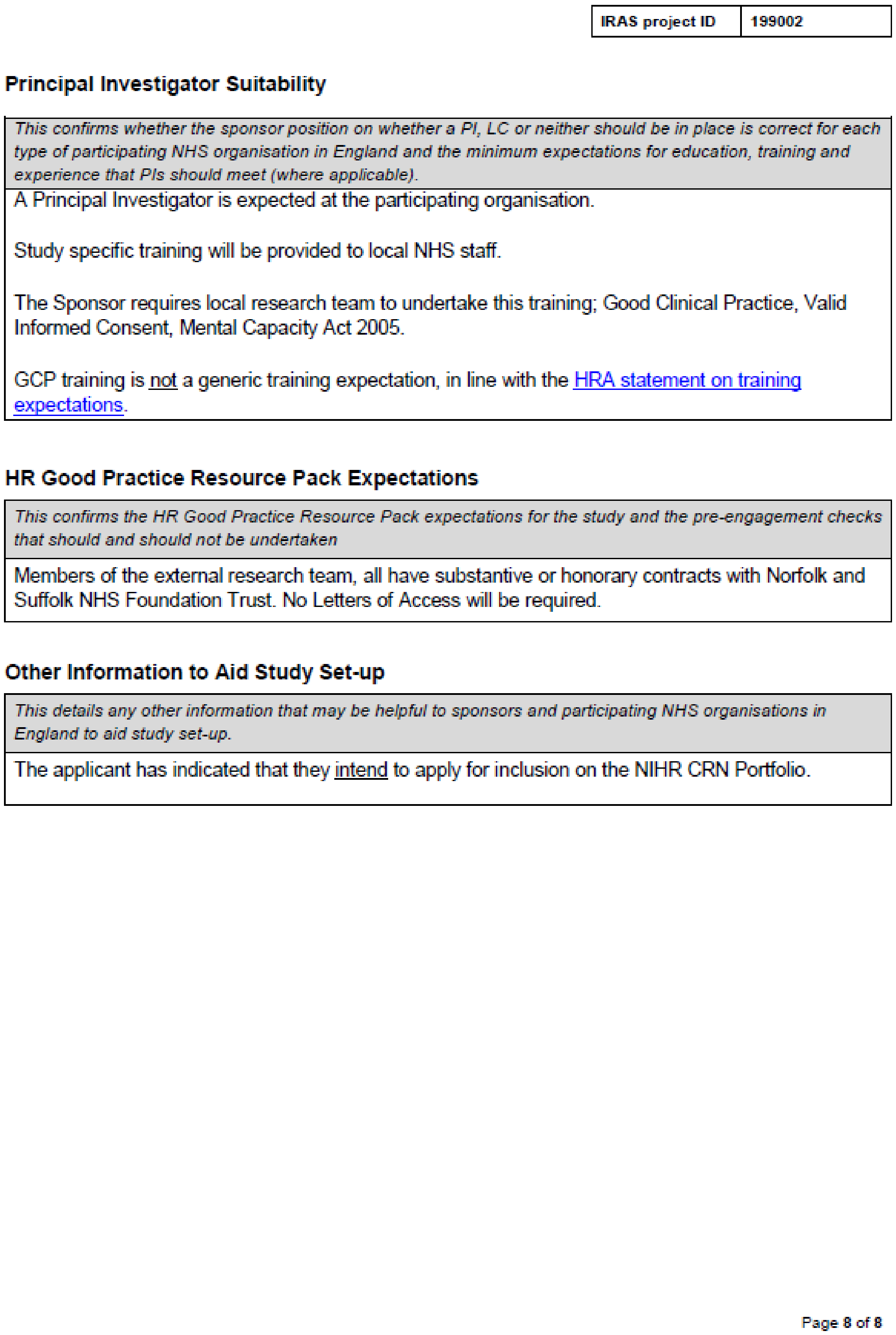
If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research**.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capacity will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The Assessing, Arranging, and Confirming document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.



IRAS project ID	**199002**

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A Principal Investigator is expected at the participating organisation.

Study specific training will be provided to local NHS staff.

The Sponsor requires local research team to undertake this training; Good Clinical Practice, Valid Informed Consent, Mental Capacity Act 2005.

GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

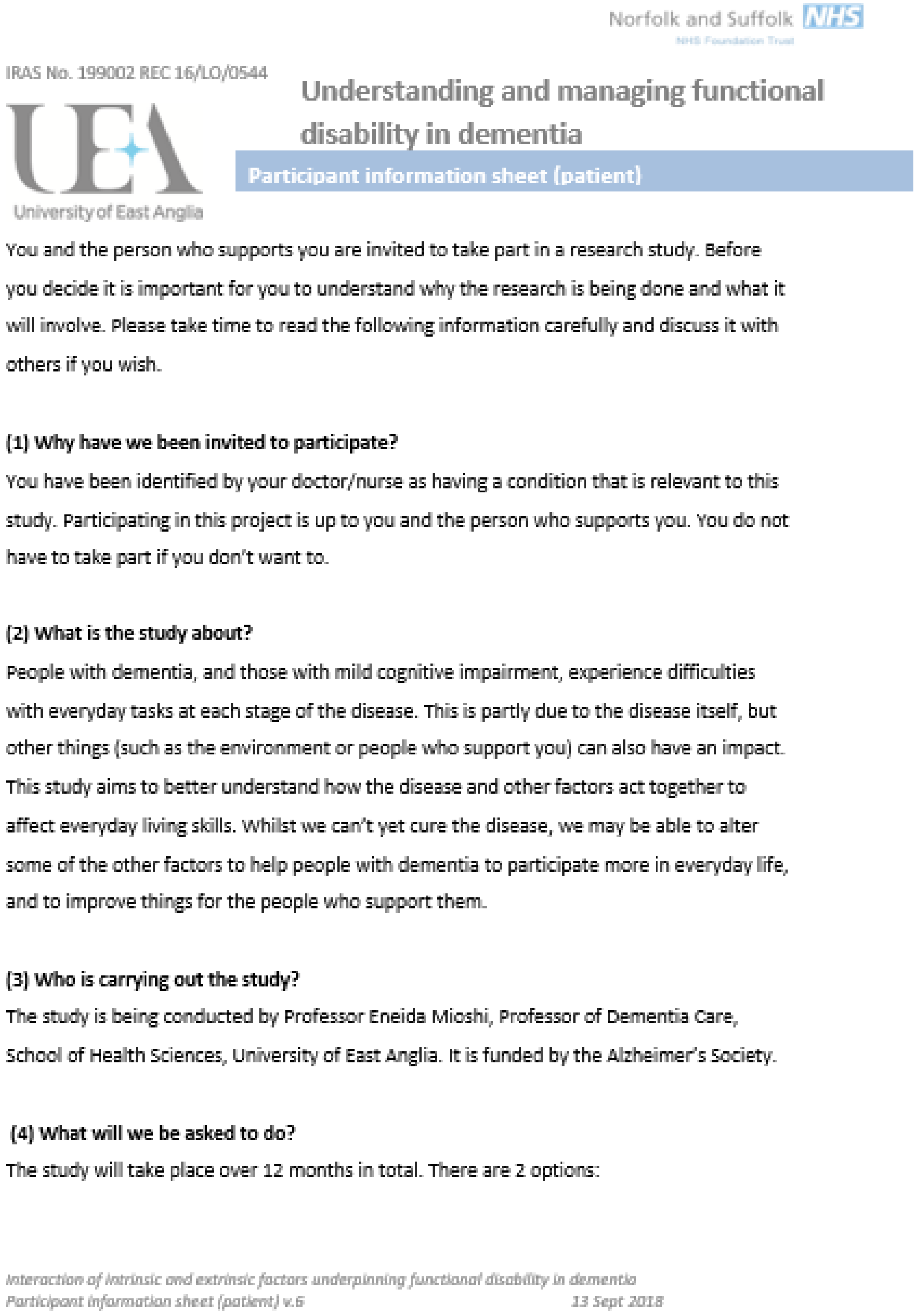
Members of the external research team, all have substantive or honorary contracts with Norfolk and Suffolk NHS Foundation Trust. No Letters of Access will be required.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they intend to apply for inclusion on the NIHR CRN Portfolio.

Supplementary material, Chapter 3, Section 3.4.2, Participant Information Sheets:
TASKed participant information sheet.



Norfolk and Suffolk NHS
NHS Foundation Trust

IRAS No. 199002 REC 16/LO/0544

University of East Anglia

Understanding and managing functional disability in dementia

Participant information sheet (patient)

You and the person who supports you are invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish.

(1) Why have we been invited to participate?

You have been identified by your doctor/nurse as having a condition that is relevant to this study. Participating in this project is up to you and the person who supports you. You do not have to take part if you don't want to.

(2) What is the study about?

People with dementia, and those with mild cognitive impairment, experience difficulties with everyday tasks at each stage of the disease. This is partly due to the disease itself, but other things (such as the environment or people who support you) can also have an impact. This study aims to better understand how the disease and other factors act together to affect everyday living skills. Whilst we can't yet cure the disease, we may be able to alter some of the other factors to help people with dementia to participate more in everyday life, and to improve things for the people who support them.

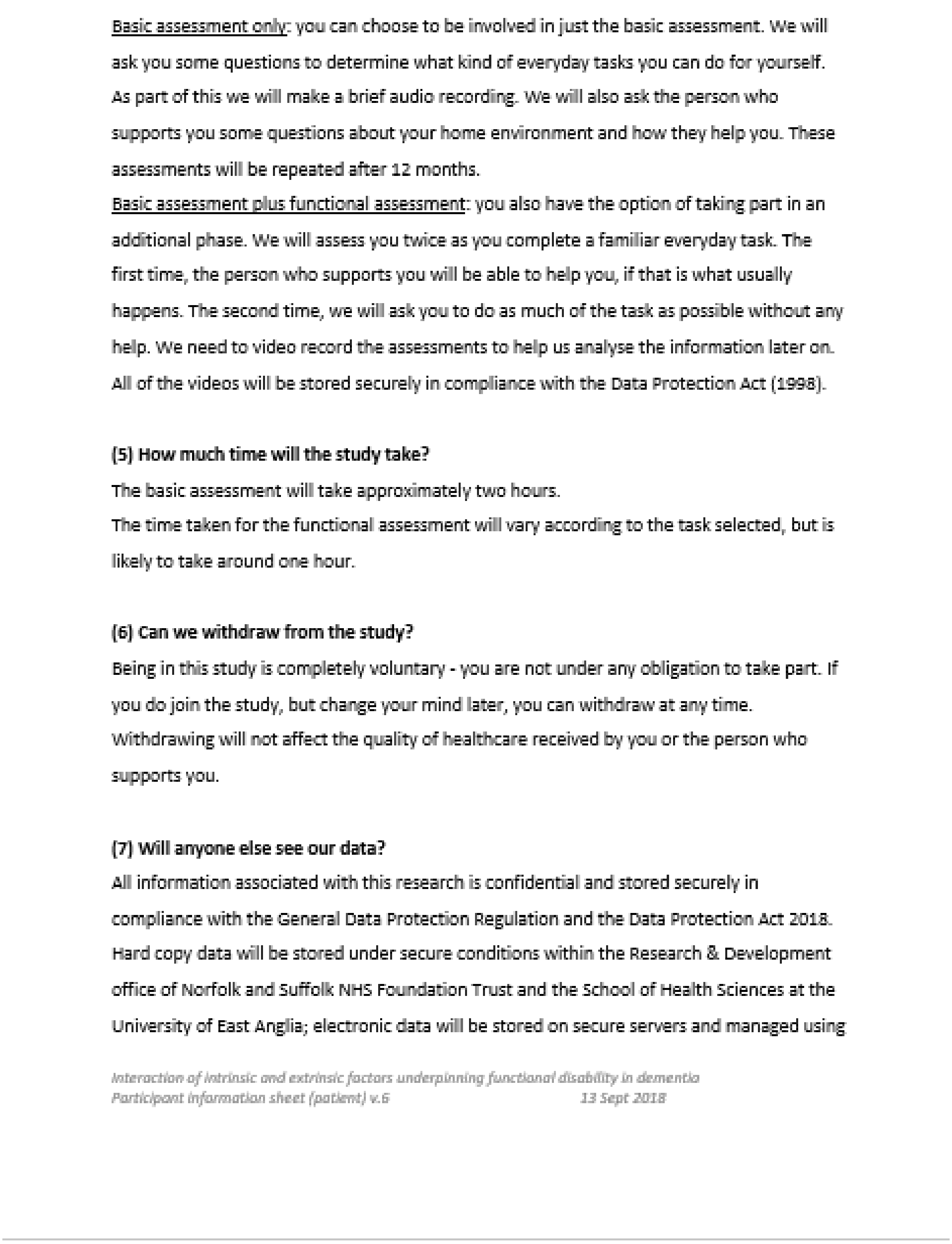
(3) Who is carrying out the study?

