Profiling Communication Ability in Dementia (P-CAD): Development and Validation of a Functional Cognitive-Communication Assessment

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Declaration

I declare that this thesis has not been submitted as an exercise for a degree at this or any other university and that it is entirely my own work.

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July 2020

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"My own Máire has left the land for the sea and I cannot follow her, nor can I bring her back. She dwells now in the sea and I on the land. She can't return to the land and I can only enter the shallows of the sea she now lives in. I watch her from the shore and sometimes she swims in close to me and sometimes she is far away. When close we touch, and she is near to me as breath yet far away as stars. Mostly I patrol the shore, keeping watch and praying that she is safe and well and at peace in her sea of dreaming. Sometimes songs more than science make sense of the heart's yearning".

From Science, Songs and Sense-making by Sé

Abbreviations

ABCD	Arizona Battery Communication Disorders
AD	Alzheimer's Disease
Bv-FTD	Behavioural Variant Fronto Temporal Dementia
CAPPCI	Conversation Analysis Profile for People with Cognitive Impairment
CAT	Comprehensive aphasia test
CAPs	Conversation Ability Profiles
CLQT	Cognitive Linguistic Quick Test
CP	Communication Partner
DPD	Dementia with Parkinson's Disease
EOAD	Early Onset Alzheimer's Disease
FLCI	Functional Linguistic Communication Inventory
FTD	Fronto Temporal Dementia
GDS	Global deterioration scale
GP	General Practitioner
HCR	Health Care Record
HSCPs	Health and Social Care Professionals
HSE	Health Service Executive
IASLT	Irish Association of Speech and Language Therapists
ICGP	Irish College of General Practitioners
INDS	Irish National Dementia Strategy
LBD	Lewy Body Dementia
MCI	Mild Cognitive Impairment
MD	Mixed Dementia

MOCA	Montreal Cognitive Assessment
NDO	National Dementia Office
PDS	Post Diagnostic Support
PPA	Primary Progressive Aphasia
P-CAD	Profiling Communication Ability in Dementia
R-CAD	Rating Communication Ability in Dementia
SIB	Severe Impairment Battery
SLT	Speech and Language Therapist
SRT	Spaced Retrieval Training
WHO	World Health Organisation
VaD	Vascular Dementia

Summary

Communication difficulties are an inevitable consequence of dementia. The impact of cognitive decline on the communication abilities of individuals with dementia is well-documented, yet communication is not often explicitly mentioned in definitions of dementia. The focus of assessment and treatment in dementia has tended to be on cognitive domains such as memory. Patterns of cognitive communication impairment vary, depending on the type and stage of dementia. While people with dementia experience decline in communication skills, they retain functional communication abilities. Each person with dementia will have a unique communication profile. This research reports the current practice of speech and language therapists (SLTs) in dementia care in Ireland, reviewing the availability of suitable cognitive communication assessments and, importantly, developing a new functional cognitive communication assessment for use with people with dementia.

The initial phase of the research was a cross-sectional clinical practice survey (Study 1) with SLTs working in dementia care. Survey results highlighted that SLTs (n=89) do not routinely manage cognitive communication difficulties associated with dementia, while the majority of SLTs reported providing dysphagia services to people with dementia. Informal communication assessments were most commonly used by SLTs and a lack of appropriate assessments was identified as a key challenge contributing to this clinical trend. Conversation therapy and environmental modification were frequently used approaches in intervention, but these areas were not reported as being formally assessed. This lack of formal assessment has implications for selecting appropriate interventions, measuring clinical effectiveness and outcomes. Chapter 4 describes SLTs' feedback on a range of issues and practices in dementia care. Survey outcomes can now inform the development of speech and language therapy services and care pathways for people with dementia in Ireland.

A scoping review of cognitive communication assessments (Study 2) available to SLTs in clinical practice was conducted. The lack of appropriate assessment tools identified by SLTs in Study 1 was confirmed in the scoping

review. Only four cognitive communication assessments met the criteria for inclusion in the final review and analysis outlined in Chapter 5. This research identified that currently available assessments are not standardised for stage and subtype of dementia, as well as having limited focus on functional communication ability. These research findings suggest that there are many aspects of cognitive communication assessment with people with dementia that need further development.

These two preliminary studies informed the development of a new cognitive communication assessment P-CAD for use with people with dementia. P-CAD was developed under the guidance of an expert group, in conjunction with a range of key stakeholders. The process involved the development of the assessment tool through feedback from focus groups, a pilot phase with SLTs and a large-scale study to examine reliability and validity.

P-CAD has been validated with people with early, mid and late stage dementia providing clinicians with a tool that can be used at all stages of dementia. The participants with dementia (n=100) were assessed in a variety of setting and locations including care homes and domiciliary home settings representative of where people with dementia live and interface with SLTs. P-CAD has been validated with people with different dementia subtypes: AD (55%), VaD (28%), mixed dementia (MD) (9%), DPD (4%), LBD (3%) and FTD (1%). The P-CAD validation study found positive and strong correlations with the Mini Mental State Examination 2(MMSE-2) ($rho=0.812$, $p<0.001$) a measure of cognition and the Functional Linguistic Communication Inventory (FLCI) ($rho=0.828$, $p<0.001$) a cognitive communication assessment. P-CAD scores fall as Global Deterioration Scale (GDS) levels increase, indicating parallels between cognitive decline and reduced communication ability in dementia. There were highly significant correlations between the two raters on total P-CAD scoring as well as all eight P-CAD subtests, indicating strong reliability. P-CAD's ability to measure change in cognitive communication ability was not established fully in this study. P-CAD provides SLTs with a tool to profile communication abilities and direct individualised advice, support and therapy from the outset with people with dementia.

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Organisation of Thesis

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Section 1: Literature Review

Chapter 1 Chapter 2 Chapter 3

Section 2: Preliminary Studies

Chapter 4 Chapter 5

Section 3: P-CAD Development and Refinement

Chapter 6 Chapter 7 Chapter 8

Section 4: P-CAD Validation and Implications for Research and Practice

Chapter 9 Chapter 10

Figure A. Organisation of Thesis

Section 1: Literature Review

This section provides a literature review presenting the context for this research in three chapters.

Chapter 1 reviews communication and ageing and the role of the SLT in managing communication disability. An overview of dementia, epidemiology and specific dementia health policy is provided. The nature of communication difficulties across dementia subtypes is examined and the impacts of communication function including psychosocial ability and the well-being of the person with dementia and their family are explored.

Chapter 2 describes the management of cognitive communication difficulties in dementia. Assessment of cognitive communication skills in dementia is considered as well as a review of communication interventions for people with dementia. There is a focus on retained communication abilities in dementia and the important role of the communication partner (CP) in revealing communication competence.

Chapter 3 draws together the relevant literature presenting the theoretical framework that underpins this research including the lack of communication-specific speech and language therapy services and resources for people with dementia. It also presents the research aims and questions guiding this dissertation.

Section 2: Preliminary Studies

This section contains two preliminary studies that provide the background on current SLT practice and more specifically a review into cognitive communication assessment in dementia. These studies provide the basis for the primary research that follows in Section 3.

Chapter 4 presents Study 1, a cross-sectional survey of SLTs in Ireland that reports on current practice of SLTs working in dementia care and explores the management of cognitive communication difficulties in dementia.

Chapter 5 describes Study 2, a scoping review of existing cognitive communication assessments for use with people with dementia.

Section 3: P-CAD Development and Refinement

This section outlines the primary research. It describes the early development of a cognitive communication assessment and the comprehensive refinement of this tool across 3 phases into the final version of the P-CAD.

Chapter 6 outlines the initial development of a cognitive communication assessment for people with dementia called Rating Communication Ability in Dementia (R-CAD). There were two small pilot studies of this cognitive communication assessment, which was found to be a useful tool by SLTs in dementia care.

Chapters 7 & 8 describe three phases of P-CAD development and refinement of the cognitive communication tool. Chapter 7 describes Phase 1 which sought feedback from SLTs on the P-CAD to inform further refinement. In Chapter 8, Phase 2, a pilot study, and Phase 3, the final refinement of the P-CAD prior to the large validation study pf the final amended P-CAD in Section 4 are presented.

Section 4: P-CAD Validation and Implications for Research and Clinical Practice

In this section, the validity and reliability of the final P-CAD assessment for people with dementia and their CPs, is tested and outcomes discussed.

Chapter 9 describes, the validation study. The concurrent validity, interrater reliability and sensitivity of the P-CAD to change over time is tested.

Chapter 10 discusses the main research findings and concludes with implications for managing cognitive communication difficulties in dementia.

Section 1: Literature Review

Chapter 1
Communication and Dementia

1.0 Introduction

This chapter reflects on fundamental descriptions of communication, communication disability and the impact of communication disability on participation in everyday life for older adults. A broad overview of dementia, the disease and typical communication profiles in dementia will be discussed. The role of the speech and language therapist (SLT) in managing communication impairment in dementia is presented as well as dementia policy in Ireland.

1.1 Communication and ageing

The complexity of human communication has been the basis of much discussion and research over the centuries going back to Aristotle and his contemporaries. There remains today little consensus on communication theory across disciplines. Communication theories that reflect the interactional, dynamic and co-relational nature of communication are the basis for this research (Butler and Randall, 2013, Fogel, 2017, Barnlund, 2017). Communication is a continuous bi-directional and dynamic process between communication partners (CPs). It is central to the way we live and enables us to participate in everyday life.

The communication process is important for living independently in older age, engaging in personal interests and maintaining close relationships. There is evidence that the number and quality of social relationships an individual has, is related to better physical and mental health across the life course (Holt-Lunstad et al., 2010). With increasing age, conditions that impact on communication function such as declining hearing and vision (Mamo et al., 2016) become more prevalent directly impacting on communication efficiency and social participation. In typical ageing, some modest changes in

attention, speed of processing and working memory can be expected along with mild word finding difficulty. Any changes in cognition will impact on an individual's communication ability. Cognition makes communication possible.

1.2 Living with communication disability

Communication impairments affect the quality and nature of friendships as well as social engagement and the emotional well-being of older adults (Davidson et al., 2008). Changes in social network occur frequently for people with communication impairment when compared with other older adults (Palmer et al., 2019). Frameworks of communication disability, participation and competence (Kagan et al., 2008, WHO, 2001, MacDonald, 2017) view conversation as an activity of daily living. Communication disability will affect the range and frequency of everyday communication activities such as mobile phone use and engaging in social events such as family and community gatherings. People with aphasia and dysarthria report a reduction in social participation as well as the number of activities that they participate in following stroke (Northcott and Hilari, 2011, Walshe and Miller, 2011). The consequences may have psychological impacts such as social isolation and depression.

Communication difficulties are among the many challenges associated with progressive decline in dementia and directly impact the ability to engage socially. Over time dementia causes disruption to the cognitive-linguistic system, changing the way in which the person communicates. Memory and communication difficulties in dementia alter the balance and dynamic in conversation and impact directly on relationships (Liddle et al., 2012). The family must carry more responsibility for conversation management as the person with dementia may be unable to consistently modify their communication. This functional decline and increased demand in care giving can lead to burnout and health problems (Small et al., 2003) for the carer. Communication becomes less effective and less flexible than prior to the onset of dementia, which can affect relationships and impact on quality of life.

Supporting personhood in person-centered care has good communication practice at its core. People with dementia will experience challenges managing conversations but retain the need to have meaningful interactions and have their social needs met (Savundranayagam et al., 2016). Good communication practice supports conversations that acknowledge the person's unique identity, their personal background and the need to engage in conversations with others. Ineffective communication can lead to social withdrawal and negative behaviours. Acknowledging and managing communication disability will improve the quality of interactions for both person with dementia and their CP. Speech and language therapists are central to the provision of interventions and psychological support for older adults living with communication disability to help preserve and enhance communication function.

1.3 The role of the SLT and scope of practice in dementia care

The practice of speech and language therapy includes the assessment, diagnosis, identification and rehabilitation of individuals presenting with communication and swallowing disorders (IASLT, 2010). The recently published and long-awaited position paper from the Irish Association of Speech and Language Therapists entitled *Speech and Language Therapy Provision for People with Dementia* (IASLT 2016) describes specifically the role and responsibilities of the SLT in working with people with dementia from the pre-diagnostic stage to end of life care (see Figure 1.1). As a profession, SLTs must be guided by evidence-based practice and the recommendations for service delivery and patient care are laid out by their professional bodies and associated international best practice guidelines such as the NICE/SCIE Guidelines (2010) on *Supporting People with Dementia in their Health and Social Care.*

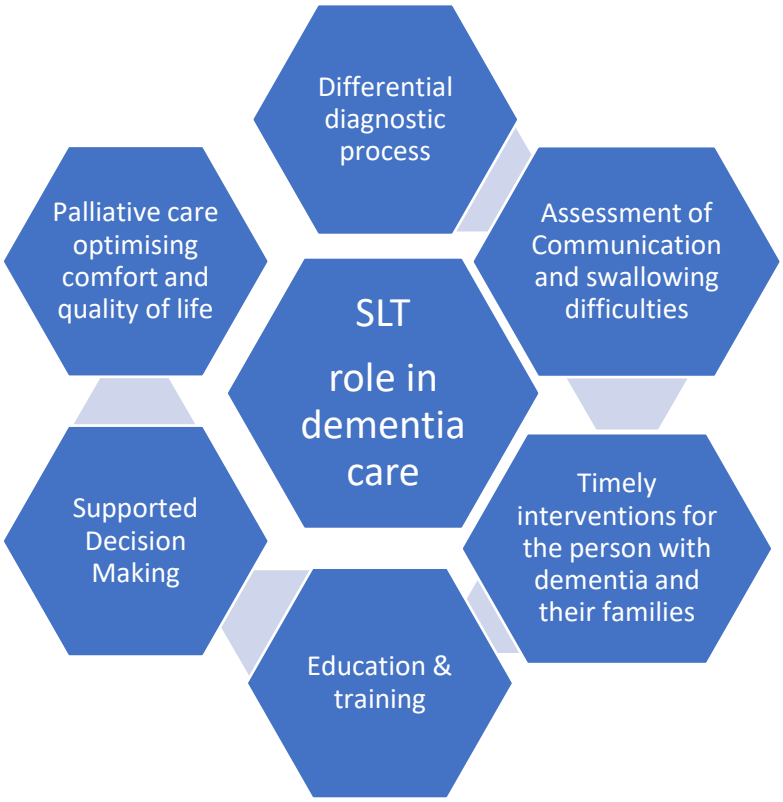


Figure 1.1 SLT in Dementia care

The role of the SLT in dementia care has been clearly described by guiding practice documents from the SLT profession internationally (Irish Association of Speech and Language Therapists Association (IASLT) 2016; Royal College of Speech and Language Therapists (RCSLT) 2014; Speech Pathology Australia (SPA) 2015; American Speech-Language Hearing Association (ASHA) 2015). SLTs have a well-defined role in supporting the person and their families to live well with dementia by managing both their communication difficulties and their eating, drinking and swallowing difficulties in a timely manner. SLTs also identify and help maintain retained cognitive communication abilities. However, in practice, SLTs are not routinely providing a comprehensive SLT service to people with dementia, this will be evaluated further in a SLT practice survey in Chapter 4.

Although there is a perception that little can be done to help mitigate communication problems associated with dementia (Hopper, 2003), research suggests that early management of communication difficulties reduces negative impact and improves quality of life for people with dementia (Hopper et al., 2013). Working with people with dementia and their families requires

a flexible approach that will provide support in everyday communication situations at home as well as in the wider community (IASLT, 2016). Ideally, this work should be carried out as part of a multidisciplinary team, as an integrated care approach helps people to live well despite the functional problems caused by dementia.

Due to the progressive and life limiting nature of dementia, SLTs are involved in service provision from diagnosis to the palliative care stages (O'Reilly and Walshe, 2015). In this context clinical domains of competence for SLTs include; optimising comfort and quality of life, loss, grief and bereavement encompassing all the principles of palliative care (Ryan et al., 2014).

In clinical practice the emphasis in the advanced stages of dementia is often on the management of swallowing disorders, which may be due to caseload prioritisation policies, limited staffing levels and resources. Historically, there has been limited focus on the provision of communication assessment and management by SLTs in the palliative care setting (O'Reilly and Walshe, 2015), which will also be discussed further in Chapter 4 (Study 1). Having an up to date communication evaluation of the person with dementia is an important aspect of meeting their care needs. Holistic care involves comprehensive speech and language therapy assessment for people with dementia (RCSLT, 2014) (Volkmer, 2013), both their swallowing and communication needs must be assessed and managed.

1.4 Dementia Health Policy in Ireland

The publication of the Irish National Dementia Strategy (NDS) in 2014 has begun to address long held concerns about the under development and inadequate funding of dementia services in Ireland (Cahill et al., 2012). This strategy recommends a basic standard of care that people with dementia can expect to receive in Ireland. These recommendations include timely access to integrated services to facilitate early diagnosis and help manage the day to day challenges of living with dementia. Memory clinics provide an integrated model of care for people with dementia and there is no one standard or guidelines internationally on the purpose and role of memory clinics. Recent figures suggest that there are 24 memory clinics across

Ireland (Revez et al., 2018). These clinics are involved in the provision of early diagnosis, information dissemination, initiation and monitoring of treatment, and/or education and training. Information on the involvement of SLTs in memory clinics nationally is not currently available.

1.5 Dementia

Dementia is a neuro-degenerative condition. It is not part of normal ageing, as healthy ageing is associated with only subtle decline in cognition (Harada et al., 2013). The specific symptoms that someone with dementia experiences will depend on the areas of the brain that are affected and the aetiology of the dementia. In the past, dementia was described more typically as a uniform condition causing memory loss and difficulties with behaviour.

In 2011, the National Institute of Ageing/Alzheimer's Association (Jack et al., 2011) revised the core clinical criteria for dementia. These criteria now include a range of cognitive and behavioural impairments that include impaired language function such as speaking, reading and writing. Current definitions such as this by Chertkow et al.(2013, p.2) reflect the complex nature of the condition;

> *"Dementia is typically defined as a clinical syndrome of cognitive decline that is sufficiently severe to interfere with social or occupational functioning. Routine clinical practice shows that the cognitive and functional changes of dementia are typically accompanied by changes in behaviour and in personality, but these have not become core criteria as they have been considered heretofore due to lack of sufficient diagnostic specificity"*

There are numerous definitions of dementia that do not acknowledge that communication difficulties are an inherent part of the condition. Dementia is frequently referred to as a disorder of memory, behaviour and cognition. However, there is a growing focus on "communication" as part of the dementia syndrome (Jones et al., 2016). Communication problems may be an initial presenting feature of dementia and can become increasingly

challenging in the later stages. While the exact nature and severity of communication impairment will vary according to the specific dementia subtype, a cognitive communication impairment will co-occur eventually in all cases and sub types of dementia (Bourgeois and Hickey, 2011).

1.5.1 Epidemiology and Impact of Dementia Worldwide

Dementia is a global health concern (see Figure 1.2). In 2015, dementia affected 47 million people worldwide which is roughly 5% of the world's elderly population and this figure is predicted to rise to 75 million in 2030 and 132 million by 2050. Recent reviews estimate that globally nearly 9.9 million people develop dementia each year (WHO, 2017).

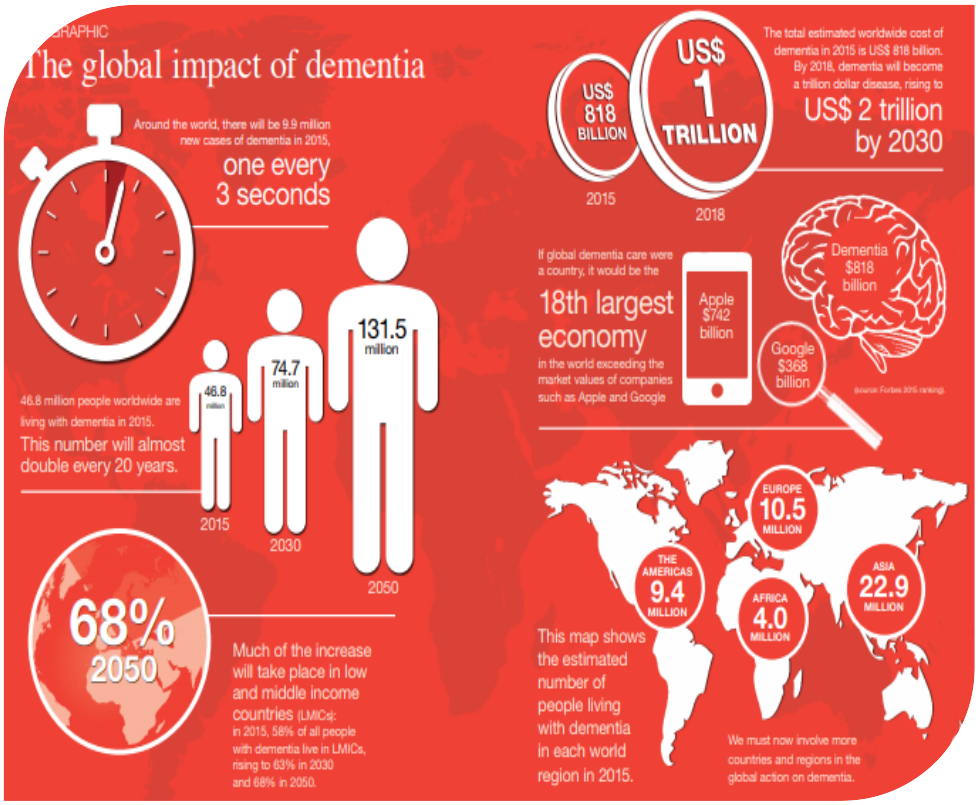


Figure 1.2 World Alzheimer's Report 2015 (Reprinted with permission from Alzheimer's Disease International, see Appendix (1.1))

Dementia impacts on the person, the family, their wider community and society also. Caring for a person with dementia puts an additional strain on the carer's physical and emotional health and well-being (Etters et al., 2008).

It is estimated that for every person that is diagnosed with dementia, three family members are directly affected (Prince, 2015). The financial impact of dementia is significant also (see Figure 1.2) due to the number of years lived with disability and dependency in older age. There is a decline in the incidence of age-specific dementia in high incomes countries, which is driven by reduced exposure to developmental, lifestyle and cardiovascular risk factors for dementia. Results from the Framington Heart Study (Satizabal et al., 2016), suggest that earlier diagnosis and more effective treatment of stroke and hypertension is reducing the incidence of vascular dementia particularly. The best available evidence as described by (Prince, 2015) indicates that age-specific prevalence of dementia is unlikely to change significantly in the coming years, even if the incidence of dementia falls due to health promotion in high income countries, as life expectancy is increasing.

There is a common misconception that dementia is a natural and inevitable part of ageing rather than a disease process. This lack of understanding also causes fear of developing dementia and leads to stigmatisation and discrimination. People with dementia frequently experience delays in diagnosis, creating barriers to accessing suitable support services and interventions. It is estimated by that by 2046 (see Figure 1.3), there will be 152,157 people in Ireland living with dementia (Department of Health, 2014), this is nearly a threefold increase from current 2017 figure of 54,793.

Estimated number and projected growth in the number of people with dementia in Ireland by age group, 2011-2046

Age group	2011	2016	2021	2026	2031	2036	2041	2046
30-59	2,866	2,935	2,934	2,869	2,854	2,864	2,889	2,991
60-64	1,200	1,301	1,449	1,615	1,738	1,906	2,044	1,896
65-69	2,776	3,287	3,827	4,020	4,485	4,876	5,315	5,645
70-74	4,604	5,532	7,013	7,442	8,367	9,378	10,211	11,188
75-79	7,475	8,213	11,298	12,560	14,055	15,928	17,968	19,692
80-84	10,958	12,265	16,099	17,868	22,348	25,364	29,102	33,196
85+	17,970	21,260	25,595	31,085	40,195	52,512	64,654	77,549
Total	47,849	54,793	68,216	77,460	94,042	112,828	132,182	152,157

Note: Estimates for 2011 based on Census of Population 2011. Projections for 2016 to 2041 based on CSO (2013) Population and Labour Force Projections, 2016-2014, Stationery Office, Dublin, Table 3, page 40 and EuroCoDe (2009) Age and gender specific dementia prevalence rates. (Source: Pierce, M. et al. (forthcoming). Prevalence and Projections of Dementia in Ireland, 2011. Genio Ltd., Mullingar).

Figure 1.3 Projected Dementia Incidence and Prevalence (Department of Health, 2014)

1.6 Dementia Types and Progression

Dementia is an umbrella term for a group of progressive diseases. There are many underlying conditions which cause the symptoms of dementia where changes happen in the brain that lead to neuro degeneration. The most common types of dementia are Alzheimer's disease (AD) and vascular dementia (VaD). Less common are Lewy-Body Dementia (LBD) and Frontotemporal Dementia (FTD). Prevalence studies of dementia subtypes exhibit varying prevalence rates (Brunnström et al., 2009, Barker et al., 2002, Jellinger, 1996, Akatsu et al., 2002). In A Swedish study (Brunnström et al., 2009) investigating dementia subtypes (n=524) distribution was based on neuropathologically reports. This thirty-year retrospective study reported the following distribution: AD (42%), VaD (23.7%), AD and VaD (21.6%) and other dementia (8.8%). The boundaries between the different dementia types is not always distinct and in some cases a diagnosis of mixed dementia is given, most commonly AD and VaD. Although dementia subtype prevalence rates are dependent on many variables including clinical judgement and diagnostic traditions this does not seem to impact the categorisation of the main dementia subgroups.

There is a well-documented pattern of language loss in the case of AD but less so with respect to VaD and FTD. This is because the profile of impairment will vary depending on the underlying neurodegenerative process. Cognitive decline may also occur in other progressive neurological conditions, dementia with Parkinson's disease (DPD), Korsakoff's syndrome, Huntington's disease and Motor Neurone Disease (Volkmer, 2013).

1.6.1 Mild Cognitive Impairment (MCI)

Like dementia, MCI can be caused by different underlying disease processes. Importantly not all people with MCI will develop dementia. Rates of progression from MCI to AD will vary from 5-10% in the general population and to 10-15% in specialised referral clinics (Petersen et al., 2014). This is of significance to SLTs as MCI is frequently associated with early language impairment (Bourgeois and Hickey, 2011). These subtle language changes can be identified through comprehensive assessment of high level cognitive-

linguistic skills that may not be evident in everyday social communication, thereby contributing to timely diagnosis and management of any existing cognitive communication impairment.

1.6.2 Alzheimer's Disease (AD)

The most common cause of dementia is AD most of these cases occurring at or after age 65. The neuropathology of AD is caused by amyloid plaques and tangles. It is not a unitary disease and predominant symptoms will vary depending on the distribution of the neuropathology (Hickey and Bourgeois, 2018). The course of AD may be gradual and, sometimes, subtle. Memory impairment will often be the earliest symptom of the disease and this impacts on communication function. The decline in cognitive communication skills is gradual and is characterised by problems with object naming, coherence and discourse production. Language comprehension also worsens gradually, although phonological and syntactic skills remain preserved until the advanced stages of the disease (Egan et al., 2010).

Early onset dementia (before the age of 65) with genetic mutation accounts for a small proportion of people with AD (less than 5%) (Mercy et al., 2008). In Ireland, there are currently approximately 4,000 people with early onset Alzheimer's disease (EOAD) (Department of Health, 2014). The difficulties experienced by younger people with dementia are more complex as they often have family, occupational and financial responsibilities associated with an earlier life stage.

1.6.3 Vascular Dementia (VaD)

The second most common cause of dementia is cerebrovascular disease causes pathological damage and cognitive decline. The underlying neuropathology is characterised by white matter lesions, which will vary in location and type. VaD is characterised by a specific cognitive profile involving preserved memory with impairment in attention and executive functioning. When multiple infarcts occur it is referred to as multi-infarct dementia (O'Brien et al., 2003) which contributes to cognitive decline. Within the VaD group there are subtypes of vascular cognitive impairment, but criteria to

define these has not yet been developed. The onset and progression of VaD is likely to be stepwise in progression.

1.6.4 Lewy Body Dementia (LBD)

Lewy body disease takes its name from the abnormal collections of protein, known as Lewy bodies, which occur in the nerve cells of the brain. Prevalence estimates for LBD vary from .2% (Brunnström et al., 2009) to 22% (Barker et al., 2002), but it forms one of the smaller dementia subtypes. This dementia type is characterised by impaired attention, recurrent visual hallucinations and the motor features of PD (Kane et al., 2018). Multiple pathologies are likely due to the presence of plaques, tangles and Lewy body inclusions (Irwin et al., 2012). Dementia develops in 18-30% of cases of people with PD.

1.6.5 Frontotemporal dementia (FTD)

FTD is generally underdiagnosed and is estimated to account for approximately 4% (Fu et al., 2004) of dementia cases. FTD is a neuro degenerative condition subdivided into a behavioural variant (bv-FTD) and a non-behavioural variant (nbv-FTD) (Gorno-Tempini et al., 2011).

In bv-FTD, there can be insidious personality or behavioural changes and impaired social cognition is a hallmark feature (Orange et al., 1998, Harciarek and Cosentino, 2013). Changes in executive functions in bv-FTD, impact on the person's pragmatic skills such as managing conversational turns and topics as well as the ability to use and understand humour.

The other group within the FTD sub-group are those people with nbv-FTD. These are a heterogenous group of language dominant dementias called primary progressive aphasia (PPA). A marked language impairment is the primary characteristic in PPA and a progressive pattern of language loss distinguishes this group from the typical dementia subtypes (Mesulam, 2001). Once a diagnosis of PPA has been given, the speech and language impairment will then determine which of the three main variants, i.e. semantic variant, non-fluent agrammatic or logopenic variant PPA is present. Eight years ago, Gorno-Tempini et al. (2011) published a framework for the

classification of PPA with these three distinctive variants determined by a clinical diagnosis, imaging and definite pathologic diagnosis. This sub-group of nbv-FTDs pose substantial challenges for diagnosis and management as some clinical presentations are not well captured by conventional classifications (Marshall et al., 2018).The specific speech and cognitive-linguistic profiles associated with PPA require comprehensive assessment by a SLT to facilitate differential diagnosis.

While different types of dementia are characterised by different patterns of communication breakdown, changes in cognition and language throughout the course of the disease lead to limitations in communication and functioning across the dementias (Mesulam, 2001). An understanding of the different dementia types, their underlying neuropathology and progression informs the management process. The assessment of communication skills in dementia can support the differential diagnosis process and guide management. Each person with dementia, however, will have their own individual communication profile and benefit from a tailored therapeutic approach. The diagnostic process will be discussed further in the following sections.

1.7 The Diagnostic Process

Diagnosing dementia can be a complex process. There are many people who experience a delayed or suspended diagnosis of dementia: it can be an anxious time for people and their families. This delayed diagnosis may be due to a functional memory complaint that is not backed up by neuro-imaging or poor access to a memory clinic. Timely diagnosis is a key priority for health service providers in order to implement the recommendations of NDS (2014) and the development of dementia care pathways, which will optimise service delivery to people with dementia.

In order to address some of the problems associated with this lengthy diagnostic process, General Practitioners in Ireland are being guided by specific dementia assessment and management guidelines from the Irish College of General Practitioners (ICGP, 2014). These guidelines provide evidence and recommendation for dementia management and give advice on commonly used cognitive tests. Key areas around dementia diagnosis,

disclosure, management and support of patients and their families are addressed.

Timely diagnoses of dementia will enable early referral to support services including speech and language therapy for communication assessment. Early intervention improves outcomes for the person with dementia (Department of Health, 2014, Cahill et al., 2012). Early referral to speech and language therapy services at the point of initial communication difficulty, enables the provision of psychosocial support as well as active intervention services. A care pathway can be initiated at the outset with the purpose of providing seamless care.

1.8 Presence of cognitive communication impairment in dementia

As discussed in section 1.6, people with dementia, regardless of time of onset, will experience communication difficulties, as the presence of cognitive impairment in any form will interfere with language production and comprehension to some extent (Hickey and Bourgeois, 2017). Language is an integral aspect of cognition. Cognitive communication abilities allow us to interact in a meaningful way with each other and the progressive deterioration of cognition interferes with communication. The neurological processes that disrupt multiple cognitive functions in dementia also disrupt information processing and production (Bayles and Tomoeda, 2007), impacting on communication ability. These impacts vary with dementia severity and subtype.

Impairment in attention, memory (working and episodic), executive function, visuospatial function and language will impact on communication resulting in cognitive communication impairment. Memory deficits disrupt both auditory processing of language and verbal expression which are essential in many everyday activities. In dementia, there is typically emphasis on memory impairment, which is characteristic of AD and will directly impact communication ability. Working memory deficits result in difficulty with encoding and decoding information (including language) so the person may become repetitive and have difficulty answering questions for example

(Hickey and Bourgeois, 2011). Language impairment is also associated with long term memory problems such as trouble recalling names of people, places and events.

Behavioural changes in dementia can be linked to declining cognitive communication skills resulting in disorientation, forgetfulness, delayed responses, reduced mental flexibility and difficulty self-monitoring (Hickey and Bourgeois, 2017). Communication breakdown caused by a cognitive communication impairment can cause frustration and stress for the person with dementia and their family.

1.8.1 Early Cognitive Communication Changes in Dementia

In early stage dementia, the differences between dementia sub types is more apparent than in the advanced stage, when the pattern is one of global cognitive communication impairment. For example, the person with VaD is more likely to have a verbal apraxia (motor speech impairment), which may be less distinctive in the latter stages as the person's language skills diminish. In AD, a distinctive dysnomia (word finding problem) in the early stages will be camouflaged in the later stages due to reduced verbal expression overall.

It is suggested that people with AD rarely have motor speech difficulties, make phonological or grammatical errors, but they do experience difficulty finding words, describing their ideas and making conversation, stemming from episodic and semantic memory deficits (Hickey and Bourgeois, 2018). As the semantic store degenerates, semantic errors become more frequent. People with AD typically have difficulty with auditory processing of language because of deficits in attention and memory, but this is less impaired than verbal expression. Auditory processing and comprehension of language is affected by the degradation and loss of knowledge (Bayles and Tomoeda, 2007), which then impacts on communication. This affects the person's everyday communication function, for example their ability to understand a news report or follow a conversation. This slows down and complicates even the most basic communication exchanges.

In early stage VaD communication ability will be impacted by reduced attentional capacity, visuospatial and executive function (Levy and Chelune, 2007). Typically, semantic knowledge and consequently auditory memory tend to be less impaired in VaD than in AD. Cognitive communication impairments change with advancing dementia.

1.8.2 Progression of cognitive communication impairment

Over time dementia causes disruption to the cognitive-linguistic system and this changes the way in which the person communicates. In conversation, people with dementia frequently repeat and/or make vague or irrelevant comments, but with support, many can participate effectively in conversation (Bayles et al., 2000). As discussed previously, differing patterns of cognitive linguistic impairment are typical in the dementia subtypes, for example reading aloud is relatively preserved in AD until the later stages of dementia, the mechanics of writing are often retained facilitating the copying of words and letters. Each person with dementia will have a unique profile of abilities and impairments. Communication breakdown will increase with the progression of dementia, with increased dependency on non-verbal interactions and the skill set of the CP.

Communication interactions will become less effective and flexible as the dementia progresses. This has a significant impact on the relationship between the person with dementia and their family (Jones, 2015). The communication dynamic can become imbalanced as the person with dementia needs increasing support to communicate their needs and wishes. By the end stages of the disease the person with dementia will have a communication impairment that impacts on everyday communication function. The SLT can help reveal the individual's communication competencies (Kagan et al., 2008) that can form the basis for meaningful verbal and non-verbal communication.

1.8.3 The psychosocial impact of dementia

The psychosocial consequences of dementia include depression, withdrawal, frustration and social isolation. Identifying depression in AD can be

challenging, since dementia can cause some of the same symptoms. It is estimated that 10% of people with dementia or lower have a major depressive disorder (Lyketsos et al., 1997) and these people are more likely to experience irritability and social isolation. Social withdrawal is characteristic in dementia (Shub et al., 2011). This may not be caused directly by the dementia but by associated feelings of isolation or boredom. This can be due to reduced ability to communicate as we as limited opportunities for engagement. Having a communication disability as discussed earlier in this chapter (Section 1.2) will impact further on psychosocial functioning and wellbeing.

The families are directly impacted by loss of companionship and the support of a life partner (Thompson and Briggs, 2000), they can become socially isolated and experience depression as the burden of care is financially, emotionally and physically significant. Depression occurs in more than one in three caregivers of people with dementia (Schoenmakers et al., 2010) and can be caused by chronic stress, social isolation and loneliness (Kovaleva et al., 2018).

There are many challenges to overcome with dementia: it is progressive in nature and the societal stigma that exists in relation to mental illness has consequences for the person with dementia. A diagnosis of "dementia" is often accompanied by feelings of shame. People with dementia are often stereotyped and there is a stigma attached to the diagnosis (Swaffer, 2014).

Dementia can lead to a feeling of disassociation from their community (Milne, 2010) and may lead to withdrawal from their usual lifestyle activities. As outlined early in this chapter, SLTs have an important role (Section 1.3) in addressing the communication needs of the person with dementia in the wider context of their families and communities. Communicating ones needs, wishes and feelings not only improves quality of life but also preserves the person's sense of identity, reducing the impact of psychosocial challenges that are experienced by people with dementia. Early identification of dementia is key to minimising these psychosocial consequences of dementia for the person and their family. The next chapter presents evidence on cognitive communication skills management in dementia.

Chapter 2
Cognitive Communication Skills Management in Dementia

2.0 Introduction

This chapter introduces assessment, provides an overview of cognitive communication interventions and explores approaches to revealing communication competence in the person with dementia.

2.1 Assessment of the cognitive communication ability of people with dementia

Subtle changes in communicative function may be an early sign of an underlying neurological condition (Harris et al., 2008). Perceptible changes in language and communication are key in facilitating timely diagnosis and reiterate the need for early involvement of SLTs in the diagnostic process. The SLT may be working in isolation or as part of a multidisciplinary team and be involved in case management from early diagnosis as well as in the later stages of dementia. Currently in Ireland, SLTs are not typically members of the diagnostic team in Memory Clinics (Reves et al., 2018). An integrated care approach to dementia management should acknowledge the cognitive communication deficits associated with dementia at the outset and seek input from a communication specialist. Access to speech and language therapy services in Ireland varies and will be discussed in Chapter 4 (Study 2) in a SLT practice survey.

There are many factors that will influence the nature of the assessment process. A firm diagnosis and staging of dementia by a medical consultant or general practitioner (GP) will impact the initial cognitive communication assessment. In some cases, the individual is referred to a memory clinic due to subjective reports of changes in memory, communication and behaviour. Cognitive communication assessment with the person with dementia should involve a review of clinical presentation and personal circumstances (Volkmer 2013). Determining the exact nature of the communication impairment will

point to a likely underlying cause. When people are referred for communication assessment with a possible diagnosis of dementia, the SLT contributes to the differential diagnostic process by providing information on the nature and severity of the communication impairment. This can be complex when people present with multiple co-morbidities. However, a multi-disciplinary approach and thorough discussion with the person and their family facilitates this process.

The assessment phase evaluates cognitive-linguistic skills and communication function. Communication ability in dementia will be influenced by the nature and severity of the underlying cognitive impairment, so it is important to consider the impact of different cognitive domains such as attention, memory and visual processing on communication function. It involves the use of informal communication measures as well as standardised assessments used to evaluate communication impairment in adults. A scoping review on the availability of standardised functional communication assessment for use with people with dementia formed a cornerstone of this research and will be comprehensively discussed in Section 2 Chapter 5. Typically, the assessment of language will include evaluation of auditory comprehension, verbal expression, reading, writing and functional communication.

Early detection will ensure that people with dementia and their families are linked in with SLT services at the point of initial difficulty, providing psychosocial support as well as active intervention services. Communication assessment should focus on communication ability in everyday life to provide a meaningful basis for therapy planning, such as including the CP to evaluate day to day communication with family carers and professional carers. Communication is collaborative (Perkins et al., 1998, Eggenberger et al., 2013) as already discussed and the involvement of CPs enhances the effectiveness of relevant interventions and carryover from therapy.

Comprehensive cognitive communication assessment provides a basis from which to measure the effectiveness of interventions and monitor the progression of the dementia. The lack of tools that evaluate functional communication skills sensitive to change over time, is not only a challenge

for differential diagnosis and timely assessment but, also cited as a major obstacle in evaluating the efficacy of communication interventions in dementia (Bourgeois and Hickey, 2011, Hopper et al., 2013). Intervention should be based on assessment findings, which demonstrate the impaired and spared functions of the individual (Hopper, 2003). Therapy programmes can then be tailored to meet the changing communication needs of the person with dementia. A care pathway can be initiated at the outset with the purpose of providing seamless care.

2.2 Cognitive communication interventions in dementia management

Communication therapy can minimise the frustration experienced by the person with dementia and their CPs. It is an important aspect of post-diagnostic support (PDS), enabling the person with dementia and their family to come to terms with the diagnosis and make the best use of their retained abilities. The benefits of PDS have been widely researched and are recommended in dementia policy and guidance documents (Cahill et al., 2012, Department of Health, 2014). A range of cognitive-communication approaches and interventions are available to enhance retained communication skills, support lost function and provide education and training to people with dementia, their families and carers.

These cognitive communication therapy approaches range from intensive one-to-one therapy to group-based communication training. The type and frequency of therapy service offered will be unique to the individual with dementia. The therapeutic approach taken may vary depending on the needs of the person with dementia and the clinical setting. A summary of communication enhancing interventions (Table 2.1) used by SLTs in practice have been categorised into three broad areas; 1. Psychosocial interventions, 2. Cognitive-communication interventions and 3. Environmental modification. Cognitive communication intervention is not a primary focus of this research and is therefore only broadly discussed.

There is a large body of research evidence to support psychosocial interventions such as communication partner training where several

structured programs have been associated with positive outcomes and this is presented in Section 2.3.5. There is positive evidence for spaced retrieval training (SRT) (Brush and Camp, 1999), a cognitive communication therapy that focuses directly on improved acquisition, retention and generalization of the trained skill or information. SRT targets memory function involving intensive skill training.The goal being to compensate for problems in activities and participation as a result of cognitive impairment by training a specific skill. SRT has potential therapy benefit that can last up to a few months following intervention (Hopper et al., 2013).

Conversation therapy is another intervention approach used that can impact positively on the person's ability to engage in everyday communication and be an active participant in their own lives (Simmons-Mackie et al., 2014). This approach is frequently used in aphasia therapy and is suitable also for people with dementia (Kindell et al., 2017). Conversation therapy fits better with a psychosocial model of intervention (Kindell et al., 2012) than SRT and aims to enhance communication function. It involves a direct planned treatment that is designed to enhance conversational skills and communication confidence (Simmons-Mackie et al., 2014). Specific therapy tasks target various aspect of conversation such as coherence, language processing, verbal expression and pragmatics. This approach to intervention can be guided by functional communication assessment including discourse analysis. Conversation therapy fits well the cognitive communication assessment at the centre of this research (Chapter 9).

Relatively less attention has been given to the effect of the physical environment on cognitive communication ability but this evidence base is growing (Brush et al., 2012, Bourgeois, 1991). Adjusting the communication environment can have many positive benefits for people with dementia. Further exploration of communication enhancing interventions such as environmental modification and CP coaching are relevant to this research will be discussed later in this chapter (Section 2.3.2 and 2.3.4).