The study is being conducted by Professor Eneida Mioshi, Professor of Dementia Care, School of Health Sciences, University of East Anglia. It is funded by the Alzheimer's Society.

(4) What will we be asked to do?

The study will take place over 12 months in total. There are 2 options:

Interaction of intrinsic and extrinsic factors underpinning functional disability in dementia
Participant information sheet (patient) v.6 *13 Sept 2018*



Basic assessment only: you can choose to be involved in just the basic assessment. We will ask you some questions to determine what kind of everyday tasks you can do for yourself. As part of this we will make a brief audio recording. We will also ask the person who supports you some questions about your home environment and how they help you. These assessments will be repeated after 12 months.

Basic assessment plus functional assessment: you also have the option of taking part in an additional phase. We will assess you twice as you complete a familiar everyday task. The first time, the person who supports you will be able to help you, if that is what usually happens. The second time, we will ask you to do as much of the task as possible without any help. We need to video record the assessments to help us analyse the information later on. All of the videos will be stored securely in compliance with the Data Protection Act (1998).

(5) How much time will the study take?

The basic assessment will take approximately two hours.

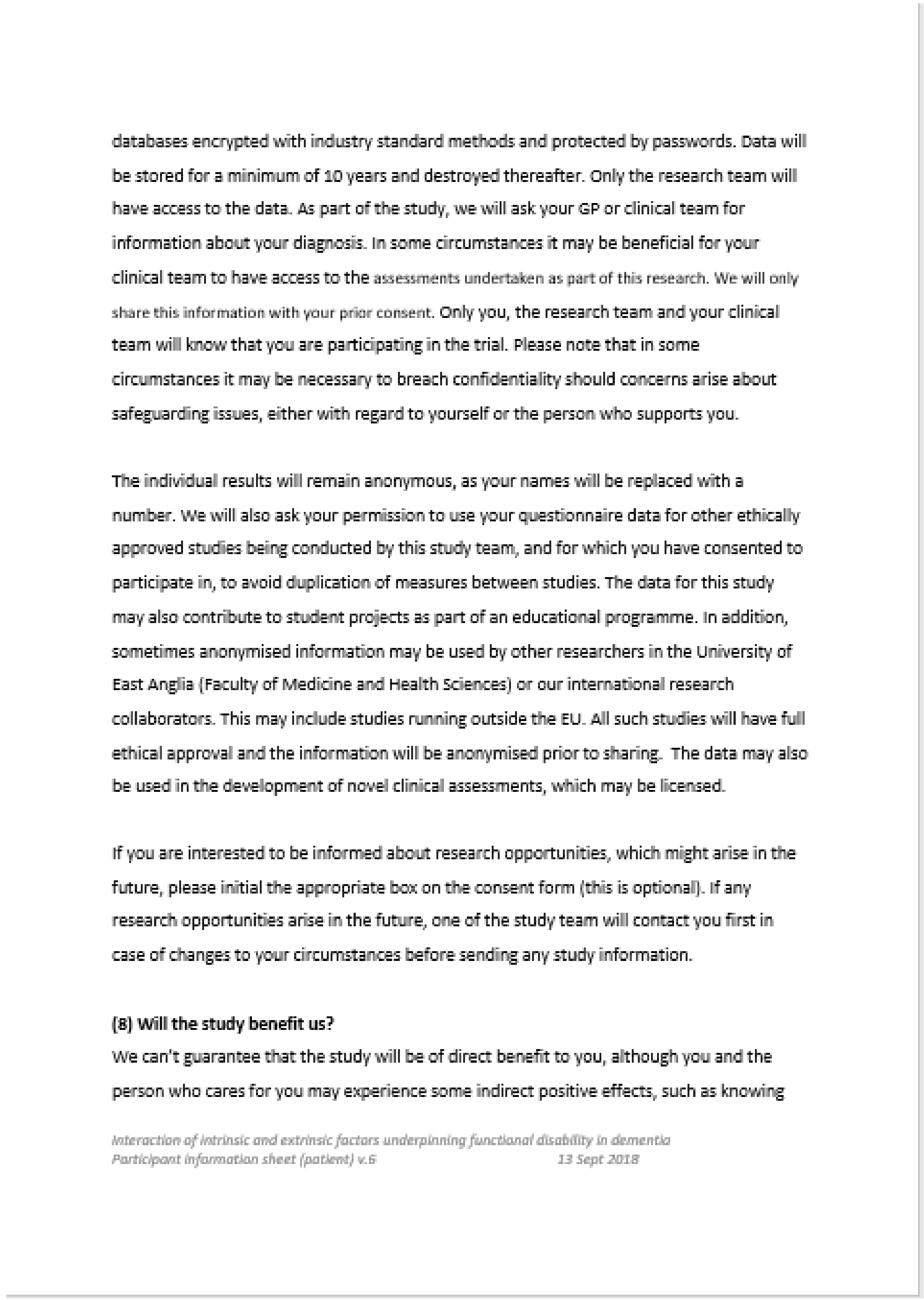
The time taken for the functional assessment will vary according to the task selected, but is likely to take around one hour.