Table 2.1 Summary of communication enhancing interventions

Intervention Category	**Sub-types of intervention**	**Citation**
1)Psychosocial Interventions	Life Story Work	(Elfrink et al., 2017, McKeown et al., 2010)
	Simulated Presence Therapy	(Zetteler, 2008, Bayles et al., 2006)
	Montessori Based Intervention	(Boyle et al., 2006, Malone and Camp, 2007, Brush and Camp, 1999)
	Communication Partner Training	(Broughton et al., 2011, Ripich et al., 1995, Conway and Chenery, 2016) (Liddle et al., 2012)
2)Cognitive communication Interventions	Conversation Therapy	(Dooley and Conway, April 2016, Perkins et al., 1998, Kindell et al., 2017)
	Spaced Retrieval Training	(Hopper et al., 2013, Brush and Camp, 1999)
	Reminiscence Therapy	(Woods et al., 2009, Kim et al., 2006)
	Validation Therapy	(Neal and Briggs, 2003, Day, 1997)
3)Environmental Modification	Dementia Friendly Environments	(Galvin et al., 2010, Brush et al., 2012)
	Use of Memory and Communication Supports	(Fried-Oken, 2008, Ekström et al., 2015, Hickey and Bourgeois, 2011)

2.3 Revealing the communication competence of people with dementia

The provision of person-centred care can maximise communication independence and well-being by identifying and supporting retained communication abilities. The communication competence of the person with dementia relies partly on the ability of the CP to adapt their own communication behaviour and style. Sometimes CPs are not able to adjust their communication style, while others can adapt more easily. Speech and language therapy assessment and intervention can guide these adjustments in supportive communication behaviour. The following section focuses on supporting communication through person centred care (PCC) using environmental modification, CP training and emphasising retained communication skills.

2.3.1 Supporting communication is at the core of dementia care philosophies

Over the past 20 years PCC has been the dominant approach to dementia management (Kitwood, 1997, Brooker and Latham, 2015). This approach involves fostering and retaining personhood through positive engagement. This means understanding and acknowledging the person's values and beliefs and striving to help them maintain their own personal identity. PCC is central to the provision of communication support in dementia care. Validation therapy (Feil, 1993) supports communication by acknowledging communication attempts as purposeful, building trust, reducing anxiety and restoring dignity.

As dementia progresses it can be more challenging to decipher the person's words or communication intent, though the feelings being expressed are often evident by the context and non-verbal communication. In the advanced stages of dementia using responsive communication skills with the person with dementia provides communication opportunities, validating non-verbal communication and promoting engagement.

Everyday interactions are key to establishing and maintaining relationships in compassionate care (Dewar and Nolan, 2013). Compassionate care involves effective communication that builds trust and empathy supporting the person with dementia to "have a voice". Over time this enables the person to have an active part in decision making with the support of their CP as their advocate when there is a severe communication disability. Supportive communication promotes the sharing of personal information and use of humour. An inherent trust that builds between CPs reveals the communication competence of the person with dementia.

2.3.2 Creating dementia friendly communication environments

There is increasing awareness of the importance of modifying homes, workplaces, clinics, hospitals and communities to make them "Dementia friendly". Physically modifying the environment means having good signage, lighting, way finding and reducing ambient noise. There are interventions targeting normalising disturbed sleep patterns experienced by people with dementia which include modification of activity timing, exercise, light exposure, nocturnal darkness, and ambient temperature adjustment (Luxenberg, 1997). These environmental modifications can have an impact on maximising the functional independence of the person with dementia.

Lighting and contrast conditions are important to consider as age and dementia-related changes in the eyes and visual processing systems, such as sensitivity to glare, acuity reduction, impaired motion and color discrimination, and diminished contrast sensitivity, can all have a profound negative effect on a client's visual abilities. In the context of everyday communication having an accessible communication environment may involve altering lighting, reducing the volume of competing noise, maximising the seating arrangements and ensuring that the person with dementia is wearing their hearing aids and/or glasses.

The communication environment can also be enhanced using life story books, communication passports and memory aids like watches and diaries. Enhancing the environment with communication supports improves the

communication between the person with dementia, their family and carers(Brush et al., 2012, Bruce et al., 2013). Memory books with autobiographical information and daily schedules with prompts have been reported to increase clients' frequency of utterances, duration of speaking time, and range of discourse characteristics (Bourgeois, 2001). SLTs are in a unique position to address the environmental barriers that affect communication. A key principle underlying supportive communication is focusing on retained cognitive communication skills.

2.3.3 Focusing on retained cognitive communication skills

It is widely acknowledged that people with dementia have residual communication abilities even in the advanced stages of dementia. The neuropsychological profile of people with dementia has been mapped as dementia progresses (Hopper et al., 2001). In the early stages, people with dementia can communicate with a minimum level of communication support. They benefit from a slower paced conversation where their CP not only speaks more slowly, but also gives them more time to respond. As the dementia evolves increased compensation is needed to support reduced attention, impaired semantic memory and reduced linguistic capacity. This can involve the use of external memory aids and other support strategies such as repetition, clarification and simplification of the language used.

In the mid to advanced stages of dementia there is increased reliance on non-verbal communication. Many people with dementia retain the social aspects of conversation such as greeting, leave taking and turn taking. This can allow them to maintain some communication independence and participation within their families and communities. When facilitated to communicate, the person with dementia can reveal their communication competence and increase the success and enjoyment of meaningfully engagement (Hopper et al., 2001). Science fiction author Terry Pratchett gave a very frank account of the challenges of living with dementia while emphasising how to maximise functional ability and promote creativity with support, he said *"it is possible to live well with dementia and write best-sellers 'like wot I do"* (Pratchett, 2011). Revealing the communication competence of the person with dementia and developing support strategies to enhance retained

communication skills is a core element of speech and language therapy practice. SLTs work with CPs to help reveal the communication competence of both the CP and the person with dementia.

2.3.4 Communication Partner Training

It is proposed that people with dementia and their CPs can achieve great success in resolving communication breakdown in spite of declining cognitive, linguistic and conversational ability (Orange and Colton-Hudson, 1998). CPs play an essential role in providing scaffolding for the conversation to enable the person with dementia to communicate to their best ability. Enabling carers to understand dementia and develop compensatory strategies is an important aspect of carer training. Interventions that focus on a collaborative approach to dealing with communication breakdown have been shown to be a highly effective way of improving communication (Mok et al., 2019, Perkins et al., 1998) for both the people with dementia and their family and/or professional carers.

Communication skills training programs typically consist of education on the nature of communication impairment in dementia, face to face teaching and/or individualised hands on training programs. A systematic review of the efficacy of communication training by Eggenberger et. al. in 2013 suggests that intervention can significantly improve quality of life and well-being of the person with dementia and increase positive interactions across a range of settings. This review evaluated the outcomes of twelve studies, including 831 people with dementia and their care givers. They included training provided in the home and residential care settings. The communication training provided positively influenced the family and professional carer's knowledge, competencies and communication skills. Six of the studies (Burgio et al., 2001, Burgio et al., 2003, Haberstroh et al., 2009, Haberstroh et al., 2006, McCallion et al., 1999, Teri et al., 2005) educating carers of people with AD by training communication strategies, showed positive outcomes in terms of quality of life for the person with dementia, increased knowledge of communication breakdown, strategy use and a reduction in aggressive behaviours.

There are many published and easily available communication training programmes available such as the FOCUSED Caregiver Training (Ripich et al., 1995), the RECAPS Memory Strategies (Broughton et al., 2011), the MESSAGE Communication Strategies in Dementia (Conway and Chenery, 2016)and the TANDEM Communication Training for Informal Caregivers of People with Dementia (Haberstroh et al., 2011). These programs aim to maintain and maximise communication ability, personalise communication strategies and incorporate the specific communication needs of the person with dementia. Conversation coaching is another approach to training CPs and is used routinely in the management of aphasia (Hopper et al., 2002). This approach may involve appreciative enquiry which seeks to engage stakeholders in self-determined change. Appreciative enquiry promoting behavioural change has been used successfully (Whitney and Trosten-Bloom, 2010, Dewar and Nolan, 2013) in enhancing caring conversations in health care provision as a way of enhancing behaviour change rather than a traditional pedagogic approach. A conversation coaching approach is suitable for use with people with dementia and their CPs, it will be explored further in Chapter 10. The development of a cognitive communication assessment that can direct conversation coaching therapy is the core motivation for this research.

2.4 Summary

Communication difficulties are inherent in dementia. SLTs are considered experts in communication disability and can provide individualised cognitive communication intervention for people with dementia. Some of the key challenges for SLTs in meeting professional and national guidelines on dementia intervention include having access to appropriate clinical resources such as cognitive communication assessments and individualised therapies.

As previously outlined, this research aims to address these challenges, by validating and addressing these gaps in cognitive communication services for people with dementia. The next chapter considers and presents the theoretical basis for this research.

Chapter 3
Conceptual origins and a model for communication assessment in dementia

3.0 Introduction

This chapter describes the background that led to this research. It considers the underpinning themes, motivational factors and research questions that drove the refinement and validation of a cognitive communication assessment for people with dementia. These are that communication disability is inevitable in dementia, there are limited services to deal with the current demand and that SLT practice is restricted by the limited availability of appropriate communication assessments.

The dementia care landscape in Ireland has changed with the publication of the Irish National Dementia Strategy (2014). This has resulted in increased funding to research and development of services for people with dementia, including a focus on communication. Currently there is a lack of speech and language therapy services in dementia care, this emanates from a history of limited SLT personnel and a misperception that cognitive communication assessment and intervention in dementia is not worthwhile.

This was the researcher's personal experience as a SLT working in community health when her father was diagnosed with vascular dementia 15 years ago. The diagnostic process was protracted and while home care support was available, it was focused on his physical care needs only. Cognitive linguistic rehabilitation would have been beneficial but there were none available. Having 20 years clinical experience as a speech and language therapist in the area of adult neurology, I was aware of the huge potential of communication therapy with people with dementia. Over the following years I focused on developing communication services for people with dementia. This involved setting up a speech and language therapy assessment service as part of a memory clinic, providing communication interventions, undertaking research, networking with SLTs in dementia care and the Irish Association of Speech

and Language Therapists (IASLT) to produce clinical guidance for SLTs in practice.

Although it is hypothesised that these services are underdeveloped there is no current data on the practice of SLTs in dementia care in Ireland. Lack of tools that evaluate functional communication skills and which are sensitive to change over time is cited as a major obstacle in evaluating the efficacy of communication interventions in dementia. When people with dementia are referred for communication intervention there are few valid assessments to direct management. Supporting evidence for these underlying themes will be described in the following sections.

3.1 Communication disability: an inevitable consequence of dementia

Difficulties with memory and communication are prominent and distressing features of dementia (Broughton et al., 2011). Some dementias are not associated with communication impairments in the early stages, but these are evident in all subtypes and stages of dementia (Bourgeois and Hickey, 2011). The psychosocial impacts of communication impairment in dementia are well documented and include social isolation, depression, withdrawal, frustration and agitation. This has consequences for the person with dementia and their social network: they may lose confidence and withdraw from social interaction. Conversation is associated with our psychosocial identity and is important in maintaining relationships. Impaired cognitive communication skills affect the person's ability to engage successfully and easily in conversation and can severely impact on their feelings of competence and self-image. Communication impairment can also contribute to carer stress and burden (Savundranayagam et al., 2005), as discussed in Chapter 1. Communication interventions, outlined in Chapter 2, can help manage these consequences of communication disability. However, people with dementia internationally (Nóbrega et al., 2016, Cleary et al., 2003, Volkmer et al., 2018b) frequently do not have access to appropriate post diagnostic support services such as speech and language therapy.

3.2 Limited provision of speech and language therapy services to people with dementia

In Ireland Speech and language therapy services for people with dementia are underdeveloped and SLTs are not routinely members of inter disciplinary diagnostic dementia teams (Revez et al., 2018). This is particularly evident in the management of communication disability identified in a recent survey of practice (Dooley and Walshe in Press) of causative factors for inadequate service provision may include limited staffing resources, low clinical priority of communication disorders, limited opportunities for education and continuing professional development in dementia care and poor availability of appropriate assessment and intervention resources. Current trends in service provision and the reasons for reduced SLT services to people with dementia will be investigated in detail in Chapter 4.

Restricted availability to communication interventions results in people with dementia not being provided with early intervention and post-diagnostic support. Early assessment and intervention for people living with dementia, their care partner and family, is best practice in dementia management (RCSLT, 2014, Department of Health, 2014). As well as reduced service provision to people with dementia there is also a limited range of resources available to SLTs for assessment and management of the cognitive communication difficulties that occur in dementia.

3.3 A lack of functional cognitive communication assessments for people with dementia identifying retained abilities

Assessment of functional communication skills is an appropriate and often preferable approach to cognitive communication evaluation with people with dementia. There are limited communication assessments developed for use with people with dementia. This poses a challenge in clinical practice. The lack of availability of high-quality communication assessment measures in dementia management impacts on the clinician's ability to provide an evidence-based approach. This challenge is not unique to assessment of

cognitive communication disorders in dementia, communication assessments standardised with one clinical population are often administered with other clinical populations e.g. assessment from the field of aphasia are commonly used with clients following traumatic brain injury.

Assessment is frequently the starting point to explore the nature and severity of a communication impairment (Volkmer, 2013). It occurs early in the therapeutic process and guides management as well as providing a basis to measure change over time. Frequently in practice the focus of communication assessment is on deficits rather than on retained abilities (Hopper, Bayles & Kim 2001): this is true for many communication disorders but particularly evident in dementia. The lack of assessment alternatives available to SLTs for clinical use was validated by a scoping review that will be described in Chapter 5 (Study 2) of this thesis. Focusing on retained communication abilities shifts the mind-set to enabling the person with dementia and their CPs to use their retained communication skills to improve everyday conversations and maximise quality of life.

While some assessments from the field of aphasia therapy can be adapted for use with people with dementia (LaPointe and Horner, 1998, Kay et al., 1992, Swinburn et al., 2004), these do not adopt a psycho-social approach to communication assessment. SLTs can investigate the specific communication barriers and facilitators relevant to the person and their social environment so that appropriate adaptive and restorative recommendations can be developed. Without access to appropriate assessment tools there will be challenges in eliciting functional and objective information to guide therapy. It is a core tenet of the researcher's theoretical framework that contextual and meaningful assessment in dementia is essential to high quality care, as acknowledging communication problems and providing communication interventions will enable the person to express their needs, wishes and opinions in their communication environments, be it a home, hospital or residential setting.

3.4 Evaluating the communication dyad

Cognitive communication assessments frequently do not acknowledge the important role of the CPs in helping the person to overcome communication challenges and reduce communication breakdown. This is an important part of supporting communication and alleviating the negative impacts of cognitive communication impairment in dementia. A social contextual model captures the importance of including both the care partner and the person with dementia in post-diagnostic interventions to minimise the potential risk of a decline in well-being and relationship quality as a result of poor communication or misunderstandings (Moon and Adams, 2013).

Dyadic interventions (Gaugler et al., 2011) can help people living with dementia and their CPs to develop strategies and support structures to manage the condition post-diagnosis (Whitlatch et al., 2006). Using a conversational approach in dementia management such as that described in the aphasia and child language literature (Simmons-Mackie et al., 2014, Kindell et al., 2017, Watson, 1995) and used widely in clinical practice in aphasia provides a meaningful basis to assess communication and plan intervention. Existing assessments in dementia fall short when it comes to evaluating the person with dementia and their CP, as a dyad. There is need for a new cognitive communication assessment to address this imbalance by evaluating the communication skills of both CPs, as part of a comprehensive cognitive communication assessment for use with people with dementia.

3.5 A model for functional cognitive communication assessment

Comprehensive assessment of cognitive communication skills forms the basis for intervention. Such assessments should evaluate a range of cognitive communication skills that underpin everyday communication. Cognitive communication assessments should guide clinicians in determining the best interventions to address communication difficulties and enable them to recommend the best possible adaptations by the person with dementia and their family. A broadened definition of communication competence (MacDonald 2017) (see Figure 3.1) acknowledges the multiple cognitive

processes that influence communication and are influenced by the person's unique communication environment. Cognitive domains (i.e. executive function, attention, working memory, speed of processing, social cognition, reasoning and problem solving) impact on communication domains (i.e. auditory comprehension, verbal expression, pragmatics, reading and writing).

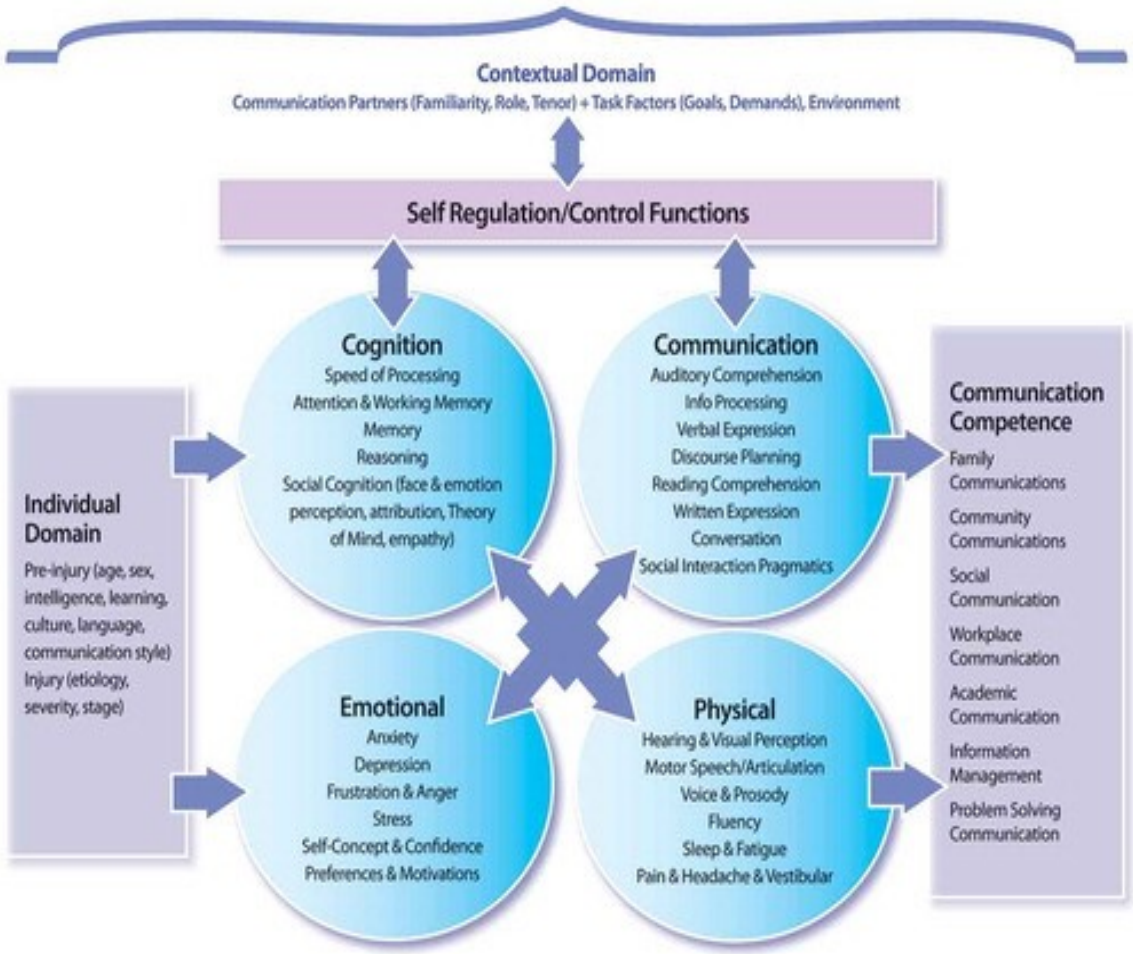


Figure 3.1 A model of cognitive-communication competence (MacDonald 2017) with permission of Taylor & Francis (see Appendix 5.2)

A comprehensive focus on the individual's communication domain takes account of the physical (e.g. hearing and visual perception) and emotional (e.g., anxiety, confidence, depression) factors that can influence communication performance. This specifically refers to the person's functional communication ability to participate and fulfil his/her social, work and family roles.

For every person with dementia it is argued that there will be a dynamic relationship between these contexts and domains (environment, cognitive, communication, physical and emotional), which will determine the communication competence of the individual. This is the context in which cognitive communication assessment should be undertaken which will then reflect each person with dementia's unique communication profile. Measuring change in communication function in dementia requires consideration of outcomes related to activities and participation in daily life.

3.6 Summary

This chapter has laid out the fundamental drivers for the development of a new cognitive communication assessment for people with dementia. involvement in the management of the communication disorders associated with dementia is restricted and there is a lack of suitable assessments for addressing the communication difficulties inherent in dementia.

The development of a suitable functional cognitive communication assessment for use with people with dementia would provide a foundation for communication therapy. This functional cognitive communication assessment would support communication between the person with dementia and their families as well as the health care team. A profile of the person's communication ability will facilitate involvement in health care and life planning decisions. The research aims are presented in section 3.6 and 3.7.

3.7 Research Aims

The primary research aims are to develop, refine and validate a cognitive communication assessment, the Profiling Communication Ability in Dementia (P-CAD) tool, for people with dementia. It is hypothesised that no appropriate cognitive communication assessment exists and that this impacts on the clinical practice of SLTs. Two preliminary studies will establish a basis for the primary research study. Study 1 (Chapter 4) investigates SLT practice in the management of cognitive communication disorders in Ireland, to identify patterns in the assessment and management of cognitive communication disorders, explores both the strengths and challenges of current speech and

language therapy provision and to elicits SLTs' perspectives on the NDS. Study 2 is a scoping review (Chapter 5) of the availability of appropriate cognitive communication assessments for people with dementia. The final study is the validation (Chapter 9) of the P-CAD.

3.8 Research questions

1. What are current SLT practices in the management of cognitive communication disorders in dementia in Ireland? (Study 1)
2. What psychometrically sound cognitive communication assessments are available for use by SLTs who work with people with dementia? (Study 2)
3. Is the P-CAD a valid and reliable tool for the assessment of cognitive communication disorders in dementia?

Section 2: Preliminary Studies

Chapter 4
Study 1: Management of Cognitive Communication Difficulties in Dementia: A Cross-Sectional Survey of Speech & Language Therapists (SLTs) in Ireland

4.1 Introduction

This chapter describes Study 1, a cross sectional survey of SLTs working in dementia care. This survey identifies patterns in the assessment and management of cognitive communication disorders and explores both the strengths and challenges of current service provision. Surveyed SLTs share their perspectives on a range of topics including the Irish National Dementia Strategy (Department of Health, 2014).

The role of the SLT in the management of dementia is well referenced in practice documents by the profession internationally (American Speech Hearing Association, 2016, IASLT, 2016, RCSLT, 2014). Clinical experience and SLT research suggest that much clinical time is focused on the management of swallowing rather than cognitive communication disorders.

In Portugal, there are limited SLT services available to people with dementia (Nóbrega et al., 2016), with just 14% (n=33) of SLTs surveyed were working in the area of dementia care. The American Speech-Language-Hearing Association conducted a survey of caseload characteristics of SLTs (ASHA, 2011), which found that 60% of SLTs surveyed (n=1012) work with adults and spend 42% of their clinical time addressing swallowing difficulties and 15% of their time with cognitive communication disorders in dementia. This is not an indication of the prevalence of communication and swallowing disorders in this population, but rather further confirmation that SLTs do not routinely provide a comprehensive speech and language therapy service to people with dementia. There is an awareness of the low rates of referral to SLT services (Cleary et al., 2003) and the poorly understood role of the SLT although there is limited information on the reasons behind this.

This lack of information about the clinical practice of SLTs in dementia care in Ireland impacts on the development and delivery of comprehensive services for people with dementia. The aim of Study 1 was to survey SLTs working in dementia services in Ireland to review current practice, and to gain insight into SLT experiences and opinions.

4.2 Method

A cross sectional survey design was selected to systematically review the current practice of SLTs working in dementia services. This survey collected qualitative information on the SLTs opinions and experiences. Ethical approval was obtained (Ref: HT13) from the School of Linguistic, Speech and Communication Sciences, Trinity College Dublin (see Appendix 4.1).

4.2.1 Survey Design

Survey content was informed by a literature review on previous surveys in the area, along with consultation with two experienced SLT colleagues working in dementia care. Topics relevant to the current practice of SLTs working with people with dementia were selected to fit with the aims of the study and were in keeping with the literature. An initial version of the survey was piloted with these SLTs and their feedback informed further the content, face and ecological validity of the survey. Survey revisions included addressing omissions in some dementia assessments listed in the survey, inclusion of questions on palliative care and expanded questions on the INDS. The survey was then refined based on their feedback: these SLTs did not participate further in the study.

The final survey comprised 21 questions using various question formats; multiple choice, open questions, closed questions, rating scales and matrix questions (see Table 4.1). Open-ended questions and comment boxes were incorporated to allow for individual comments and expansion of opinions. Information was sought on SLT respondent demographics, current practice in the management of cognitive communication disorders in dementia, involvement in research,

the levels of satisfaction with existing services for people with dementia and familiarity with the INDS.

Table 4.1 Survey: SLT Practice in Management of Cognitive Communication Difficulties in People with Dementia in Ireland

Questions and Response Options
Section 1: Demographics
1. In what type of setting are you currently working with people with dementia?
2. Approximately what percentage of your clinical time do you spend working in dementia?
3. Approximately what percentage of this clinical time is spent working with people with dementia on the assessment and management of their communication difficulties (i.e. not dysphagia management)?
4. At which stage of their dementia are people most commonly referred?
5. Who most frequently refers the person with dementia to your speech & language therapy service?
Section 2: Service delivery
6. How satisfied are you with the current level of speech & language therapy service delivery to people with dementia in your setting?
7. Please rank the following factors by how you believe they would improve service delivery for people with dementia in your clinical setting. (Rank in order of importance from 1-6, 1 being the most important factor and 6 being the least important). • Early referral to your speech & language therapy services from medical and community health teams • Timely access to your speech & language therapy services • Improved knowledge of the role of the SLT by other professions such as physiotherapy, occupational therapy, medical and nursing professions • Increased multi-disciplinary management of people with dementia • The use of a speech & language therapy care pathways for people with dementia • Access to community supports such as "Dementia Cafes" and "Living Well with Dementia" programmes

8. Please rank the following factors by how you believe they would improve your management of communication difficulties in people with dementia in your clinical setting? (Rank in order of importance from 1-5, 1 being the most important factor and 5 being the least important).

- Allocated clinical time for services to people with dementia
- Availability of appropriate cognitive communication assessments for dementia
- Availability of a range of resources for intervention approaches in dementia
- Ease of access to the primary communication partner of the person with dementia
- Direct clinical experience and specialist clinical skills working with people with dementia

9. If you could change one aspect of the current speech & language therapy service for people with dementia, what would that be?

10. If you could retain one aspect of the current speech & language therapy service to people with dementia, what would that be?

11. What challenges you in the management of communication difficulties in people with dementia?

Section 3: Assessment and management of cognitive communication disorders in people with dementia

12. Please describe how frequently you complete each of these clinical practices when working with a person with dementia (Rank order from never to always):

- Informally assess the person with dementia's communication ability
- Formally assess the person with dementia's communication ability using published tools
- Liaise with the person with dementia's primary communication partner regarding their communication ability and support strategies
- Liaise with other members of the care team about the person with dementia's cognitive communication difficulties
- Provide "one to one" communication therapy to people with dementia
- Provide communication therapy groups for people with dementia
- Deliver communication support groups for care givers of people with dementia
- Deliver therapy groups for people with dementia and their communication partners

- Provide staff training on how to support the communications of people with dementia
- Provide training to family and/or staff on enhancing the physical communication environment
- Deliver therapy groups for people with dementia jointly with other allied health professionals
- Provide communication support with decision making for the person with dementia, the family and multidisciplinary team

13. What tools do you currently use to assess the communication of people with dementia? (Please select all applicable)

- Arizona Battery of Communication Disorders in Dementia (ABCD)
- Functional Linguistic Communication Inventory (FLCI)
- Cognitive Analysis Profile for People with Cognitive Impairment (CAPPCI)
- Communication Effectiveness Index (CETI)
- Severe Impairment Battery (SIB)
- Cognitive Linguistic Quick Test (CLQT)
- Threadgold Communication Tool for Persons with Dementia (TCT)
- Evaluation of the Environment and Communication Assessment Toolkit (ECAT)
- ASHA Functional Assessment of Communication Skills (ASHA FACS)
- Measure of Cognitive Linguistic Ability (MCLA)
- Communication Activities of Daily Living (CADl-2)
- Ross Information Processing Assessment-2 (RIPA-2)
- Boston Naming Test (BNT)
- Conversational Analysis Tools

14. From the list provided below, please identify the equipment used in your work with people with dementia

- Audio recorder, MP3
- Video cameras
- Wearable cameras (Sense Cam/ProCam)
- Android tablets and/or i-Pads
- Phones e.g. mobile, big button phones, photo memory phones
- White boards
- Memory aids
- Wii
- Nintendo DS
- GPS watches
- Other

15. Please identify which of the following communication and memory supports you routinely use with people with dementia

• Memory aids e.g. diaries, timetables and white boards, alarms • Life story books • Memory boxes • Communication support books • Talking Mats ™
16. Which of the following intervention approaches do you use when working with people with dementia? • Conversation therapy • Environment modification • Simulated presence therapy • Cognitive stimulation therapy • Reminiscence therapy • Montessori based therapy • Validation therapy • Intensive interaction therapy
17. Do you recommend people with dementia and their families to engage with non-clinical activities and/or services in their communities (e.g. dementia cafes, support groups, choirs, active retirement clubs, online resources)?
18. Have you carried out dementia related research? Yes/No
19. Are you involved in the management of cognitive communication difficulties in people with dementia, in the palliative stages of care? Yes/No
Section 4: Irish National Dementia Strategy
20. How familiar are you with the recommendations of the Irish National Dementia Strategy 2014? (Ranked response: Not at all familiar to extremely familiar)
21. How confident are you in your ability to meet the recommendations outlined in the Irish National Dementia Strategy 2014 (such as; timely diagnosis & intervention, integrated care and support for people with dementia and their families across all care settings)? (Ranked response: Not at all confident to extremely confident)

4.2.2 Participants and Recruitment

Purposive snowball sampling was used to recruit participants across the Republic of Ireland. Participants were SLTs working with people with dementia in the Republic of Ireland. There are 1,717 SLTs currently registered with CORU (Health and Social Care Professionals Council) in Ireland. The

number of these working with people with dementia and adult caseloads is unknown.

Inclusion criteria for the study were professionally qualified SLTs working in Ireland with Internet access to complete the survey. SLTs involved in initial content development and piloting were excluded from the study. Participants were recruited by gatekeepers, through the Irish SLT Dementia Network, the professional body of the IASLT, the Adult Acquired Communication Disorder Special Interest Group and the Irish SLT Managers Group. Gatekeepers were chairpersons of these groups. They received an invitation, participant information leaflet (PIL) (see Appendix 4.2 and 4.3) and an attached email (see Appendix 4.4). Potential participants were provided with information about the study and the electronic survey link via email and social media. Survey Monkey (http://surveymonkey.com) was used to create and disseminate the survey. Participants self-selected from the information provided to them in the participants' information e-mail. A reminder e-mail (see Appendix 4.5) was circulated 2 weeks before the survey closed.

4.2.3 Data collection and analysis

This survey was conducted between 15th January to 31st March 2018. An initial informal survey was completed in 2015 at the start of the project, but was not published, as ethical approval was not sought for this initial survey. In 2018 this research was completed more thoroughly and officially with ethical approval.

Responses were downloaded and collated using an Excel spreadsheet. Data was anonymised in accordance with data protection legislation (Data Protection Commission, 2018). Descriptive statistic and thematic analysis were used to analyse the data. Analysis of closed questions was completed using descriptive statistics, providing a summary of the data. Thematic analysis (TA) (Braun et al., 2019) enabled a more in-depth analysis of respondents' expanded qualitative comments. This phase involved; familiarisation with the data, code generation, searching for themes and reviewing and defining themes. Important themes from within the data were coded and analysed. All survey responses were analysed.

4.3 Results

Eighty-nine (89) SLTs responded to the survey. The response rate was considered representative of the range of clinical settings where SLTs work with people with dementia and was in line with other international practice surveys (Nóbrega et al., 2016, ASHA, 2011). There was a completion rate of 73% (n=65). Survey participation reduced once SLTs were asked about their level of satisfaction with their dementia service (Question 6), response rates reduced further when they were specifically questioned about communication assessment and intervention for people with dementia (Questions12-16).

4.3.1 SLTs' work settings and caseloads

Surveyed SLTs worked in a variety of clinical settings and some (11/89, 12%) in a combination of settings such as acute care, long term care and community hospital-community care. Most respondents were employed either in an acute hospital (34/89, 38%) or community care setting (25/89, 29%). The overall proportion of their clinical time working with people with dementia was high with 68% (66/89) of respondees, working 50% of the time or more with people with dementia. However, this time accounts for management of swallowing disorders as well as cognitive communication impairments. All SLT respondents worked with people with dementia and all provided a dysphagia service, but frequently exclusively a dysphagia service. Thirteen percent (12/89) reported never managing communication difficulties as part of their dementia service. The number of SLTs working in a fulltime capacity in dementia services (dysphagia and communication service) was considered low at 5.6% (5/89). There was just one respondent who worked full time in the management of communication disorders in dementia.

Participants were asked to identify the amount of time spent managing communication impairments. Over half of the SLT respondents (54/89, 61%) worked less than 25% of their clinical time with communication impairments. They were concerned about the lack of clinical time available for the management of the communication needs (32/69,46%) as the management of eating, drinking and swallowing problems demands a higher clinical priority.

4.3.2 Referral pattern

Responses to Question 4, "Who refers the person with dementia to your speech and language therapy service?", identified medical consultants (51/84, 60%), public health nurses/clinical nurse managers (40/84), 48%) and occupational therapists (34/84, 40%). People with dementia do not often self-refer for speech and language therapy (4/84, 5%,). Memory clinics were identified as a regular source of referral to speech and language therapy (18/84, 21%). Other health and social care professionals (HSCPs) that refer people to speech and language therapy were physiotherapists and psychologists. Some SLTs reported that due to local policy they can only receive referrals from medical consultants, which restricts the rate and type of referrals to their service. Another participant commented *that "all new residents are seen automatically for baseline assessment on admission".* A range of referral practices were identified which are unique to their clinical settings and multidisciplinary teams.

Participants were asked (Question 5) at which stages of dementia people were most consistently (regularly or always) referred to speech and language therapy (see Table 4.2). The Global Deterioration Scale (GDS) (Reisberg et al., 1985) (see Appendix 4.6) was used to guide responses to this question. Responses indicate that referrals to speech and language therapy services increase with advancing dementia.

Table 4.2 When are people with dementia referred to Speech and Language Therapy

Stages of Dementia	**GDS Levels (Reisberg et. al., 1985)**	**Regularly or always referred to Speech and Language Therapy**	**Response rate**
MCI	2-3	10%	8/81
Early Dementia	4	20%	17/84
Mid-Stage Dementia	5-6	62%	52/84
Late Dementia	7	75%	64/85

4.3.3 Assessment Practice

Only 15% (10/65) of respondents reported that they regularly or always use formal assessments with people with dementia (see Table 4.3). Informal cognitive communication assessments were reported as commonly used by three quarters of SLT respondents (49/65, 75%). Respondents cited the following challenges in the use of formal assessment: the clinical setting (acute care) and the lack of available and appropriate cognitive communication assessments.

The four most frequently used cognitive communication assessments reported were; (1) Boston Naming Test (BNT) (Kaplan et al., 2001), (2) Arizona Battery of Communication Disorders of Dementia (ABCD) (Bayles and Tomoeda, 1993), (3) Cognitive Linguistic Quick Test (CLQT) (Helm-Estabrooks, 2001) (4) Functional Linguistic Communication Inventory (FLCI) (Bayles and Tomoeda, 1994). Two SLT (2/56, 4%) reported using aphasia batteries; the Comprehensive Aphasia Test (CAT) (Swinburn et al., 2004) and the Western Aphasia Battery (WAB) (Kertesz, 2006) to assess communication. Discourse analysis was infrequently used with the Cognitive Analysis Profile for People with Cognitive Impairment (CAPPCI) being used by just one SLT respondent. Three SLTs (3/56, 5%) reported using cognitive screening assessments such as the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005).

Expanded feedback from respondents about assessment practice working with people with intellectually disability (2/56, 4%) said, they use informal assessment more frequently as there is a lack of access to appropriate communication assessments. Informal assessment is a suitable approach to assessment of people with severe intellectual disability and dementia. Three SLTs (3/56, 5%) commented that they never use formal communication assessments.

Table 4.3 Communication Assessment Usage (N= 56)

Formal Assessments	**Respondents**	
	Number of respondents	**Percentage of respondents**
Arizona Battery Of Communication Disorders in Dementia (ABCD) (Bayles and Tomoeda, 1993)	30	54%
Functional Linguistic Communication Inventory (FLCI) (Bayles and Tomoeda, 1994)	23	41%
Cognitive Analysis Profile For People With Cognitive Impairment (CAPPCI)(Perkins et al., 1997)	1	2%
Communication Effectiveness Index (CETI) (Lomas et al., 1989)	1	2%
Severe Impairment Battery (SIB) (Ferris et al., 2009)	0	0%
Cognitive Linguistics Quick (Helm-Estabrooks, 2001)	30	54%
Threadgold Communication Tool for Persons With Dementia (TCT) (Strøm et al., 2016)	0	0%
Environmental & Communication Assessment Toolkit (ECAT) (Bruce et al., 2013)	1	2%
ASHA Functional Assessment of Communication Skills (ASHA-FACS) (Paul et al., 2004)	8	14%
Measure of Cognitive Linguistic Ability (MCLA) (Ellmo et al., 1995a)	17	30%
Communication Activities Of Daily Living (CADL-2) (Holland et al., 1999)	9	16%
Ross Information Processing Battery-2 (RIPA-2) (Ellmo et al., 1995b)	16	29%
Boston Naming Test (BNT)(Kaplan et al., 2001)	34	61%
Conversational Analysis Tools	2	4%

4.3.4 Intervention Practice

Sixty-five SLTs responded to questions on the management of communication impairments in people with dementia. SLTs reported that "one to one" communication therapy is rarely or never (46/65, 72%) provided

to people with dementia. Group therapy was rarely or never provided (55/65, 84%) also.

SLTs said they sometimes or regularly work with families and health care professionals to manage communication disabilities indirectly. They reported providing communication training for staff (33/64, 52%), CP training and training on modifying the physical environment to enhance communication (31/65, 47%). Working directly with the CP to improve communication support was the most commonly reported communication intervention by SLTs (61/64, 88%). SLTs said they often (57/65, 87%) liaised with the MDT about the person with dementia's cognitive communication difficulties and were frequently (32/65, 67%) involved in supporting communication in decision making meetings.

Conversation therapy and reminiscence therapy are popular therapeutic approaches, used by over 70% of SLT respondents. This finding does not reflect the initial reports by SLTs outlined in the previous paragraph, that they do not often provide "one to one" therapy, as a conversational therapy approach is a direct approach to intervention. This finding will be discussed in Section 4.4. Environmental modification (see Figure 4.1) was reported as the most frequently used intervention with people with dementia (48/58, 82.76%).

Types of communication and memory support routinely used by SLTs in therapy with people with dementia (Question 15), were identified (see Figure 4.2). Communication support books are used by the majority of SLTs (43/60, 72%) and Talking Mats™ (13/60), 22%) were used by a smaller number of SLT respondents. Eight percent of SLT respondents (48/60) used both memory aids (diaries and calendars) and life story books. Fewer SLTs use reminiscence materials such as memory boxes (16/60, 27%).

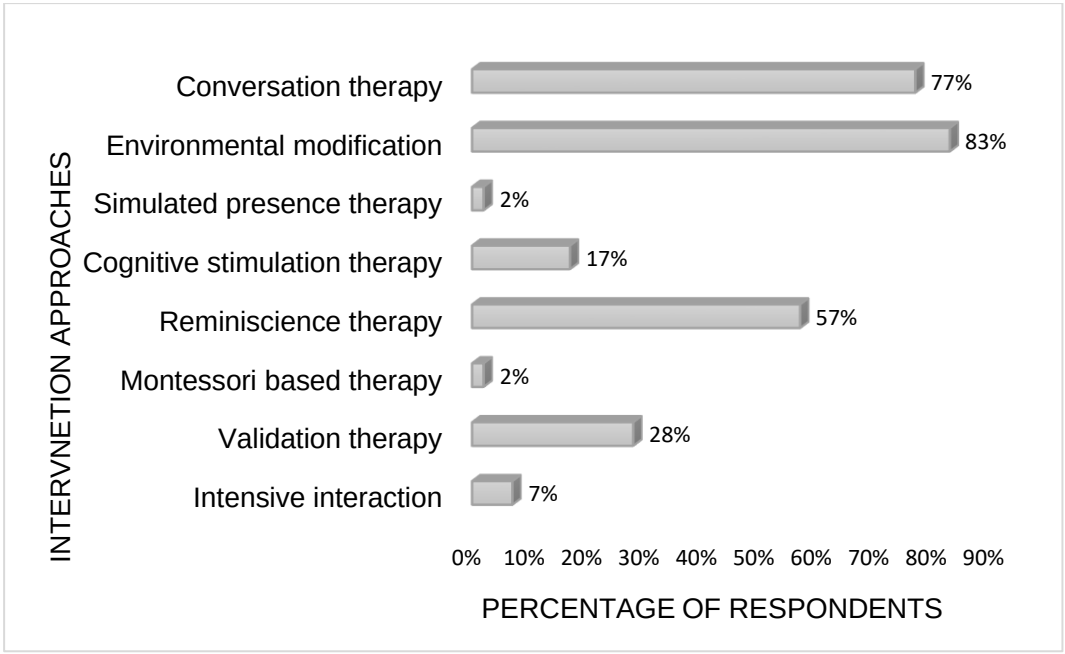


Figure *4.1. Intervention approaches used with people with dementia*

Clinical equipment used by SLT respondents (see Figure 4.3) to provide communication and memory support, include phones (20/56, 36%) and tablets (22/60,39%). Low-tech communication aids such as white boards are also used (36/60, 64%). However, some SLTs (6/56, 10%) reported not using any such equipment, "none used routinely".

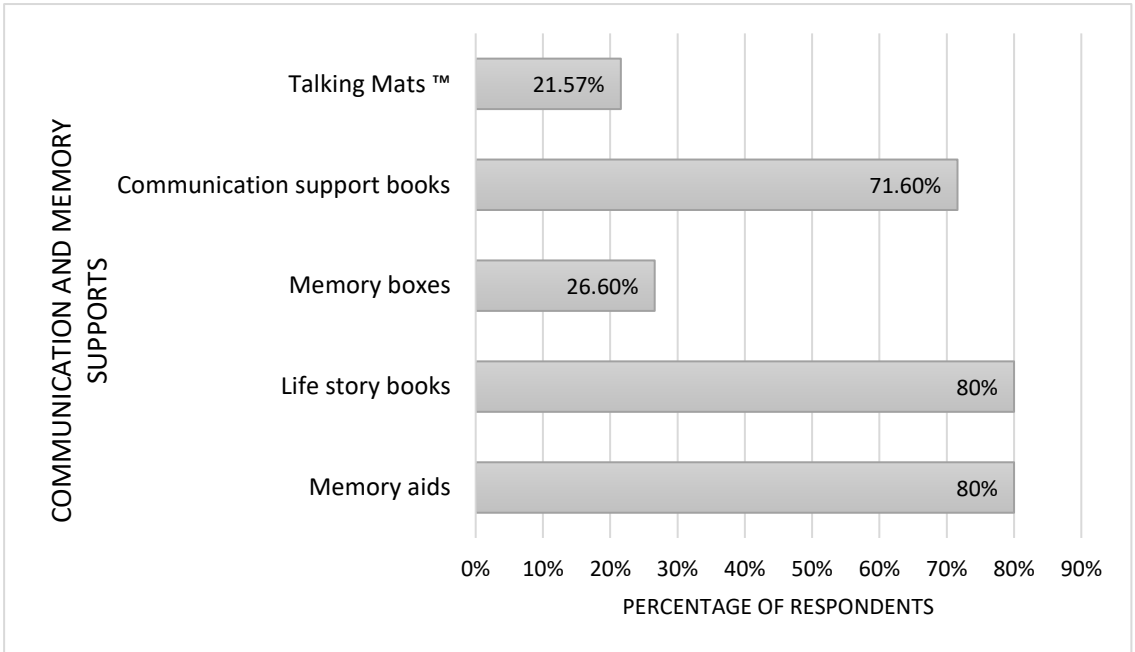


Figure 4.2 Communication and memory supports used

Survey Question 17 enquired about the practice of social prescribing (i.e. advising people with dementia and their families to engage in non-clinical activities such as sporting, artistic and social interests). This was common practice (47/64,73%) amongst respondents. SLTs said that they recommend and refer people with dementia to dementia specific and/or local community-based clubs including; tea dances, choirs, walking groups, "Men's Sheds" and Dementia Cafés. In terms of long-term management of communication difficulties in people with dementia, over a third of SLTs surveyed (24/64, 37%) provide communication intervention in the palliative stages of care (Question 19). Nine percent (6/64) of SLTs commented that their clinical management in the palliative phase of care was exclusively a dysphagia service; "very much dysphagia focused at this stage" and "dysphagia input but not communication".