(6) Can we withdraw from the study?

Being in this study is completely voluntary - you are not under any obligation to take part. If you do join the study, but change your mind later, you can withdraw at any time. Withdrawing will not affect the quality of healthcare received by you or the person who supports you.

(7) Will anyone else see our data?

All information associated with this research is confidential and stored securely in compliance with the General Data Protection Regulation and the Data Protection Act 2018. Hard copy data will be stored under secure conditions within the Research & Development office of Norfolk and Suffolk NHS Foundation Trust and the School of Health Sciences at the University of East Anglia; electronic data will be stored on secure servers and managed using



databases encrypted with industry standard methods and protected by passwords. Data will be stored for a minimum of 10 years and destroyed thereafter. Only the research team will have access to the data. As part of the study, we will ask your GP or clinical team for information about your diagnosis. In some circumstances it may be beneficial for your clinical team to have access to the assessments undertaken as part of this research. We will only share this information with your prior consent. Only you, the research team and your clinical team will know that you are participating in the trial. Please note that in some circumstances it may be necessary to breach confidentiality should concerns arise about safeguarding issues, either with regard to yourself or the person who supports you.

The individual results will remain anonymous, as your names will be replaced with a number. We will also ask your permission to use your questionnaire data for other ethically approved studies being conducted by this study team, and for which you have consented to participate in, to avoid duplication of measures between studies. The data for this study may also contribute to student projects as part of an educational programme. In addition, sometimes anonymised information may be used by other researchers in the University of East Anglia (Faculty of Medicine and Health Sciences) or our international research collaborators. This may include studies running outside the EU. All such studies will have full ethical approval and the information will be anonymised prior to sharing. The data may also be used in the development of novel clinical assessments, which may be licensed.

If you are interested to be informed about research opportunities, which might arise in the future, please initial the appropriate box on the consent form (this is optional). If any research opportunities arise in the future, one of the study team will contact you first in case of changes to your circumstances before sending any study information.

(8) Will the study benefit us?

We can't guarantee that the study will be of direct benefit to you, although you and the person who cares for you may experience some indirect positive effects, such as knowing that you are helping researchers learn more about dementia, which may improve the wellbeing of others, now or in the future.

You will not receive any payment for taking part in the study, however any travel costs incurred will be paid back.

(9) What are the risks of taking part?

There are no known risks and no anticipated discomfort from taking part in this study. However, some people may find it upsetting to talk about certain aspects of living with dementia or mild cognitive impairment; the researchers are experienced in supporting people during conversations like this and will do everything possible to make you feel more comfortable.

(10) What happens at the end of the study?

A report of the results from the study will be submitted for publication (individual participants will not be identifiable). Trial outcomes will be shared with Older People's Services and dementia teams across the Trust. We will also send you a summary of the findings at the end of the study.

(11) Can we tell other people about the study?