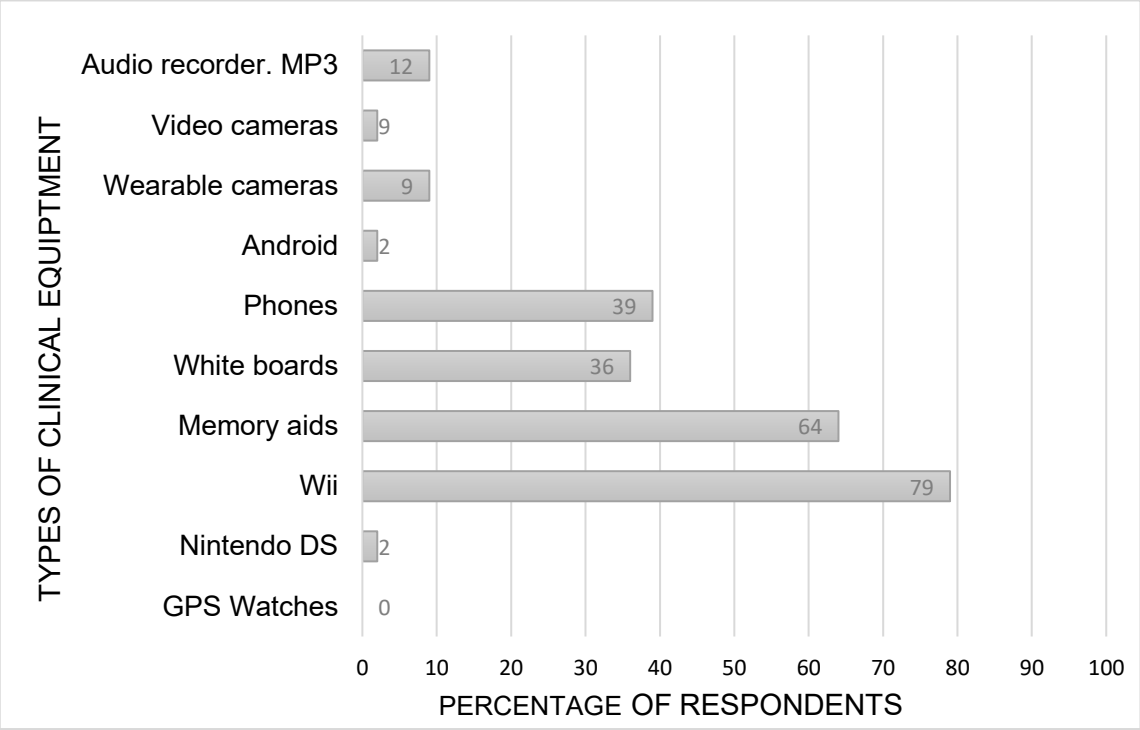


Figure 4.3 Equipment used with people with dementia

A small number of SLTs (9/65, 14%) said that they have undertaken dementia related research. Their research interests included; "family carer's views on feeding and swallowing challenges in the person with dementia", "the communication environment in the acute care setting", "the use of

communication passports in acute care" and "the efficacy of speech and language therapy with the younger person with dementia".

4.3.5 SLT satisfaction levels with current service

Participants were asked to rate their satisfaction levels with the current level of SLT service (Question 6) on a 5-point scale ("not at all satisfied" to "extremely satisfied"). Descriptive statistics were used to analyse this SLT feedback. Forty one percent of SLT respondents (28/68) were "moderately satisfied", while 21% (14/68) were "not at all satisfied", with no participants feeling "extremely satisfied" with service delivery. Participants were then asked to identify and rank the most important factors in improving service delivery to people with dementia (Question 7)). These included early referral, timely access to services, improved knowledge of the role of the SLT by other professionals, increased MDT liaison, the use of speech and language therapy care pathways and improved access to community-based dementia support groups. The highest ranked factors on improving service delivery were; early referral to speech and language therapy (22/69,35%) and improved knowledge of the role of SLTs by other healthcare professionals (20/69, 31%). MDT management (12/69,18%) and the use of SLT care pathways were also identified as important factors in improving service delivery.

4.3.6 Key areas for service improvement

SLT participants were asked to describe key areas for service improvement. SLT respondents' views and experiences were analysed and their recommendations charted (see Table 4.4). They made specific recommendations for service improvement including; increased focus on the management of communication, improved staffing levels, MDT working, and clinical specialist positions.

Respondents ranked issues impacting on the management of communication difficulties using these headings; SLT clinical experience, availability of appropriate cognitive communication assessments and interventions and availability of the primary CP to engage in therapy sessions. More than half of the participants (51%, 35/69) ranked the allocation of clinical time as the most important factor in improving service delivery. This reflects the feedback

given on service challenges also. Direct clinical experience and training of the SLT (14/69, 21%) was identified as a priority as was the availability of appropriate assessment and intervention resources (12/69,18.5%).

4.3.7 SLT familiarity and confidence levels with current dementia policy

The INDS was published in 2014 with the aim of improving dementia care in Ireland. Strategy objectives include that people with dementia have timely services and supports delivered in the best way possible. SLTs were asked two questions; "How familiar are you with the recommendations of the INDS?" and "How confident are you in your ability to meet the recommendations outlined in the strategy?". These recommendations include timely diagnosis and intervention, integrated care and support for people with dementia and their families across all care settings. SLT feedback has been charted (see Figures 4.4 and 4.5). Four years after its publication, the majority of SLTs said they were familiar with the strategy to some degree (58/65, 89%).

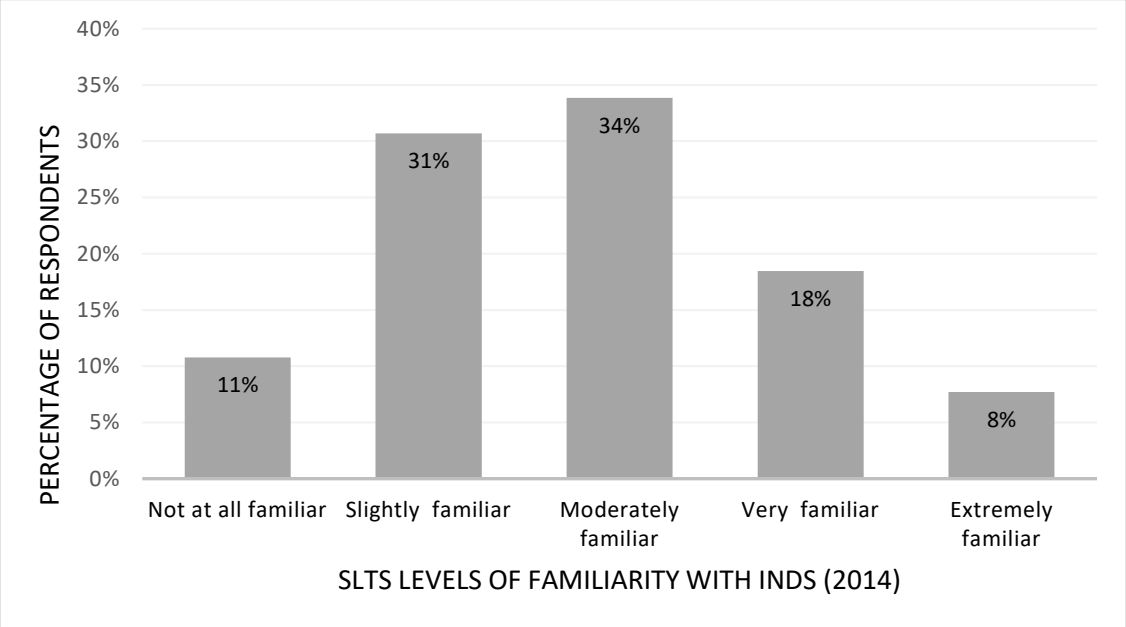


Figure 4.4 SLT Rating of their familiarity with the INDS

Table 4.4 Recommended Service Improvements

Key areas for change	**No. of references to key area in transcripts (n=66)**	**SLT Respondent Comments**
Focus on communication needs of the person with dementia and their family	25	"Allocating time for communication focus" "Rarely get a chance to work on communication"
Increase SLT staffing levels	12	"services are ad hoc, mostly dysphagia no funded post for dementia but there are two memory clinics". "increased time and SLT resources to provide adequate level of SLT input to this population particularly around communication"
Improve interdisciplinary working	11	"better links between consultants diagnosing dementia and SLT" "reminding other professionals that SLT can and do make a difference to the quality of life of the person with dementia and their family"
Increase knowledge of the role of the SLT in dementia care	7	"educate other professionals on the role of SLT in dementia" "Raise the awareness of the role of SLT in dementia"
Increased specialized training in working with people with dementia	6	"functional approach need training on this" "more CPD opportunities in this area "
Improve referral management • Earlier referrals • Increased referrals	l6	"early referral is essential" "greater referrals, I rarely receive referrals for dementia"
Specialist SLTs in dementia	3	"Clinical specialists in dementia to advocate for integration of dysphagia/communication services for people with dementia"

A lack of confidence was expressed on the part of SLT respondents about their ability to meet INDS recommendations in Question 21. Most (55/65, 85%) were not at all confident or only slight confident that they could meet strategy recommendations. There were a range of reasons given for this; *"insufficient SLT resourcing for dementia services" and "limitations of the strategy".* Reference was also made to others awareness, of the role of SLTs in working in dementia care, *"the need for attitude change around SLTs working with people with dementia*". Issues such as being understaffed, under trained and dementia not being a clinical priority, reoccurred in the survey comments. One respondent said, *"we are limited by resources and demand for services far outstrips capacity".* However, there was the aspiration that these issues could be resolved in the future: *"I would hope that the culture of practice can change gradually, over time with sufficient advocation for our role".*

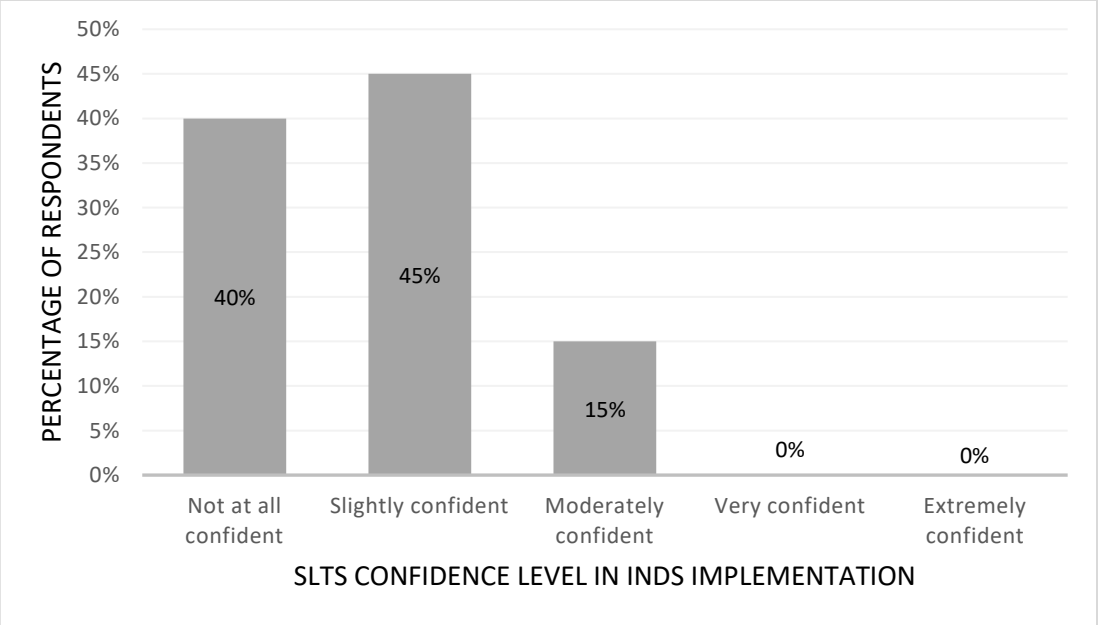


Figure 4.5 SLT confidence levels to implementation the INDS

4.3.8 Emerging themes: Speech and language therapy service delivery

SLTs were asked to identify aspects of their current service that they would like to retain and to describe the challenges they faced in service delivery (see Table 4.1). Thematic analysis (TA) (Braun and Clarke, 2006) was used

to synthesise SLT comments in more detail. There were a range of responses addressing some of the timely and appropriate care interventions available for people with dementia. Survey questions were categorised under the headings of service strengths, challenges and SLT satisfaction with service provision. Further data analysis allowed key themes to be identified; SLT's clinical competence, need for a change in service provision and challenges in practice.

4.3.8.1 SLT's Clinical Competence

Although SLT feedback related to the whole scope of SLT management in the provision of dementia care there was a clear narrative of the existence of a strong clinical competence to serve people with dementia. SLTs providing interventions "enhancing quality of life", "understanding the dynamics of communication" and "the ability to work on both dysphagia and communication". Responses reflected the range of clinical approaches being used in dementia management such as a "functional person-centered approach", "family friendly approach" and "relationship centered care". SLTs provided a lot of examples of interventions available, these referenced both dysphagia "timely access to dysphagia assessment and follow-up", and communication-based services "home visits for naturalistic communication assessments".

Dysphagia services were reported by one-fifth (14/69) of the SLTs as providing "high-quality care for people with dementia" from diagnosis to palliative care management. Levels of clinical competence in managing communication impairment in dementia varied among respondents. Some SLTs reported a lack of specific opportunities for clinical professional development in cognitive communication impairments in dementia*, "very poor experience of assessment and management of communication difficulties in dementia*" and *"lack of specialist and skilled knowledge in the area".* They want to upskill in this area and increase their knowledge and expertise. The lack of education and access to appropriate assessment and intervention resources is considered problematic by 19% of the respondents (13/69). SLTs are aware of their own gaps in knowledge in managing

communication impairments in dementia and this is a challenge in the provision of high-quality care.

4.3.8.2 Need for change

A theme of needing to expand the landscape of current service provision was identified, "it needs to revamp at the moment" in SLT feedback. SLTs were highly aware of current gaps in clinical services to people with dementia "no current communication service", "we currently only look at the dysphagia aspect" and "focusing on communication and dysphagia, not just dysphagia". Other SLTs are resourced to provide high quality and holistic dementia care. This was evident in the wide range of communication interventions being offered and approaches used (described in the previous paragraph). Collaborative team working was frequently expressed by respondents "good MDT collaboration", "MDT seem to acknowledge the importance of SLT" and "continue to work closely with OT". These reports point to changes in SLT practice where timely intervention can sometimes be provided as part of an integrated team approach.

4.3.8.3 Challenges in Practice

There were many responses identifying "*lack of time"* as a frequent and ongoing frustration for SLTs in practice. It seems that communication therapy services to people with dementia are often not available, restricted or not timely. SLTs must give priority to dysphagia management. This is a current challenge for SLTs in practice. SLTs said they were frustrated that more could be done but there is no time resource to provide communication assessment and therapy, "*Due to caseload demands, I feel as though providing an optimum service i.e. in-depth and multifaceted assessment, diagnosis and treatment of cognitive communication difficulties, is very limited. I am constantly aware that addressing these difficulties is within my scope of practice, however it is not routinely provided*".

Another identified challenge in clinical practice was others knowledge about the role of SLT in dementia care*; "there is a lack of awareness on the ground of the role of SLT".* Providing training for the MDT was identified across comments on service challenges and recommended improvements

"*education of staff on the possibility that we can help out with communication"* and *"lack of understanding from other services, what SLT can offer".* This lack of awareness of the SLT role impacts in turn on the rate and timing of referrals to speech and language therapy services.

4.4 Discussion

Survey findings provide perspectives on the clinical practice of a group of SLTs in the management of cognitive communication disorders in dementia in Ireland. SLTs have low expertise in the assessment and management of communication disorders, which can contribute to earlier diagnosis, timely intervention and effective interventions (Bourgeois and Hickey, 2011). Speech and language therapy services in this area, as suggested in the survey are underdeveloped and under resourced.

4.4.1 Understanding the SLT role

The role of the SLT in dementia care in Ireland is not widely understood by other professionals and this was frequently expressed by SLT respondents. This lack of awareness of our role impacts on the timing and rate of referral of people with dementia for SLT management and this is in keeping with findings reported in a SLT clinical practice surveys in Ireland (O'Reilly and Walshe, 2015) and internationally (Nóbrega et al., 2016). The need to promote the work of SLTs in dementia management is acknowledged by the profession, to ensure better outcomes for people with dementia (IASLT, 2016). This IASLT position paper for SLTs working in dementia care published 2016 as discussed in Chapter 1, has provided clinical guidance for SLTs in practice. Lack of awareness of the role of SLT may result in under referral. Lack of awareness of the SLT role seems to apply predominantly to the management of cognitive communication impairments and not dysphagia.

4.4.2 Dysphagia versus Communication

Clinical setting frequently determines the level and range of SLT services available to the person with dementia. The dominant focus on dysphagia management rather than communication therapy was not surprising and has been a service delivery trend for the past 20 years (Cleary et al., 2003,

Enderby and Petheram, 2002). The prevalence of dysphagia at different stages of dementia has been estimated at up to 50% (Alagiakrishnan et al., 2013, Langmore et al., 2002). The trend towards later referral is associated with the development of eating, drinking and swallowing problems as dementia progresses. Opportunities for early intervention will be missed when the person is referred in the later stages of dementia. Modifying diet consistency may increase life expectancy in people with dementia although it may not increase quality of life (Flynn et al., 2018). Dysphagia services are rightly driven by clinical priority, however in some settings this is the only service offered to people with dementia. Some SLTs reported a "high-quality" dysphagia service that is timely and "person centered". The proportion of time allocated to the management of cognitive communication disorders was reported as low and multiple causative factors (including those already described) were identified by respondents; prioritization policies, limited staff and clinical resources and training.

Communication difficulties can then be overlooked or inadequately managed due to service prioritisation. This theme of "lack of time" was recurrent in the survey feedback and is a frustration for SLTs who want to be able to provide a quality service to people with dementia. Some established memory services do not have an associated SLTs position "no funded post for dementia but there are two memory clinics", which impacts on service provision and emphasises the lack of knowledge of our role in dementia management. Restricted time resources for managing communication difficulties has been reported as a barrier to service provision in SLT management post stroke and with Parkinson's disease (Miller et al., 2011, Miller and Bloch, 2017) also.

4.4.3 Communication assessment

Informal assessment (75%) of cognitive communication disorders in dementia was reported as more commonly used than formal assessment (15%). This may partly be due to a high proportion of respondents working in an acute setting where a rapidly changing clinical baseline is more suited to informal and screening evaluations rather than detailed assessments that would soon be out of date. Only 4% of SLT respondents reported using conversation analysis tools as part of routine communication assessment,

although conversation therapy was identified by 77% of SLT respondees as a popular approach to therapy. Likewise, environmental modification was frequently (83%) used as a communication intervention, but very few SLTs (2%) used a formal assessment tool such as the ECAT to guide intervention. Informal communication evaluation of people with dementia is very appropriate and can guide management (Volkmer, 2013), however it is not sufficient to inform differential diagnosis, to develop comprehensive communication profiles, to measure interventions and for clinical research. Comprehensive assessment requires both formal and informal assessment providing the foundation for appropriate, individualised interventions (Bayles et al., 2006, Zientz et al., 2007).

SLT respondent feedback demonstrated the lack of availability of suitable assessments for working with people with dementia. The RIPA-2 and MCLA are used for assessment with people with dementia, by about one third of respondents (29% and 30% respectively). However, both these assessments were standardised will normal research participants and designed for use with people with traumatic brain injury. Many respondents also reported in their comments using, aphasia batteries such as the Western Aphasia Battery (Kertesz, 1982) and the Comprehensive Aphasia Test (Swinburn et al., 2004), which are not standardized for use with people with dementia. A review of existing cognitive-communication assessments for people with dementia is presented in Chapter 5. The issue of lack of suitable assessments is not unique to communication assessment in dementia but was also a finding in a SLT practice survey on the management of non-progressive dysarthria (Conway and Walshe, 2015) also.

It is important that SLTs have access to appropriate assessments to profile cognitive communication skills (Cleary et al., 2003) and guide therapy. SLTs in this survey highlighted that they also have limited assessment tools for use with people with intellectual disability and dementia. A longitudinal follow-up of people with dementia and Down Syndrome in Ireland called for the greater use of appropriate assessment tools that could be used by clinicians (McCarron et al., 2014).

4.4.4 Communication intervention

A variety of communication interventions including psychosocial therapy, cognitive communication and environmental modification interventions (see Figure 4.1) were identified by respondees, these interventions are well evidenced for use with people with dementia (Kim et al., 2006, Mahendra et al., 2005, Bahar-Fuchs et al., 2013, Zetteler, 2008). However, survey responses indicate that these interventions are not routinely offered to people with dementia. Delivery of interventions to people with dementia was low, only 14% of SLTs (9/64) provide one to one communication therapy regularly (Question 12) and 19% (12/64) provide group therapy. This low level of direct therapy cannot be justified when there is clear evidence of the effectiveness of communication intervention in improving quality of life (Moon and Adams, 2013, Zientz et al., 2007, NDO, 2019) and being integral to the delivery of better health care to people (Tomoeda, 2001, Planalp and Trost, 2008).

Linking people with dementia in with local activity and support groups can be beneficial and successful once there are established collaborating networks (Baker and Irving, 2016) and was a popular non-pharmalogical early response to dementia by surveyed SLTs (73%, 47/64). This practice of social prescribing has grown, but it is important for SLTs to evaluate the psychosocial benefits for the person with dementia.

A lack of communication intervention does not apply to SLT management of people with other neurological conditions such as aphasia (Brady et al., 2016, Simmons-Mackie et al., 2014), dysarthria (Park et al., 2016) and PD (Fox et al., 2012) but is the norm in dementia care.

4.4.5 Need for further training and education for SLTs

SLT are well placed as communication experts to provide communication therapy to people with dementia, but some SLTs expressed concern about their clinical skills and competence "*I do not have enough clinical experience and supervision in this area"*, "*lack of skills and confidence*" and "*lack of education*". Feedback from four SLTs (4/69, 6%), described high quality and tailored services being delivered to people with dementia and their families, but this was not a general trend in practice.

Inadequate education and training for SLTs in the management of cognitive communication disorders was a reoccurring theme. It was identified as the second biggest challenge faced by SLTs working in the field after lack of clinical time. Despite a current lack of one to one communication therapy, SLTs are approaching intervention through education and training of CPs and HSCPs. The clinical practice survey pointed to frequent involvement of the SLT in the provision of education and training. The provision of psychoeducation (53%, 33/64) and communication training (47%, 31/65) were provided by SLTs and is key to the provision of dementia services across Ireland. Group training is an effective and efficient approach to the delivery of dementia services. While timely individualised management of communication difficulties is recommended for people with dementia the resources to provide it are not always available.

4.4.6 Irish National Dementia Strategy

SLTs reported that they were familiar with the 2014 INDS but most of them did not feel confident that they could implement the recommendations. The reasons for this are multifactorial and can be attributed to a range of challenges described by SLTs earlier in this discussion; lack of resources, time and experience. Despite this SLTs expressed an awareness of what needs to change, the need for both service equity and a comprehensive approach to SLT management of people with dementia. SLTs are conscious of these gaps in service delivery and expressed frustration at being unable to address the "communication needs" of people with dementia due to a lack of resources. Does this lack of commitment by service providers reflect the view that " they are just going to get worse" (Hopper, 2003). This view is no longer acceptable in a modern health care system (National Positive Aging Strategy, 2013), where equity of service provision will influence service funding. When communication impairment is not comprehensively managed it will impact on the psychological and emotional well-being of the person with dementia and their family. The dementia care landscape is changing, with the publication of the INDS (2014) and public campaigns driven by the National Dementia Office to raise awareness, reduce stigmatisation and improve services to people with dementia.

4.5 Limitations of Survey

There were a low number of responses to the survey, but this is possibly representative of SLTs working in dementia. There was the possibility of respondent bias as the researcher is known to SLTs working clinically in dementia care in Ireland, as dementia management is an developing speciality.

While frequent comment boxes provided participants with the chance to elaborate on responses, focus groups would have afforded the opportunity to expand the discussion and facilitate a more in-depth exploration of themes. However, this survey succeeds in reporting preliminary feedback from SLTs on the management of cognitive communication difficulties in dementia Ireland.

4.6 Conclusions

This is the first Irish survey to date of SLT management of cognitive communication difficulties in people with dementia. These results reflect the complex range of issues facing SLTs in clinical practice. There is growing awareness of the gaps in service delivery to people with dementia. While the majority of SLTs provide dysphagia services there is huge scope for the development of a range of assessment and treatment options to address inherent communication difficulties in dementia.

A key finding of this survey was that SLTs do not routinely manage the cognitive communication difficulties that are associated with dementia. This was the most commonly expressed concern or service inadequacy across the survey. One key deficit is the lack of appropriate and available assessments which impacts assessment practice.

A review of available assessments in this area may identify gaps in current resources available to SLTs and inform their clinical practice. In Chapter 5, a scoping review of cognitive communication assessments is described. Having identified the practices, the next question involved the assessments available to SLTs. This is considered in Study 2.

Chapter 5
Study 2: Assessing Cognitive Communication Skills in Dementia: A scoping review *

5.1 Introduction

In this Chapter, a review of existing cognitive-communication assessments for people with dementia will be reviewed, prompted by feedback from SLTs in clinical practice as to the lack of suitable assessments available for people with dementia. Although several communication assessment tools exist, a comprehensive examination of the characteristics of these assessments for people with dementia has not been conducted. The assessment of cognitive communication skills can present a challenge to SLTs in practice (Volkmer, 2013). The objective of this review is to facilitate SLTs in their management of cognitive communication impairments, providing necessary information on assessment tools accessible to clinicians who work with people with dementia. For the purposes of this study, cognitive communication assessments were defined as objective tests available and appropriate for use by SLTs to evaluate a range of cognitive, linguistic and communication skills associated with dementia.

The main research question was, what psychometrically sound cognitive communication assessments for dementia are available to SLTs?

Further sub-questions were posed for the assessments retrieved:

(a) Are available assessments validated on all types and stages of dementia?

(b) Do these assessments evaluate everyday (functional) communication skills?

(c) Do these assessments involve the CP?

(d) Do they inform intervention and care pathways?

*This chapter was published as manuscript in the International Journal of Language and Communication Disorders (see Appendix 5.1)

Study 1 involving 89 SLTs in Republic of Ireland in 2018 by Dooley and Walshe described in Chapter 4, reported that only 15% of respondents regularly or always carry out formal communication assessments with people with dementia. There are many contributing factors to this clinical practice, but limited availability of appropriate assessments was cited as a significant reason. This lack of assessment resources affects the clinician's ability to evaluate and manage communication services for individuals with dementia. Appropriate evaluation tools are necessary to facilitate description of communication deficits, to identify spared and impaired abilities around which to develop comprehensive plans of care.

5.2 Methods

A scoping review of the literature was conducted using the methodological framework set out by Arksey and O'Malley (2005). This review framework was considered most suited to meet the aims of the study, as it facilitates the synthesis of the main evidence available. It is considered a broad and detailed reviewing method that can facilitate the identification of gaps in the area under review. There are six stages to this framework (Arksey and O'Malley, 2005) (see Table 5.1).

Table 5.1 Scoping Review Framework

1. Identifying the research question
2. Identifying relevant studies
3. Study selection
4. Charting the data
5. Collating, summarizing and reporting the results
6. Optional Stage: Consultation exercise

This review framework included Stage 6 (Table 5.1), consultation with speech and language therapy experts in dementia. These SLTs were purposively

selected as clinicians that would have a wide range of experience in the assessment of cognitive communication disorders in dementia. Recommendations for future research were made following the review.

5.2.1 Scoping Review Framework

The research question was already formulated (see Section 5.1). The second stage of the process was to find relevant assessments and research articles through a comprehensive search of evidence from different sources; electronic databases, reference lists, websites, conference proceedings, hand searches etc. Inclusion criteria were publicly available, published cognitive communication assessments validated in English for people with dementia. A comprehensive search strategy was formulated in conjunction with a university librarian. A search string was devised for PubMed, which consisted of a combination of medical subject headings (MeSH) and Title/Abstract keywords. This search was then applied across selected databases and adapted accordingly. Other literature outside of standard academic publications and reference lists of relevant studies were also searched. No language filters were applied. Date filters were applied.

The search terms were as follows: (communication, communications, communication AND Alzheimer OR alzheimer's OR alzheimers OR dementia OR dementias OR Dementia). The eight relevant electronic databases searched from inception of the database to March 2017 were PubMed, EMBASE, Science direct, Web of Science, LLBA, PsycINFo, Scopus and SpeechBite. Other forms of searching undertaken were reviewing relevant article reference lists, hand searching of relevant textbooks and consulting with expert clinicians in dementia.

Reference manager software (EndNote X8) was used to manage the search findings. Inclusion criteria were as follows: publicly available published cognitive communication assessments validated in English for people with dementia. The inclusion criteria were then applied to the identified literature, to determine their relevance. Eligibility for inclusion was determined by screening titles and abstracts to retrieve full research articles. Electronic database searching yielded 7,584 articles, which were then screened for

inclusion (PubMed 4,276, EMBASE 1,103, Science Direct 1,692, Web of Science 378, LLBA 61, PscyINFO 12, Scopus 25, SpeechBite 37).

5.2.2 Study Selection

The third step was study selection. There were 7,584 records identified through the electronic data base search and hand searches in the library yielded 4 assessments that were not initially identified by the database search. After duplicates were removed, 7,572 records were available for screening. Broad application of the search terminology in the literature resulted in many irrelevant studies being identified, most of these records (n=7,470) were excluded on reading the study titles. To identify the studies that best addressed the research question, the researcher again applied inclusion criteria to all the remaining records. The reviewers read 102 abstracts to determine suitability for inclusion. When relevance of a study was unclear from the abstract, the full article was retrieved. A third reviewer was identified to arbitrate where there was disagreement regarding inclusion, but this did not occur. Consultation was sought and received from SLTs who had clinical experience working with people with dementia. These SLTs comprised Irish and international therapists (n=5) who worked in a range of clinical settings with at least five years' experience in the dementia field. They confirmed that they were not aware of any cognitive communication assessment for people with dementia additional to those identified within this search. Following preliminary analysis, nine cognitive communication assessments were selected. Data were extracted and collated on these nine assessments. However, at the final stage (Section 5.2.3), five of the nine assessments were excluded (see Table 5.2) and just four assessments (all test manuals) were included in the final review.

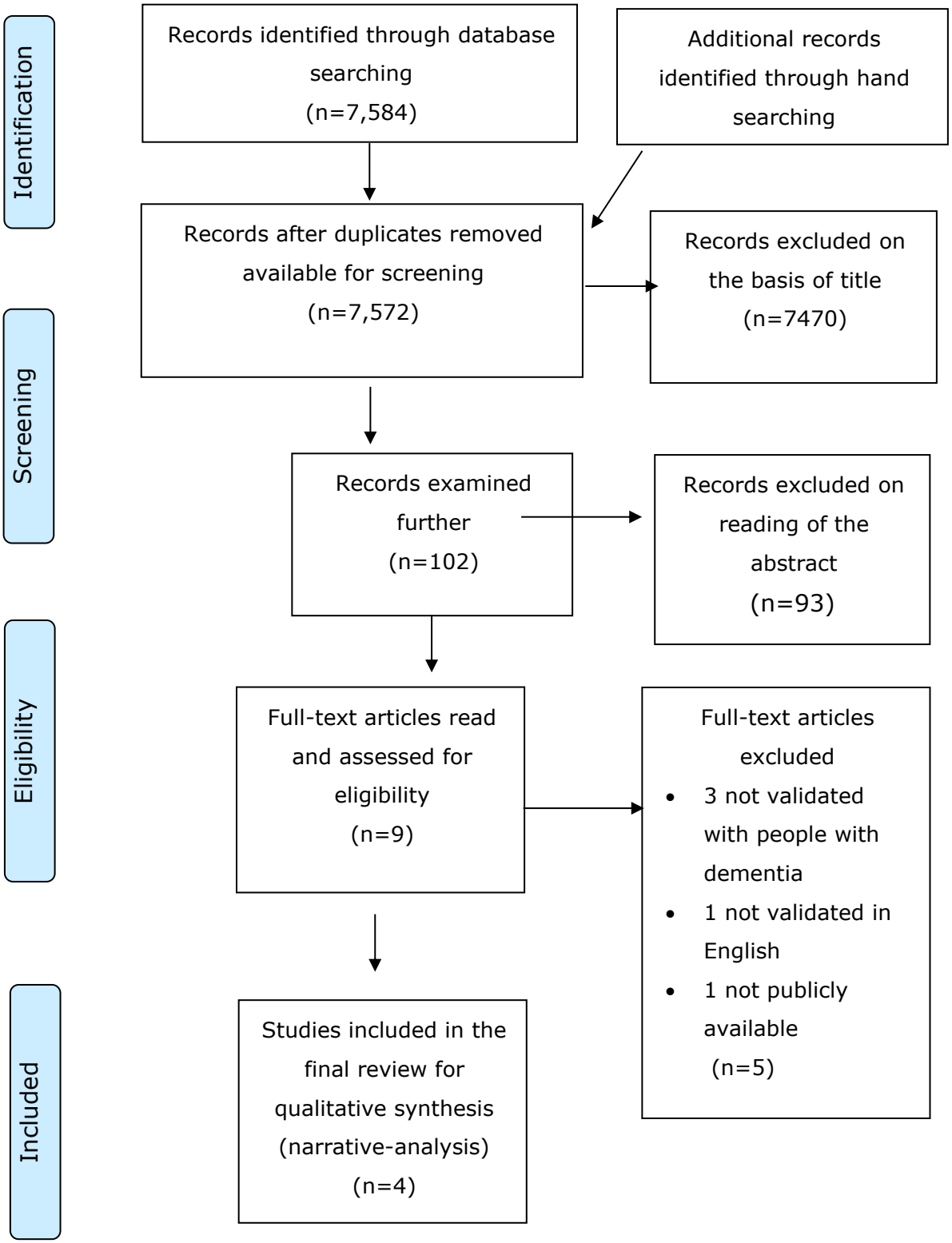


Figure 5.2. PRISMA Flow Diagram

Reasons for exclusion were the populations involved in validating the test and the lack of availability of the test for use by SLTs. For example, the CADL-2 (Holland et al., 1999) was validated with people following stroke and traumatic brain injury and the Environmental and Communication Assessment Toolkit for Dementia Care (ECAT) (Brush et al., 2012) with older persons without neurological disease/disorder. The Barnes Language Assessment (Bryan et al., 2001) was published in a journal and not as an assessment and therefore is not available for clinical use. Both researchers individually analysed and assessed the methodological quality of these assessments. Where appropriate the test manuals of these assessments were retrieved, as much of the validation data were only available in these manuals.

Table 5.2 Cognitive Communication Assessments excluded from the review

Assessment	Author & Year	Type of Assessment	Main Domains Assessed	Reasons for exclusion
Environmental and communication assessment toolkit for dementia care (ECAT)	Brush et al. 2012	Assessment of the communication environment	Provides information on the impact of the environment on communication and makes recommendations	Standardised on older people without neurological disorder/disease; not standardized for people with dementia
Barnes language assessment	Bryan. 2001	Psychometric Language Assessment	Useful diagnostic tool, can assess and profile language skills, giving indications for further interventions	Assessment not published and therefore not available for SLTs in clinical practice
Functional assessment of communication skills for adults (ASHA-FACS)	Frattali et al. 1995	Functional Communication Proxy based Assessment	Functional Communication Assessment; social communication and communication of basic needs, reading, writing and daily planning	Validated in English with people with Aphasia and TBI not validated for use with people with dementia
Communication activities of daily living (CADL-2)	Holland, Frattali & Fromm 1999	Functional communication assessment	Social interaction Nonverbal communication Reading, writing, and using numbers	Validated in English for use with people with Stroke and TBI not validated for use with people with dementia
Threadgold Communication tool for dementia (TCT)	Strom, Engeda & Grove 2016	Functional communication assessment	Eye contact Gesture Facial expression Vocalisation Posture	Not yet published as a standalone assessment. For use by licenced Sonas practitioners only

5.2.3 Charting the Data

The next stage of the review involved organizing and recording key information obtained from the four assessments included in the review. The researchers developed data chart forms to facilitate data extraction. Charting is described as an iterative process (Levac et al., 2010) where the data charting form is updated on an ongoing basis, as required. As the researchers became more familiar with the data, the form was refined, so that key data could be charted. The charting approach takes a broader view (Pawson, 2002) that can include more specific information about the study and, in this case, assessment of psychometric characteristics of validity and reliability. The next stage of the scoping review framework involved collating, summarising and reporting the results.

5.3 Results

Four cognitive communication assessments were eligible for inclusion in the final review (Table 5.3). All four are available for SLTs working with people with dementia. These assessments are as follows:

- Severe Impairment Battery (SIB) (Ferris et al., 2009),
- Arizona Battery for Communication Disorders (ABCD) (Bayles and Tomoeda, 1993),
- Functional Linguistic Communication Inventory (FLCI) (Bayles and Tomoeda, 1994),
- Cognitive Linguistic Quick Test (CLQT).

5.3.1 Publication details and validation cohorts

Publication dates of assessment included in the review ranged from 1993-2001. The most recently published was the CLQT, 17 years ago. They are all commercially available to SLTs through publishers in the UK and USA. SIB validation study was carried out using the second of three versions of this assessment, as described in their test manual. The ABCD and FLCI were both developed using a combination of data from retrospective and prospective

studies. Approximately half of the test items in the FLCI originated from a five-year longitudinal study (n=91) and remaining items were developed for the standardization study. The FLCI standardization cohort had 40 subjects (Bayles and Tomoeda 1994). Longitudinal study data matched test suitability to the stage of dementia. CLQT was developed following a pilot study and three subsequent research studies described in the test manual.

Participants in these validation studies had conditions other than dementia and in two of the four assessments the dementia populations were proportionately small, ranging from 8 to 86 participants. The CLQT (Study 3) was validated with a clinical research population of 38 participants of which 8 had AD, representing 9% of the clinical population and just 5% of the overall research participants (n=119). The total FLCI standardisation sample comprised 40 people with dementia. ABCD had 86 people with dementia (32%) out of 272 participants. In the case of SIB, 70 participants were selected for the validation study 50 of these (71%) were identified as having "probable AD" and 19 (27%) as having "possible AD".

5.3.2 The validity and reliability of included assessments

None of the included assessments were specifically designed to address the full range of cognitive-linguistic domains that are typically impaired in dementia (i.e., attention, visual processing, memory, executive functioning, and auditory comprehension, verbal expression, reading and writing).

Concurrent validity testing varied across the reviewed assessments. The SIB was measured against the Mini Mental State Exam (MMSE) (Folstein et al., 1975) and the Dementia Rating Scale (Mattis, 1988). ABCD performance was measured against three well know measures of dementia severity: the MMSE, the Global Deterioration Scale (GDS) (Reisberg et al., 1985) and the Block Design subtest of the WAIS-R (Weschsler, 1981). Fifty of the total participants with AD (n=86) from this ABCD standardisation study were tested with these three measures. The FLCI was measured against the ABCD (see Table 5.4) but only 13 of the 40 FLCI study participants could be tested on the ABCD. Although participant numbers for FLCI validity testing were small (n=13) a measure of communication was used.

Table 5.3 Included assessments; Publication date, population sample, study type and test suitability across dementia stages

Cognitive communication assessment	**Authors, date & country of publication**	**Study type**	**Sample size**	**No. Of people with dementia & subtype in study**	**Stage of dementia assessment is developed for**
Severe Impairment Battery (SIB)	Saxton et al., 1993 UK	Validation study	70	69 AD 1 VaD	Mid to late-stage
Arizona Battery for Communication Disorders (ABCD)	Bayles and Tomoeda 1993 USA	Standardisation Longitudinal	272	86 AD 8 DPD	Early to mid-stage
Functional Linguistic Communication inventory (FLCI)	Bayles and Tomoeda 1994 USA	Standardisation Longitudinal	40	40 AD	Mid to late-stage
Cognitive Linguistic Quick Test (CLQT)	Helms-Estabrook 2001 USA	Standardisation	38	8 AD	Unclear

Finally, validation of CLQT comprised one pilot test and three research studies. One of these studies involved the CLQT being used by 30 SLTs. It was then refined without use of concurrent assessment measures.

5.3.2.1 Internal consistency, test-retest reliability and interrater reliability

No reference to the internal consistency values was made for SIB, FLCI and CLQT. Internal consistency was tested on the ABCD subtests for 50 AD participants (see Table 5.5). Cronbach's alpha scores were highest (> 0.9) for storytelling and Figure copying and lowest for comparative questions (0.5).

Test-retest reliability is used as a measure of the stability of a test, but the stability of the condition tested must also be considered. All tests included in the review were administered by the same tester on two separate occasions.

Table 5.4 Concurrent Validity

Cognitive Communication Assessment	No of people with dementia in the validation study	Measures of concurrent validity	Correlation coefficient
Severe Impairment Battery (SIB)	70	MMSE MDRS	0.76 ($p \leq .001$) 0.88 ($p \leq .001$)
Arizona Battery for Communication Disorders (ABCD)	50	MMSE GDS WAIS-R	0.78 2-sided ($p \leq .0005$) 0.84 2-sided ($p \leq .0005$) 0.75 2-sided ($p \leq .0005$)
Functional Communication inventory (FLCI)	13	ABCD	0.78 ($p \leq .002$)
Cognitive Linguistic Quick Test (CLQT)	8	Measured and refined against itself	

Key: MMSE Mini-mental state exam, MDRS Mattis Dementia Rating Scale, GDS Global Deterioration Scale, WAIS-R Wechsler Adult Intelligence Scale-Revised, Modified FAST

SIB was retested within a time interval of 30 days and the correlation coefficient between tests was high (r=.99, P≤.001). In the case of ABCD, 20 of the 50 participants with AD in the standardization study were retested after one-week, moderate positive correlation (r^2= 0.5) was found between both tests of scores. Half of the FLCI participants (20/40) involved in the standardization study were retested one week after the initial assessment. There was high-test retest reliability between both results using Pearson's product-moment and Kendell's Tau (>0.8 for 7/10 subtests) with this test. FLCI and ABCD tests were administered again after a week, one might consider familiarization with test materials within this timeframe.