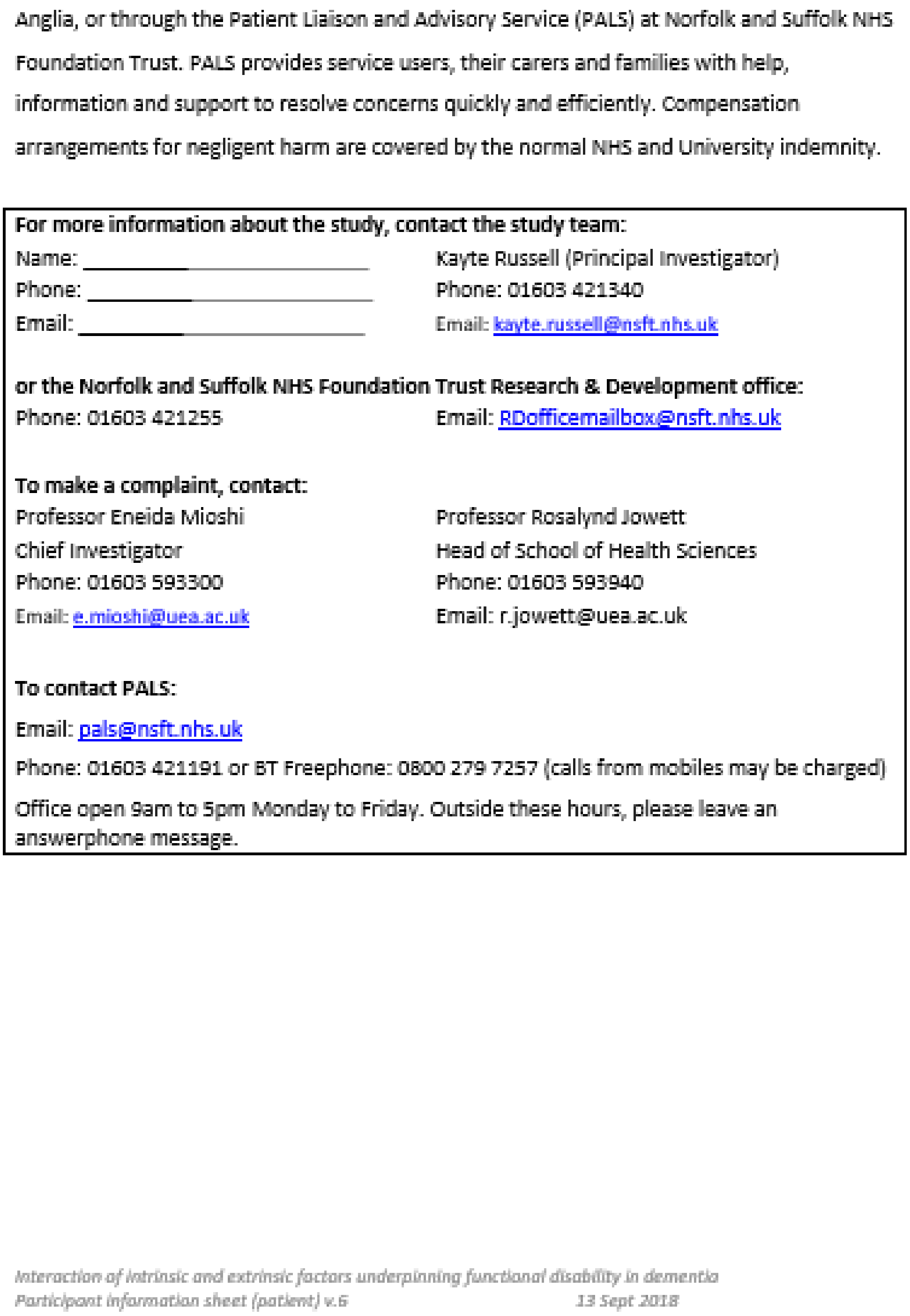
Yes, you can tell your family and friends about the study.

(12) What if we require further information about the study or our involvement in it?

When you have read this information, a member of the study team will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, contact details for the study team are provided at the end of this information sheet.

(13) What if we have a complaint or any concerns?

In the unlikely event of anything untoward happening, you may complain either directly to the Chief Investigator, the Head of the School of Health Sciences at the University of East



Anglia, or through the Patient Liaison and Advisory Service (PALS) at Norfolk and Suffolk NHS Foundation Trust. PALS provides service users, their carers and families with help, information and support to resolve concerns quickly and efficiently. Compensation arrangements for negligent harm are covered by the normal NHS and University indemnity.

For more information about the study, contact the study team:

Name: ____________	Kayte Russell (Principal Investigator)
Phone: ____________	Phone: 01603 421340
Email: ____________	Email: kayte.russell@nsft.nhs.uk

or the Norfolk and Suffolk NHS Foundation Trust Research & Development office:

Phone: 01603 421255	Email: RDofficemailbox@nsft.nhs.uk

To make a complaint, contact:

Professor Eneida Mioshi	Professor Rosalynd Jowett
Chief Investigator	Head of School of Health Sciences
Phone: 01603 593300	Phone: 01603 593940
Email: e.mioshi@uea.ac.uk	Email: r.jowett@uea.ac.uk

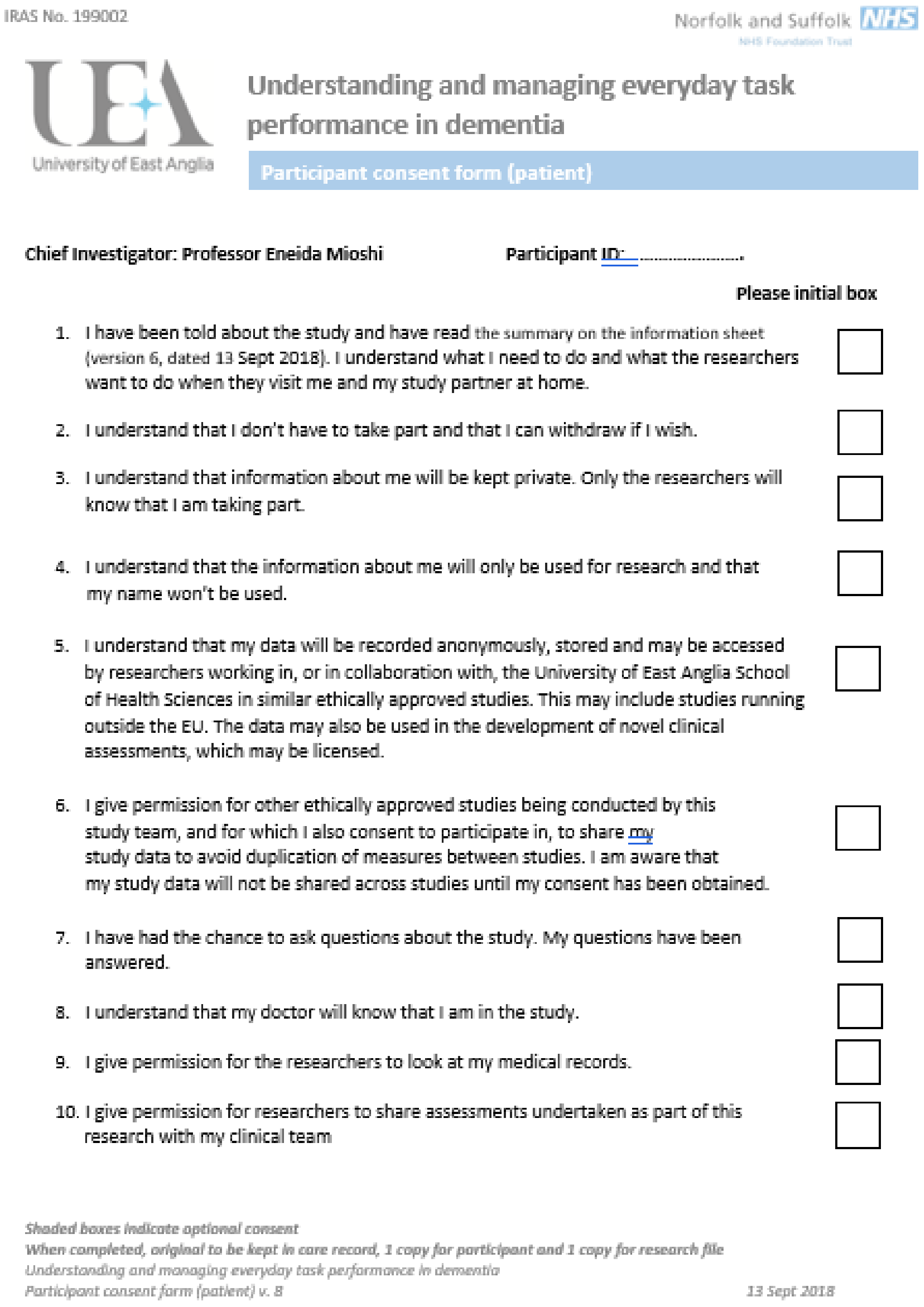
To contact PALS:

Email: pals@nsft.nhs.uk

Phone: 01603 421191 or BT Freephone: 0800 279 7257 (calls from mobiles may be charged)

Office open 9am to 5pm Monday to Friday. Outside these hours, please leave an answerphone message.

Supplementary material, Chapter 3, Section 3.4.3, Consent Forms: TASKed consent form (PwD).



IRAS No. 199002

Norfolk and Suffolk NHS
NHS Foundation Trust

University of East Anglia

Understanding and managing everyday task performance in dementia

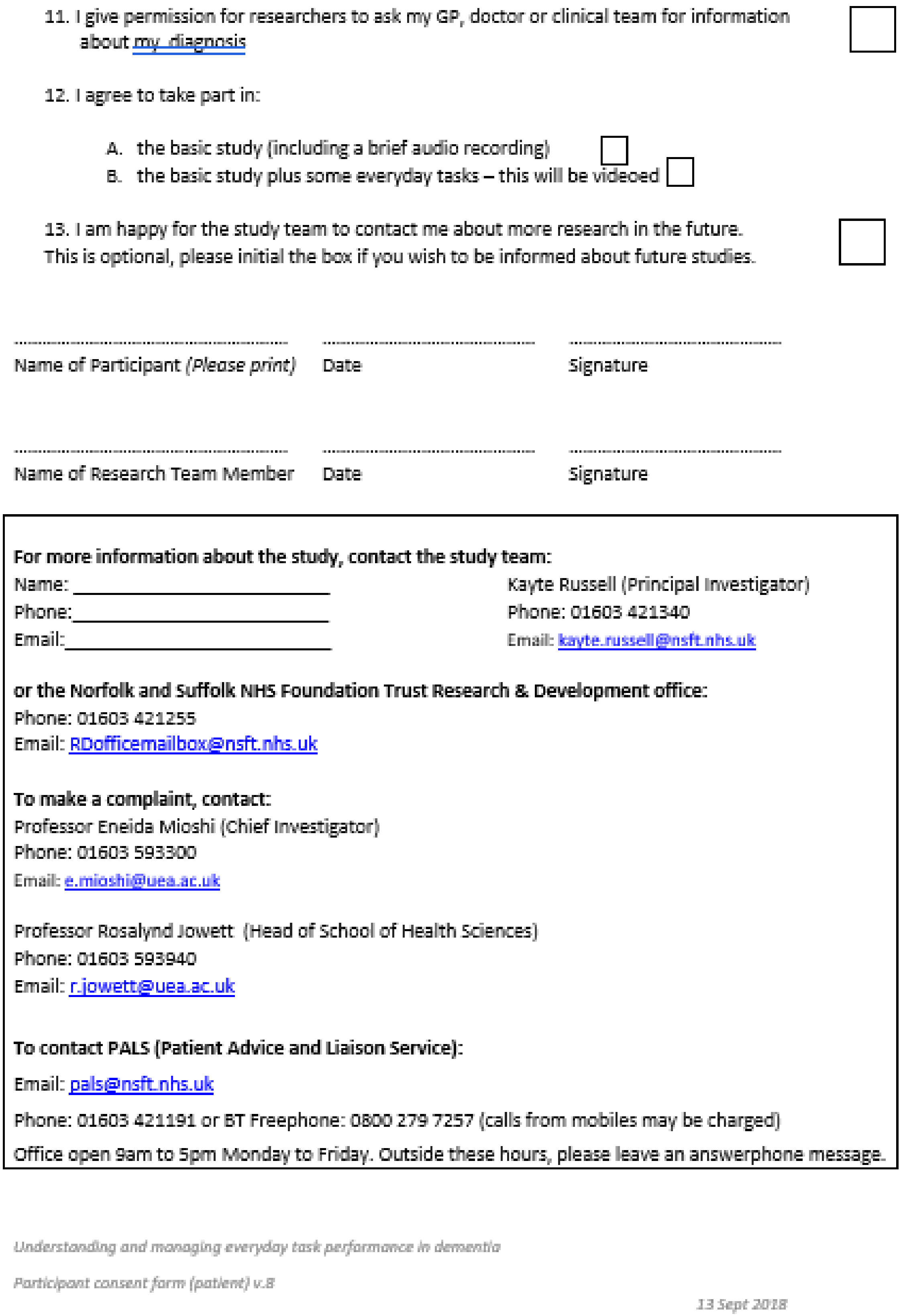
Participant consent form (patient)

Chief Investigator: Professor Eneida Mioshi **Participant ID:** …………………….