Table 5.5. Overview of Validity and Reliability of Cognitive Communication Assessments

Assessment	Face /content validity	Construct validity	Criterion validity	Internal consistency	Test-retest reliability	Inter-rater reliability	Acceptability/ Feasibility
SIB	✓	✓	✓	x	✓	✓	x
ABCD	✓	✓	✓	✓	✓	✓	x
FLCI	✓	✓	✓	x	✓	?	x
CLQT	✓	✓	x	x	✓	✓	x

Key: Green= present, red= not present, yellow= unclear

The CLQT was retested after 80 and 140 days with a non-clinical sample of 46 participants. According to the test manual "test-retest stability coefficients ranged between 0.61 and 0.90 for the cognitive domains". As would be expected with a non-clinical sample, there was minimal difference in performances between test and retest, with most participants receiving a

perfect score on most tasks. There were also ceiling effects due to the low number of points per task. Absolute score differences were generally small indicating high consistency of scores across administrations.

Inter rater reliability for the SIB was reported as high ($r = 0.99$, $p \leq 0.001$). For the ABCD, inter rater agreement was between 93.3%-98.3% on the 4 subtests evaluated. Inter rater reliability was not reported for the FLCI. Inter rater agreement for CLQT with 170 healthy participants was reported on two subtests that require clinical judgment. It was not clear how the correlation coefficient between both scorers was calculated, but it was reported as strong (Clock Drawing $r= 0.86$ and on the Generative Naming Task $r=0.99$).

5.3.2.2 Acceptability and feasibility

Factors considered in judging acceptability and feasibility were the currency of assessments (i.e. the length of time since validation), time taken to complete the test and stages and types of dementia subtypes covered by the test.

Currency of assessments given that some tests were published as early as 1993, some of the stimulus test materials are considered outdated. For example, the use of a telephone from the early 1900s as part of the reminiscence subtest of the FLCI might seem out of date in 2018. Time taken to complete tests: administration times: of 30 mins or less (SIB, FLCI, CLQT) are suitable for administration with people with dementia, as there is reduced participant burden associated with a shorter assessment process. The estimated time taken to administer these assessments ranges from 15 mins (CLQT) to 90 mins (ABCD). The ABCD is time intensive (45-90 mins) to administer and may need to be completed over several short assessment sessions, it is unclear from the test manual if this was a consideration in the validation process. However, certain subtests can be administered in isolation, which can reduce the assessment time and refine the assessment process. The other assessments (SIB, FLCI and CLQT) can be completed within a 30-minute clinical session. These administration times were stated in the assessment test manuals, but also fit with the direct clinical experience of the researcher.

The inclusion of people with different dementia subtypes such as vascular dementia (VAD), frontotemporal dementia (FTD) and dementia with Lewy bodies (LBD) in these validation studies was limited. The SIB included one participant with vascular dementia and 69 participants with AD. ABCD validation was carried out with 86 people with AD (32%). 70 participants had PD (26%), of whom 8 had dementia (2.9% of the total sample): differences between the performances of those with and without dementia were evident. A control group consisted of 86 age-matched healthy participants and 30 young healthy participants. The ABCD was the only assessment that attempted to address the difference in cognitive-linguistic profiles that occur within dementia subtypes, albeit with just 2 subtypes; AD and non-demented PD.

The ABCD was standardised with people with AD with mild (n=41) and moderate (n= 45) cognitive decline as defined by the GDS and therefore, it is more suitable for use with people in the early to mid-stages of dementia. CLQT studies do not specify information on stages of dementia. FLCI standarisation study was completed with people with moderate to severe cognitive decline (n=40), SIB was standardised with people with mid and late stage AD (N=70). None of the assessments in this scoping review are suitable for use with people with dementia across all the stages of cognitive decline.

5.3.2.3 Comprehensiveness of Available Assessments

The ultimate goal of assessment is to inform intervention. For people with dementia the key areas of assessment are the evaluation of functional communication skills and the involvement of a CP in assessment to address the collaborative nature of conversation. The comprehensiveness of the assessments was evaluated according to the following parameters.

(a) Evaluation of functional communication skills within assessments

All 4 assessments give a total score/percentile rating and profile of cognitive linguistic impairment, but the assessment of functional communication skills is either restricted (SIB, FLCI) or absent (ABCD, CLQT). SIB screens for deficits in attention, language, memory, visuospatial and construction skills. It has a short subtest evaluating social interaction, where the person is

engaged in conversation. ABCD is an assessment of higher-level language and cognitive skills. It includes subtests for screening hearing and visual impairments, which made it unique among this group of assessments. However, it does not evaluate writing, pragmatics or conversation skills (see Table 5.6).

FLCI assesses core linguistic parameters (comprehension, verbal expression, reading and writing) as well as non-verbal communication. As its title suggests, it evaluates aspects of functional communication skills, such as greeting and leave taking, conversational contributions, appropriateness and the use of gesture. The CLQT assesses cognitive skills such as attention, visuospatial and executive functions rather than linguistic skills. Language subtests provide an overview of naming, story retelling and comprehension. Functional communication is only briefly addressed by all four included assessments and there is limited evaluation of the non-verbal aspects of communication (SIB, FLCI).

(b) Involvement of the CP in assessment

Contextual analysis of communication skills is absent across all four assessments with no involvement of the CPs in the assessment process. The CPs are not interviewed regarding everyday communication and/or functional communication ability. The emphasis is on the person with dementia rather than on their conversation partner and/or the dyad. There is also no focus either on the skills of the CP in supporting the person with dementia in conversation in any of the reviewed assessments.

All four assessments evaluated a range of cognitive, linguistic and in some cases functional communication skills, but none of these assessments involved the CP in the assessment process.

Table 5.6 Summary of cognitive, linguistic and functional communication domains

Cognitive Communication Assessment	**Time taken to administer**	**Type of Assessment**	**Primary cognitive-linguistic domains**		**Is functional communication assessed?**	**Involvement of communication partner**	**Directly informs intervention**
Severe Impairment Battery-Language scale SIB	20 mins	Brief screening evaluation of a range of cognitive and linguistic skills	Attention Orientation Language Reading Writing	Memory Visuospatial Construction Social Interaction	Partially	No	No
Arizona Battery for Communication Disorders ABCD	45-90 mins	Comprehensive evaluation of specific cognitive-linguistic skills	Orientation Memory Auditory comprehension Naming & Verbal expression	Repetition tasks Reading comprehension Drawing	No	No	No
Functional Communication inventory FLCI	30 mins	Functional Communication assessment Evaluating a range of communication skills	Naming Verbal expression Auditory comprehension	Reading Comprehension Writing Reminiscing	Yes	No	No
Cognitive Linguistic Quick Test CLQT	15-20 mins	Brief cognitive-linguistic screening assessment	Attention Memory Executive Functions	Language Visuospatial Skills Clock Drawing	No	No	No

5.4 Discussion

This scoping review of cognitive communication assessments for people with dementia adds to the current body of evidence on assessment in people with dementia. The researcher has critically appraised specific cognitive communication assessments in people with dementia. Several important findings from this review include; the limited availability of cognitive communication assessments that can be used with a range of subtypes and across the stages of dementia, the available assessments reviewed do not comprehensively evaluate functional communication and/or include CPs.

5.4.1 Limited availability of cognitive communication assessments

It is evident that SLTs have a limited number of psychometrically sound cognitive communication assessments available for use with people with dementia that include parameters that are directly relevant to the management of cognitive communication disorders associated with dementia.

5.4.2 Available assessments not validated with a range of dementia subtypes and stages

Perceptible changes in language and communication are key in facilitating timely diagnosis and highlight the need for early involvement of SLTs in the diagnostic process. Subtle changes in communicative function may be an early sign of underlying neurological condition (Harris et al., 2008). Objectively measuring and comparing changes in communication across the spectrum of dementia severity is impacted by limited availability of standardized assessments.

Currently available assessments are restricted by the type of clients they can be used with and their appropriateness for the stage of dementia. This impacts on the clinician's ability to determine the communication profile of the person with dementia, reducing the efficiency of the assessment process, and the ability to measure objective change in functional communication. Only the authors of the ABCD attempted to validate the test with people with dementia subtypes other than AD. There is a lack of cognitive communication

assessments that are suitable for use with other sub types of dementia such as VAD and FTD.

These reviewed assessments were developed for people in the early to mid-stages or mid to late stages of dementia, so they cannot be used as repeatable assessment measures across all the stages. It is widely acknowledged that people with dementia have residual communication abilities even in the advanced stages of dementia (Hopper, 2003). This lack of assessment tools provides a challenge for SLTs and may restrict interventions offered to people who require maximum communication support in the late stages of dementia.

5.4.3 Restricted emphasis on functional communication

The results of this review support the hypothesis that clinicians must rely on informal assessments or those that are not developed with people with dementia. The identification of individualised functional goals and effective compensatory strategies for communication is more challenging without access to a range of cognitive communication assessments. The lack of functional communication assessment tools restricts the evaluation process and reduces the likelihood that meaningful interventions may be offered to people who require maximum communication support particularly in the mid to late stages of dementia.

Comprehensive assessment involves the consideration of a range of aspects of communication as reflected in the Mc Donald's model (2017). When the evaluation of functional communication skills is limited, as was found in the reviewed assessments, this impedes the identification of specific support strategies to maximise retained functional skills. The identification of individualised functional goals and effective compensatory strategies for communication is more challenging without access to a range of cognitive communication assessments. There is a growing body of evidence (Eggenberger et al., 2013, Liddle et al., 2012) as to the multiple benefits of SLT intervention in the promotion of effective communication for people with dementia and their CPs. In addition, cognitive communication assessments should evaluate beyond the level of impairment to consider the range of

medical, personal, and contextual influences that impact on the person with dementia's communication competence (MacDonald, 2017). There is a clear benefit to the person with dementia especially in terms of enhancing positive behavior, and meaningful interactions.

5.4.4 Interactions with CP not evaluated

CPs play an essential role by enabling the person with dementia to communicate to their best ability (Kindell et al., 2017). This review found no involvement of the CP in these assessments of cognitive communication ability. Interventions that focus on a collaborative approach to dealing with communication breakdown have been widely researched and shown to be a highly effective way of improving communication for both the people with dementia and their family and/or professional carers (Conway and Chenery, 2016, Broughton et al., 2011). Conversation coaching (Dooley and Conway, April 2016) is a communication intervention that focuses on the dyad (the person with dementia and their CP to profile abilities and to target any behaviours that are impacting on communication confidence and conversational effectiveness. There is increasing research to support the positive impacts of carer training for those with even the most severe communication impairments. There is a growing body of evidence (Eggenberger et al., 2013, Liddle et al., 2012) as to the multiple benefits of SLT intervention in the promotion of effective communication for people with dementia and their CPs.

Adaptation by the CP can help communication with the person with dementia and maintain their autonomy and independence. None of the four assessments reviewed assessed conversational skills, impacting on the clinician's ability to recommend appropriate interventions to enhance everyday conversation ability.

5.5 Limitations of Study 2

The review did not include assessments that evaluate language as part of a cognitive screening test such as the Addenbrookes Cognitive Examination III (Noone, 2015) and the Montreal Cognitive Assessment (Nasreddine et al., 2005). The Communication Abilities in Daily Living (CADL-3) (Holland et al.,

2018) was not included as it was published after the scoping review commenced.

5.6 Conclusions

This review identified the lack of validated communication assessment tools that are available for use with people with dementia (see Appendices 5.1 and 5.2). A comprehensive examination of the characteristics of these assessments was conducted considering the key areas for the assessment of communication skills in dementia. It is unrealistic to expect that one cognitive communication assessment will meet all the requirements discussed here to evoke a comprehensive evaluation of functional communication.

These available assessments are restricted by what type of clients they can be used with and the stage of dementia they are appropriate for. SLTs are best placed to determine the cognitive, linguistic and communication abilities of people with dementia and the development of new assessment tools, will facilitate them in their management. Lack of access to appropriate assessments is a barrier to SLT management and this was identified.

There are an increasing number of evidenced based interventions that can be used with people with dementia such as cognitive stimulation therapy (Hopper et al., 2013), conversation based therapy (Kindell et al., 2017), simulated presence therapy (Bayles et al., 2006) and Montessori based approaches (Boyle et al., 2006). SLTs are in a unique position to develop, implement and evaluate cognitive communication interventions for people with dementia (Cleary et al., 2003). But without high quality cognitive communication assessment tools clinicians will be challenged to establish the effectiveness of individual interventions.

Section 2 Summary

This section presented two preliminary research studies that formed the basis for the main body of this research. These were Study 1, Management of Cognitive Communication Difficulties in Dementia and Study 2, A scoping review: Assessing Cognitive Communication Skills in Dementia.

Study 1 highlighted the range of issues facing SLTs in clinical practice. While the majority of SLTs report providing dysphagia services there is a need to address inherent communication difficulties in dementia. SLTs do not routinely manage the cognitive communication difficulties associated with dementia. An informal assessment approach to communication is most commonly used, contributed to by the lack of appropriate assessments available. This is a key clinical challenge facing SLTs in practice. Conversation therapy and environmental modification were frequently used approaches to intervention, but these areas were not reported as being formally assessed. This lack of formal assessment has implications for selecting appropriate interventions, measuring clinical effectiveness and outcomes.

A scoping review of available cognitive communication assessments in this area in Study 2 confirmed a lack of suitable, high quality assessments available to SLTs for use in clinical practice. At a minimum, clinicians require assessment tools that are up to date and standardised with people with dementia. This scoping review suggests that there are many aspects of cognitive communication assessment with people with dementia that need development This review suggests that there are many aspects of cognitive communication assessment with people with dementia that need further development. These available assessments are restricted by stage and type of dementia that they are appropriate for, as well as lacking a focus on the assessment of functional communication ability. The lack of currently available appropriate assessment tools identified in SLT feedback in Study 1 was confirmed by the scoping review findings in Study 2. These research findings informed the development of a functional cognitive communication tool for use with people with dementia.

In Section 3 the development of a cognitive communication assessment for use with people with dementia will describe the development of this tool from an initial screening tool, Rating Communication Ability in Dementia (R-CAD) to the final P-CAD (Chapter 8).

Once validated, P-CAD will facilitate functional communication evaluation providing SLTs with an alternative assessment, to guide therapy and inform communication interventions.

Section 3: P-CAD Development and Refinement

Chapter 6
Initial development of a cognitive communication assessment for with people with dementia

6.1 Introduction

The lack of valid and reliable assessments that profile communication skills in dementia and the challenges that this presents for SLTs in practice has been established in Section 2 of this thesis. These findings motivated the development of a new cognitive communication tool. The Rating Communication Ability in Dementia (R-CAD) which will be described in this chapter was a precursor to P-CAD and was developed prior to PhD registration.

6.2 The R-CAD

This cognitive communication rating scale, the R-CAD (see Figure 6.1) was developed by the researcher in 2014. Its purpose was to facilitate screening of cognitive communication skills and to improve the management of communication difficulties positively impacting on the well-being of the person with dementia and their family. The R-CAD would provide a basic profile of the client's communication ability and provide a basis for onward referral following discharge from acute care.

The R-CAD was used in routine clinical practice as a service quality initiative and refined following two pilot studies. Assessment outcomes would identify the person's communication strengths and weaknesses supporting clinical decision making, inform communication intervention and integrated care planning.

6.2.1 R-CAD structure and format

The R-CAD screening tool rated seven communication parameters; (1) functional communication, (2) attention, (3) auditory comprehension,

(4) verbal expression, (5) conversation management, (6) reading and (7) writing skills. Routine informal assessment of cognitive communication skills carried out by the SLT would identify a communication baseline. This baseline was then used to complete the R-CAD Profile by rating communication ability and identifying levels of communication support required across the communication parameters.

There were three levels of communication support recommended on completion of the R-CAD; 'minimum', 'moderate' and 'maximum'. When evaluating functional communication skills such as auditory comprehension the SLT had three descriptors differentiating levels of auditory comprehension for example; "understands all but the most complex", "understand everyday conversation" and "basic understanding is intact". Types of communication support and the perspective of the CP was also rated for each of the communication parameters on the form under the heading "other". Each communication parameter was rated in terms of level of function and the type and degree of communication support required. Each communication parameter was then scored based on functional ability and a total R-CAD score (maximum score 30) calculated. The higher the R-CAD score the greater the level of communication support required.

A communication profile summary on the reverse-side of the R-CAD form (see Figure 6.2) included a section for SLT recommendations that could be shared with the family and the care team to facilitate communication and clinical conversations. This summary of the key clinical outcomes included; (1) communication abilities, (2) level of communication support required, (3) support strategies and (4) the R-CAD score. The completed R-CAD profile summary form was then filed in the health care record (HCR).

The R-CAD was piloted in two stages in an acute and community care setting by four SLTs and the researcher, with the goal of identifying any issues with the appearance and content with the tool.

Rating Communication Ability in Dementia R-CAD

Client_____

MRN_____

AFFIX HOSPITAL LABEL HERE

Date of Assessment_____

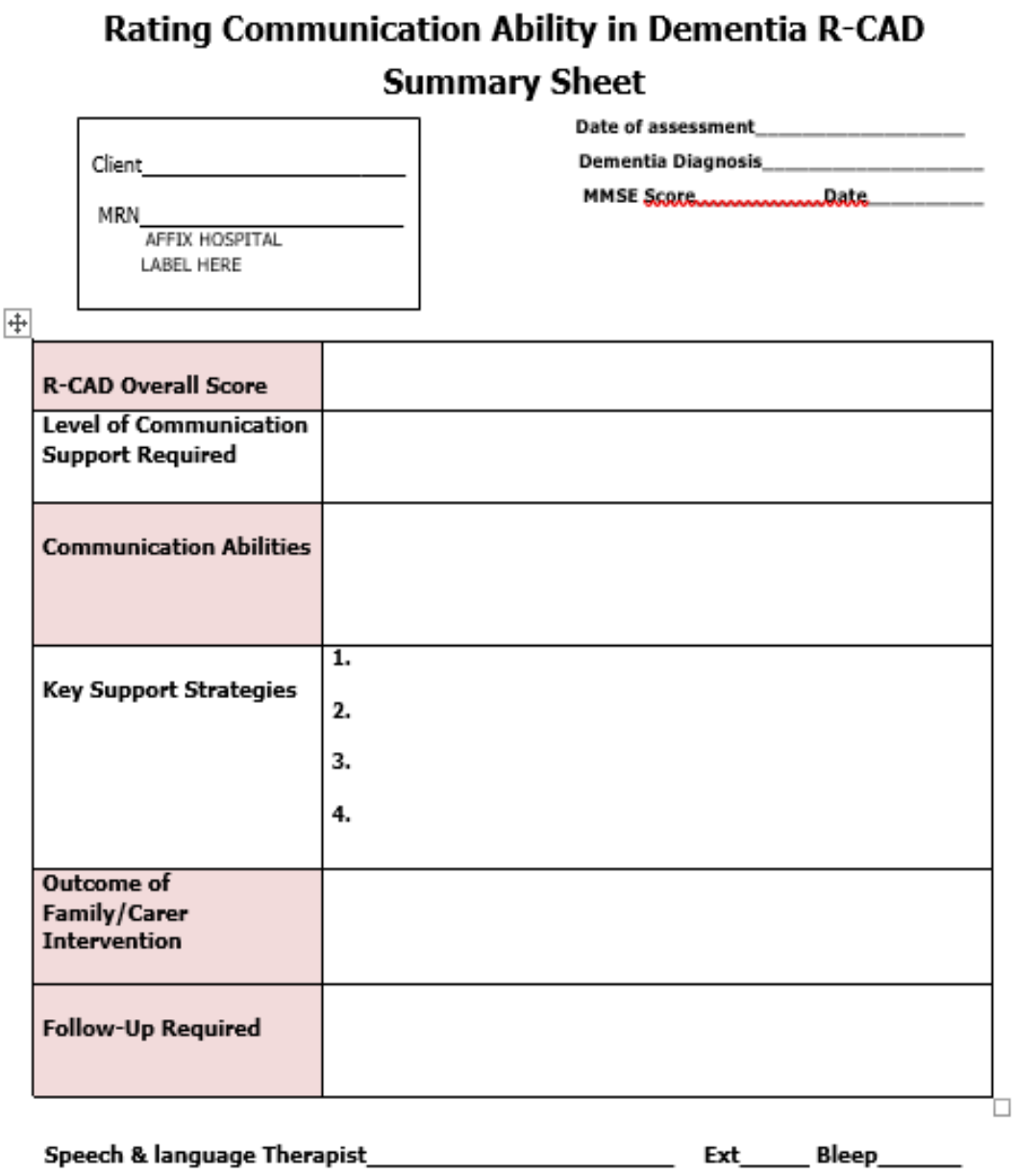
Speech & language Therapist_____

Allocate one score per row. 0 = within functional limits

Cognitive Communication Abilities		Min Communication Support (Score=1)	Mod Communication Support (Score=2)	Max Communication Support (Score=3)
Functional Communication	Client	**Minimal level of communication support** • May need extra time to talk and/or to plan for more complex conversations • Otherwise functional	**Moderate level of communication support** • Consistently able to make needs known but can convey more information than this. • May need to clarify details in conversation	**Maximum level of communication support** • Unable to express basic care needs. • Very limited ability to engage in social communication
	Others	• May need to clarify details or give occasional prompts. • Communication burden: little more than half 50%	• Partner may have to do a lot of the initiation. Some inconsistency with unfamiliar partners. • Communication burden: well over half 50-75%	• All communications heavily dependent on background knowledge of client. • Communication burden: carries all 100%
Attention & Concentration	Client	• Good focused and sustained attention • Unable to focus in noisy environments • Difficulty multi-tasking	• Can sustain attention for up to 10 minutes • Difficulty with selective attention • May lose track of the conversation	• Can focus attention • Difficulty sustaining attention for more than 5 minutes • Fluctuating levels of alertness, may be drowsy
Auditory Comprehension	Client	**Understands all but the most complex** • Has subtle comprehension difficulties with complex information • Reduce inferential processing ability	**Understands everyday conversations** • Can follow simple conversation and directions. • Just one idea at a time	**Basic Understanding is inconsistent** • May understand some everyday words and phrases. • Gets most meaning from the speaker's intonation, visual and situational clues.
	Others	• Some clarification may be needed • Challenged in group conversations.	• Partner needs to slow down • May need to reiterate • Simplifying verbal information is useful	• Partner needs to capitalise on known personal themes • Conversation must be simple and direct
Verbal Expression	Client	**Expresses most ideas adequately** • Experiences mild word-finding difficulty • Verbal explanations may lack detail	**Moderate reduction in verbal fluency** • Can say quite a few single words and phrases • Expressions can be stereotypical and lack detail	**Little or no verbal communication** • Occasional recognisable words used • May point, vocalise or use gesture to express needs
	Others	• Requires occasional prompts • Can talk comfortably in small groups	• Participates in everyday social conversations with some support • Functions better one to one	• Communication can be very difficult to interpret • Heavily reliant on non-verbal clues
Reading & Writing	Reading	• Can read the paper and maybe short stories • Difficulty with inference • May write but will have spelling errors	• Can read words and sentences like headlines in paper • Unable to write meaningfully	• Unable to read or write meaningfully
Conversation Management	Engagement	**Engages well in conversation** • Copes well in small groups may be avoiding certain situations • Better to avoid abrupt topic changes	**Engages in simple social exchanges** • Meets, greets and leave-takes well • Copes with short meaningful conversations	**No Spontaneous conversation** • Largely passive but may respond with gestures and expression • Enjoys social engagement
	Self-Monitoring	• Can cover up and compensate for communication errors	• Turn-taking ability varies • Repeats topics/ideas in conversation	• Heavily dependent on partner to initiate and maintain interaction
				Total:

R-CAD score ratings: 0-7 Normal. For scores >8
Communication support required: 8-15 Minimum, 16-24 Moderate, 25-30 Maximum

Figure 6.1 R-CAD Form



Rating Communication Ability in Dementia R-CAD

Summary Sheet

Client_____

MRN_____

AFFIX HOSPITAL LABEL HERE

Date of assessment_____

Dementia Diagnosis_____

MMSE Score_____ **Date**_____

R-CAD Overall Score	
Level of Communication Support Required	
Communication Abilities	
Key Support Strategies	**1.** **2.** **3.** **4.**
Outcome of Family/Carer Intervention	
Follow-Up Required	

Speech & language Therapist_____ **Ext**_____ **Bleep**_____

Figure 6.2 R-CAD Summary Sheet

6.3 R-CAD Development Methodology

Both pilot studies were carried out using a qualitative descriptive methodology (Sandelowski, 2010). The first R-CAD pilot study was undertaken in the researcher's place of work (an acute care setting) as a service improvement initiative in clinical practice.