Please initial box

1. I have been told about the study and have read the summary on the information sheet (version 6, dated 13 Sept 2018). I understand what I need to do and what the researchers want to do when they visit me and my study partner at home. ☐
2. I understand that I don't have to take part and that I can withdraw if I wish. ☐
3. I understand that information about me will be kept private. Only the researchers will know that I am taking part. ☐
4. I understand that the information about me will only be used for research and that my name won't be used. ☐
5. I understand that my data will be recorded anonymously, stored and may be accessed by researchers working in, or in collaboration with, the University of East Anglia School of Health Sciences in similar ethically approved studies. This may include studies running outside the EU. The data may also be used in the development of novel clinical assessments, which may be licensed. ☐
6. I give permission for other ethically approved studies being conducted by this study team, and for which I also consent to participate in, to share my study data to avoid duplication of measures between studies. I am aware that my study data will not be shared across studies until my consent has been obtained. ☐
7. I have had the chance to ask questions about the study. My questions have been answered. ☐
8. I understand that my doctor will know that I am in the study. ☐
9. I give permission for the researchers to look at my medical records. ☐
10. I give permission for researchers to share assessments undertaken as part of this research with my clinical team ☐

Shaded boxes indicate optional consent
When completed, original to be kept in care record, 1 copy for participant and 1 copy for research file
Understanding and managing everyday task performance in dementia
Participant consent form (patient) v. 8 *13 Sept 2018*



11. I give permission for researchers to ask my GP, doctor or clinical team for information about my diagnosis ☐

12. I agree to take part in:

    A. the basic study (including a brief audio recording) ☐
    B. the basic study plus some everyday tasks – this will be videoed ☐

13. I am happy for the study team to contact me about more research in the future. This is optional, please initial the box if you wish to be informed about future studies. ☐

………………………………………… ………………………………… …………………………………
Name of Participant *(Please print)* Date Signature

………………………………………… ………………………………… …………………………………
Name of Research Team Member Date Signature

For more information about the study, contact the study team:

Name: ______________________
Phone: ______________________
Email: ______________________

Kayte Russell (Principal Investigator)
Phone: 01603 421340
Email: kayte.russell@nsft.nhs.uk

or the Norfolk and Suffolk NHS Foundation Trust Research & Development office:
Phone: 01603 421255
Email: RDofficemailbox@nsft.nhs.uk

To make a complaint, contact:
Professor Eneida Mioshi (Chief Investigator)
Phone: 01603 593300
Email: e.mioshi@uea.ac.uk

Professor Rosalynd Jowett (Head of School of Health Sciences)
Phone: 01603 593940
Email: r.jowett@uea.ac.uk

To contact PALS (Patient Advice and Liaison Service):

Email: pals@nsft.nhs.uk

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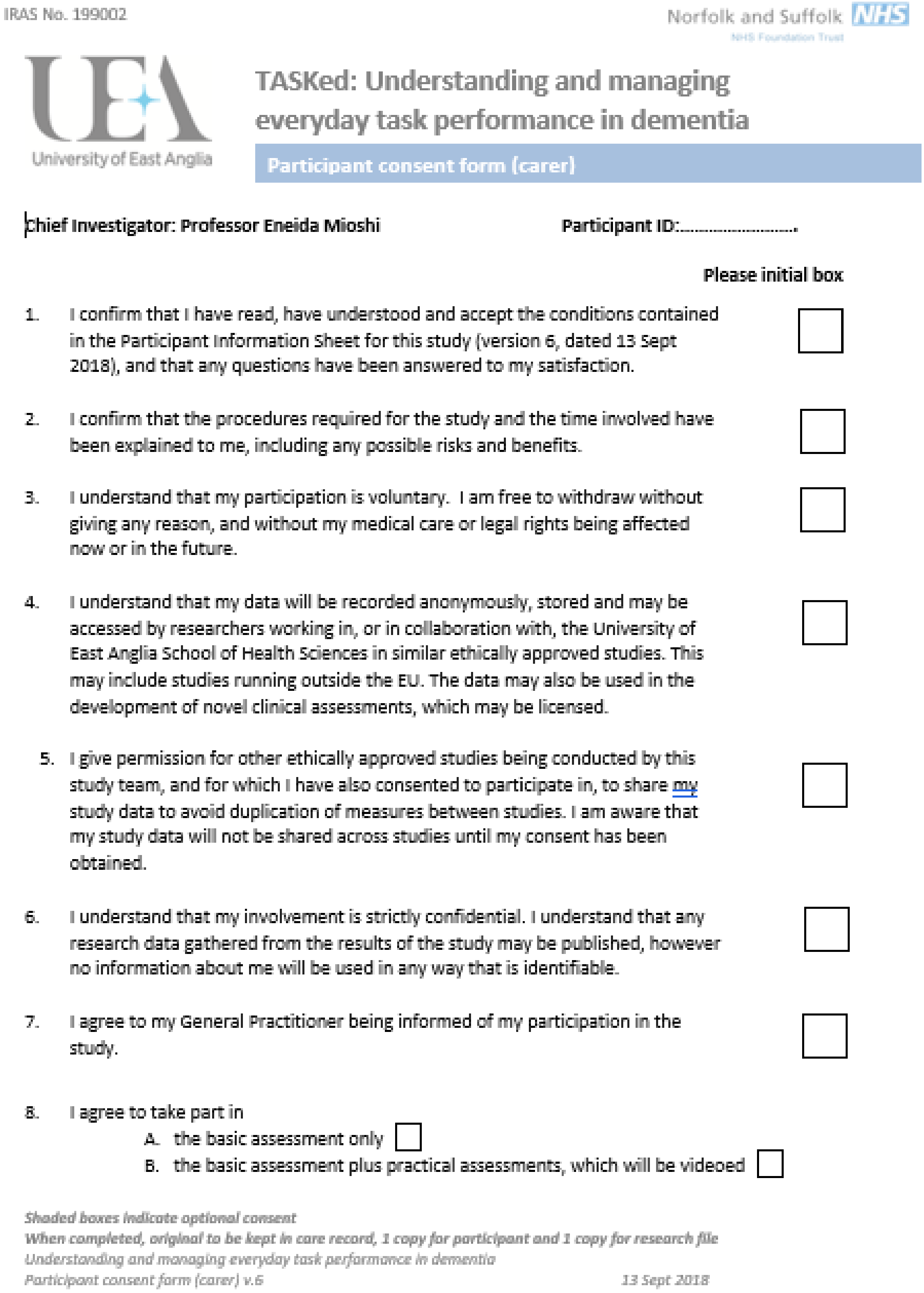
Office open 9am to 5pm Monday to Friday. Outside these hours, please leave an answerphone message.

Understanding and managing everyday task performance in dementia

Participant consent form (patient) v.8

13 Sept 2018

Supplementary material, Chapter 3, Section 3.4.3, Consent Forms: TASKed consent form (carer).



IRAS No. 199002

Norfolk and Suffolk NHS
NHS Foundation Trust

UEA
University of East Anglia

TASKed: Understanding and managing everyday task performance in dementia

Participant consent form (carer)

Chief Investigator: Professor Eneida Mioshi **Participant ID:……………………..**

Please initial box

1. I confirm that I have read, have understood and accept the conditions contained in the Participant Information Sheet for this study (version 6, dated 13 Sept 2018), and that any questions have been answered to my satisfaction. ☐
2. I confirm that the procedures required for the study and the time involved have been explained to me, including any possible risks and benefits. ☐
3. I understand that my participation is voluntary. I am free to withdraw without giving any reason, and without my medical care or legal rights being affected now or in the future. ☐
4. I understand that my data will be recorded anonymously, stored and may be accessed by researchers working in, or in collaboration with, the University of East Anglia School of Health Sciences in similar ethically approved studies. This may include studies running outside the EU. The data may also be used in the development of novel clinical assessments, which may be licensed. ☐
5. I give permission for other ethically approved studies being conducted by this study team, and for which I have also consented to participate in, to share my study data to avoid duplication of measures between studies. I am aware that my study data will not be shared across studies until my consent has been obtained. ☐
6. I understand that my involvement is strictly confidential. I understand that any research data gathered from the results of the study may be published, however no information about me will be used in any way that is identifiable. ☐
7. I agree to my General Practitioner being informed of my participation in the study. ☐
8. I agree to take part in
   - A. the basic assessment only ☐
   - B. the basic assessment plus practical assessments, which will be videoed ☐

Shaded boxes indicate optional consent
When completed, original to be kept in care record, 1 copy for participant and 1 copy for research file
Understanding and managing everyday task performance in dementia
Participant consent form (carer) v.6 *13 Sept 2018*

9. I agree to be contacted by the study team about further research opportunities which may arise in future. This is optional, please initial the box if you wish to be informed about future studies. ☐

…………………………………………	………………………………	………………………………
Name of Participant *(Please print)*	Date	Signature
…………………………………………	………………………………	………………………………
Name of Research Team Member *(Please print)*	Date	Signature

For more information about the study, contact the study team:

Name:________________________	Kayte Russell (Principal Investigator)
Phone: ________________________	Phone: 01603 421340
Email: ________________________	Email: kayte.russell@nsft.nhs.uk

or the Norfolk and Suffolk NHS Foundation Trust Research & Development office:
Phone: 01603 421255
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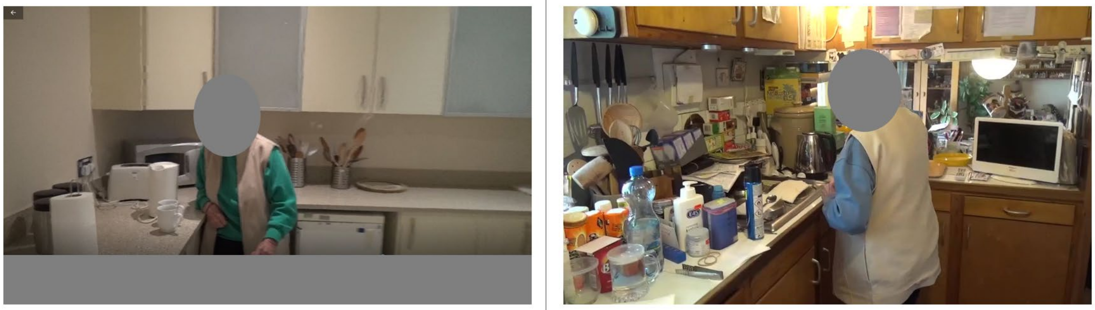
Supplementary material, Chapter 4: Example of a participant’s own home and its level of clutter and how the research-lab was decluttered for the study conducted in Chapter 4.



Clutter-free Research-lab

Participant’s home