6.3.1 Participants

Communication assessments were carried out by four SLT colleagues who were purposively recruited to pilot the R-CAD. These SLT participants were

based at the researcher's place of work. They were considered experienced (i.e.at least 3 years post graduate experience) in dementia care.

6.3.2 Procedure

The R-CAD was used as part of routine assessment of clients on the caseload and not seen as a research tool. These clients had eating, drinking and swallowing problems but also presented with cognitive-communication impairments. The SLT participants administered the R-CAD to clients on their caseloads with dementia requiring communication assessment. An informal individual interview with the participants elicited open verbal feedback from participants once they had piloted the R-CAD.

The pilot studies were carried out at two-time points in 2014, allowing for revisions to be made to the R-CAD after the first pilot study. Verbal feedback from Pilot Study 1 informed revisions and this revised R-CAD was then used in the second pilot stage.

6.3.3 Data Analysis

Feedback elicited from the informal individual interviews was documented and then analysed for themes, commonalities and differences, facilitating low level interpretation. Broad themes that emerged from the participant feedback were described and summarised (see Table 6.1) informing R-CAD revisions.

6.4 R-CAD Pilot Results

6.4.1 R-CAD Pilot 1

This study was conducted in April and May 2014. The SLTs (n=4) involved in the initial pilot study were invited to give open feedback on the R-CAD assessment having used it with at least 4 people with dementia on their caseloads. They described the R-CAD in terms of its usefulness, challenges and suggested amendments to the tool (see Table 6.1). SLT feedback affirmed the usefulness of the R-CAD in terms of identifying the retained communication skills of the person with dementia, guiding individualised

communication support strategies and engaging the family in the therapeutic process.

Suggested amendments to the R-CAD included increasing the objectivity and ecological validity of the tool. Education sessions were organised with medical teams to improve awareness of the impact of dementia on functional communication, to increase referral rates for communication assessment and to ensure that care management was informed by R-CAD outcomes and recommendations.

Table 6.1 R-CAD Pilot 1: Feedback

Usefulness	Challenges	Suggested revisions
R-CAD identifies communication abilities of people with dementia and guides intervention when supports required	Clients frequently did not have a definitive diagnosis of dementia, which influenced the clinical conversations	Review the wording and definitions of the communication support levels to increase objectivity
An efficient way to identify and document specific individualised communication support strategies	SLTs were not able to ascertain how frequently the MDT team were implementing the R-CAD recommendations	Provision of education for the MDT on the impact of dementia on communication
A useful tool for screening cognitive communication ability	Families not always available to attend for feedback meetings	R-CAD parameters could be more dementia specific
Provides a good basis for discussing communication abilities and communication breakdown		

6.4.2 R-CAD Pilot 2

A further trial of the R-CAD, Pilot 2 was conducted over a two-month period in September and October 2014**.** This pilot was undertaken by the same 4 SLT participants with up to four people with dementia on their current caseloads. Following further use in clinical practice the SLTs gave informal feedback on the R-CAD tool in the management cognitive communication impairments with people with dementia.

Feedback was sought using informal individual interviews and documented by the researcher, to ascertain the impact on R-CAD's on clinical practice (see Table 6.2). SLT participant verbal comments about the R-CAD were positive in relation to supporting improved communication between the person with dementia and their CP, communication interventions and integrated care planning.

Table 6.2 R-CAD Pilot 2: Outcomes

R-CAD Pilot 2 Outcomes		**R-CAD Revisions**
R-CAD Outcomes	SLT Feedback	
1. Provision of education sessions for MDT members	MDT reported benefits of SLT education session; "awareness raising" and having a "better understanding of the perspective of person with dementia" Increased number of SLT referrals for communication assessment after MDT education session	Improve MDT liaison by: developing a sticker for the clinical notes section in the medical chart to highlight that the client has been assessed with the R-CAD tool and that the summary sheet and support strategies are on file
2. Improved frequency and range of communication interventions being offered	R-CAD tool guiding group interventions such as the "Newstalk Group" and "Conversation Coaching" "Increased use of picture menus and communication passports on the acute care wards" Development and distribution of "Communicating well with dementia leaflets"	

Verbal feedback from SLTs described the wider benefits of using the R-CAD communication assessment such as access to intervention and integrated care planning for people with dementia. One SLT said "R-CAD went beyond the usefulness of the test itself, it guides intervention". R-CAD use in clinical practice increased awareness of medical staff of the role of the SLT in working with communication disorders in dementia. This resulted in improved rates of referral for communication assessment. Minor changes were suggested to the design and layout of the test. Facilitating dissemination of R-CAD

recommendations with the MDT was reported as important, such as where to file the test in the HCR.

6.4.3 Summary

SLT feedback confirmed that the R-CAD tool had potential as a clinical resource *"there are no other similar instruments for assessing functional communication in dementia so further research would be worthwhile*". The lack of test objectivity had not been resolved, the R-CAD tool was designed as a communication screening checklist and demonstrated potential for clinical use but required further development.

These preliminary pilot studies indicated that the R-CAD tool was potentially a useful measure of cognitive communication ability, but it would have to undergo redevelopment, to determine if it was a valid and reliable measure. A large-scale validation study would be required, to test R-CAD's potential as a psychometrically robust tool.

6.5 Strategic research planning

Research funding was sought to progress the development the R-CAD tool in December 2015. This funding was granted by Health Research Board (HRB) to the PhD supervisor, Department of Clinical Speech and Language studies, Trinity College Dublin (TCD). The assessment was renamed the Profiling Communication Ability in Dementia (P-CAD) tool. The purpose of the tool was to map the person with dementia's abilities across communication parameters. The word "profile" was more reflective of the underlying theoretical framework, that people with communication disability have unique communication profiles and their retained skills can be supported if identified as part of an assessment process.

HRB funding facilitated the development of the R-CAD assessment into the P-CAD (see Chapters 7 and 8). The development process involved seeking feedback from key user groups; people with dementia, CPs, Health and Social Care Professionals (HSPCs), medical physicians, nurses and SLTs. This feedback was then used to revise and improve the P-CAD in preparation for the validation study (see Chapter 9).

Chapter 7
Development and Refinement of the Profiling Communication Ability in Dementia Assessment (P-CAD)

7.1 Introduction

This chapter describes the development of the P-CAD with expert opinion and comprehensive feedback from user groups. Refinement of R-CAD (see Chapter 6) was required to develop this cognitive communication rating tool to a more objective cognitive communication assessment. Study 2, the scoping review of cognitive communication assessments for people with dementia in Chapter 5 identified gaps in available assessments and described the cognitive, linguistic and functional communication domains typically assessed by such tools.

7.2 The Expert Group

An expert working group was established to guide the implementation of the project. The remit of the group was consultation on research design, participant recruitment, project dissemination and revision of the final P-CAD.

A group of national and international experts were invited by the researcher to form an expert group to guide the development of the P-CAD assessment. The expert group had seven members; two Irish consultant geriatricians (one of whom is also a gerontologist), a clinical nurse specialist, a Canadian professor of speech and language pathology, the spouse of a man with early onset Alzheimer's disease, the PhD supervisor and the researcher. A statistician was also a remote member of this group. The group provided direction on improving the validity and reliability of the P-CAD as well as informing research design. Each group member was invited for their own unique expertise and perspectives on dementia. For example, one geriatrician, gave advice regarding accessing research populations, consent and research publications. Another group member contributed to many

discussions on P-CAD content and recommended that P-CAD should be developed for use cross culturally. This will involve using vocabulary that is "culture fair" and will be discussed further in Section 7.5.3.

The expert group met five times over a two-year period to guide development, providing different perspectives and opinions on P-CAD. After the initial meeting of the group, a validation plan was agreed, and some initial changes were made to the new amended P-CAD. These initial recommendations made by the expert group included: to review the scoring system, P-CAD content, develop a profile summary sheet and to use dementia staging scales as a validation measure. Consultation with a statistician also guided the data collection plan.

7.3 Overview of P-CAD development and refinement

The goal of P-CAD development and refinement was to produce a cognitive communication assessment that would be used to evaluate the functional communication ability of the person with dementia along with the communication skills of the CP. This process would involve significant refinement of the content and design of the recent R-CAD assessment under the guidance of an expert group.

There were 3 key phases of P-CAD development (see Figure 7.1).

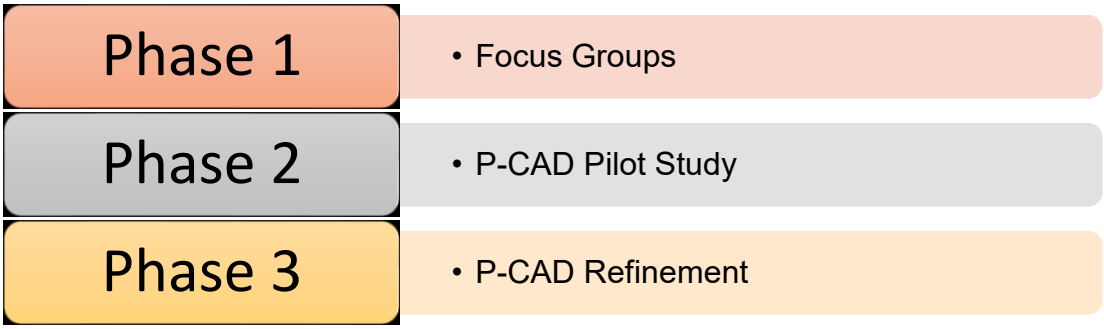


Figure 7.1 Phases of P-CAD development

The aims of Phases 1 and 2 were to amend the P-CAD improving its face, content and ecological validity. In phase 3 revisions were applied to the P-CAD.

Phase 1 P-CAD development involved focus groups and will be described in this chapter. Phases 2 and 3 of P-CAD development and refinement will be discussed in Chapter 8.

7.4 Phase 1: P-CAD Focus Groups

This phase of P-CAD development involved seeking feedback from focus groups on the initial version of P-CAD (Appendix 7.0).

7.4.1 Phase 1: Focus Groups Introduction

Phase 1 development of P-CAD involved input from user groups on the face, content, construct and ecological validity of the assessment tool, to inform its content and structure, to elicit perspectives of key stakeholders on the P-CAD. The stakeholders were people with dementia, their CPs, health and social care professionals, medical physicians and nurses as well as SLTs. These participants were divided into four specific focus groups. The goal for this phase was to improve P-CAD by synthesising stakeholder feedback and to implement changes. The research priority was to identify overarching themes in the data (Braun and Clarke, 2006), relating to the research question. A limited time frame meant that more detailed analysis was not feasible in this phase of the research. The goal was to gain feedback on the face, ecological and content validity of P-CAD and to identify areas for improvement and revision.

Face validity is a subjective measure (Drost, 2011) and is concerned with P-CAD's ability to measure cognitive communication function. Ecological validity refers to the extent to which findings can be generalised to real life settings ((Drost, 2011). Examining ecological validity will indicate the extent to which P-CAD can be used in clinical practice as a cognitive communication assessment by SLTs with people with dementia. Content validity pertains to the degree to which P-CAD fully assesses cognitive communication ability in dementia, the extent to which the measure includes all the important facets that it requires to test the target domains (Bolarinwa, 2015). This refers to the relevance of P-CAD for use with people with dementia and whether the P-CAD examines the key domains of cognitive communication function in dementia.

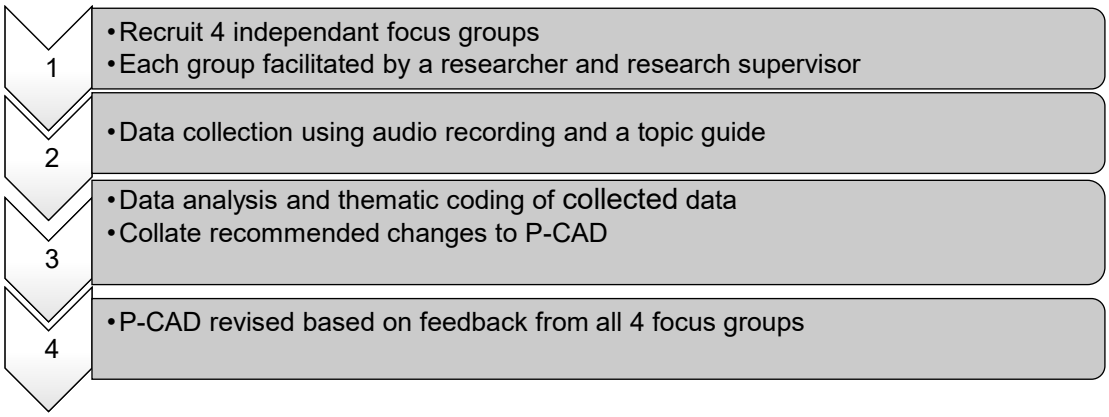


Figure 7.2 Phase 1 P-CAD: Procedure Map

7.4.2 Phase 1: Focus Groups Method

The research design was qualitative and prospective, guided by the expert group. Focus groups were chosen to capture the perspectives of stakeholders and collect specific feedback about the P-CAD. These group-based interviews were chosen as a time efficient way to gather more in-depth information. Focus groups are defined typically as a small group of people with certain characteristics, who provide qualitative data in a focused discussion about the topic of interest (Kruger and Casey, 2015). This data collection approach meant that opinions on P-CAD could be gathered, elicited and used to guide the development of P-CAD in a short time frame to meet with research timelines. Feedback was gathered over a 4-month period. Thematic analysis (TA) was used to identify, analyse and report patterns within data (Braun and Clarke, 2006). Ethical approval was obtained from the Research Ethics Committee of the School of Linguistic, Speech and Communication Sciences, Trinity College Dublin (TCD) (see Appendix 7.1). Feedback collated from user groups was used to shape the content of the final P-CAD.

There were 4 stakeholder groups:

(1) People with dementia
(2) CPs of people with dementia
(3) SLTs with clinical experience in dementia care
(4) HSCP nurses and medical physicians

Individual focus groups were held at a place of convenience for participants over a 2-week period in March 2016 in a community hospital in Dublin.

7.4.2.1 Participants

Focus group participants (see Figure 7.3) were selected using purposive sampling methods where participants are selected with a specific purpose in mind where the qualities of the people chosen are relevant to the research topic (Denscombe, 2007). Participants were recruited via a gate keeper (medical secretary at the hospital). Individual focus groups were held with each stakeholder group. It was anticipated that Group 1 comprising people with early stage dementia, would have 2 or 3 participants. This smaller group size would facilitate communication and feedback using a supportive and accessible approach. Focus Groups 2, 3 and 4 would comprise 4-5 participants.

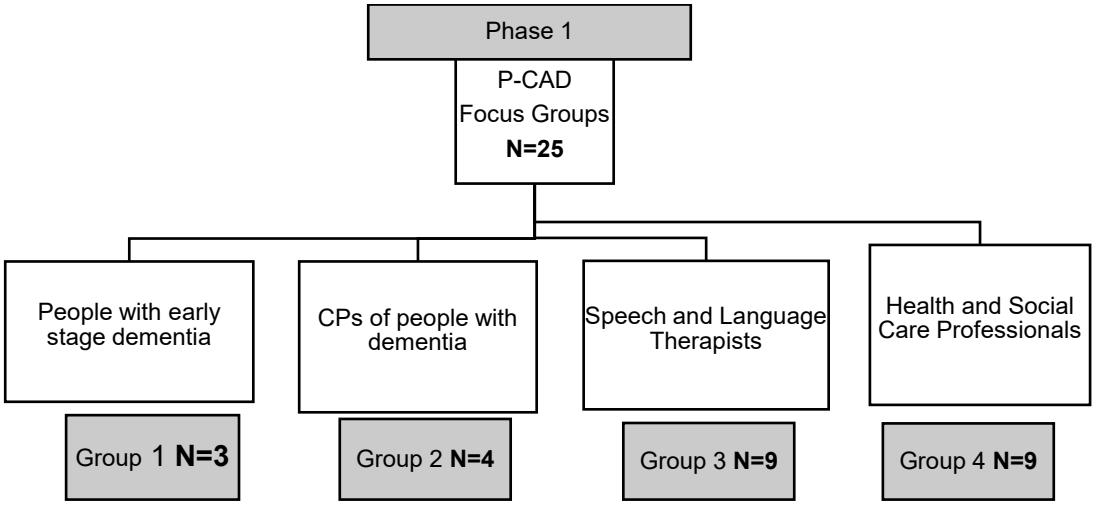


Figure 7.3 Overview Phase 1 Focus Groups

Focus Group 1: People with dementia

People in the early stages of dementia (GDS Level 2 and 3) attending memory rehabilitation groups at the hospital were invited to participate in a focus group. Cognitive communication difficulties in early stage dementia are typically mild in severity. While each person will have a unique communication profiles, they may experience some word finding difficulty, reduced attention or high-level auditory processing difficulties. These

participants had mild cognitive communication impairments, characterised for example by slowed auditory and visual processing, wording finding difficulty, repetition of ideas and writing errors.

Communication support strategies are used to facilitate open discussion among the participants. A quiet room and accessible written information along with a skilled facilitator (the researcher) would support focus group engagement and discussion.

Focus Group 2: CPs of people with dementia

CPs of people with dementia were invited to participate. CPs were defined as those who are in regular contact (2-3 times weekly) with the person with dementia. They can be spouses, partners, relatives and friends. A balance of male and female participants was sought.

Focus Group 3: SLTs

SLTs working across different dementia care services such as memory clinics and palliative care settings were invited to participate in a focus group.

Focus Group 4: HSCPs, nurses and medical physicians

Inter-disciplinary team members in one hospital site were recruited. This focus group comprised a range of professional staff from across the hospital; an occupational therapist, a physiotherapist, a medical social worker, a clinical nurse specialist in palliative care, a staff nurse, a consultant physician in geriatric medicine, two medical physicians and a dietitian.

Focus group: Inclusion/Exclusion criteria

Separate criteria were applied to each participant group (see Table 7.1)

7.4.2.2 Recruitment

The participants were recruited via a gatekeeper (the medical secretary in the medicine for the elderly department, in the hospital). Having a representative sample of each specific user group was important so that a range of perspectives were available (see Table 7.2 Participant Demographics). All participants self-selected for focus groups. Recruitment of Focus Groups 1 and 2 was via the gate keeper who identified potential

participants through the lists of people attending the Memory Rehabilitation Groups at the hospital in the previous 12 months. Memory Group attendees all have identified early stage dementia and are aware of their diagnoses. Participants in Groups 1 and 2 were self-selecting.

The gatekeeper sent out an e-mail (see Appendix 7.2 and 7.3) to these people with dementia that attend the memory groups and who had already expressed an interest in participation in the research. GDPR guidance was adhered to (Data Protection Commission, 2018). This email had an accessible (easy to read) version of the participant information leaflet (PIL) and consent forms attached (see Appendix 7.4 and 7.5) and a standard letter format used for Focus Group 2 (see Appendix 7.6 and 7.7).

Recruitment of Focus Groups 3 and 4 was facilitated by the same gatekeeper who forwarded a letter of invitation (see Appendix 7.8) via e-mail with the PIL and consent forms attached (see Appendices 7.9-7.12). Potential participants from these groups, were individuals working in dementia care in multidisciplinary teams and/or SLTs in community and hospital-based dementia services.

Prospective participants were asked to contact the researcher via email or phone for further information or to express interest in participation. The researcher provided focus group information to the participants and took written and verbal consent at the time of data collection

Table 7.1 Focus Group Inclusion and Exclusion Criteria

Focus Groups	Inclusion criteria and rationale	Exclusion criteria
Focus Group 1 **People with early stage dementia**	(a) a disclosed diagnosis of dementia diagnosis, so that the participants fully understand the purpose of the group and the need for their specific feedback. (b) can read and understand the aims of the P-CAD project so that they can understand what information is being sought and that they are not exposed to any unnecessary stress. (c) can give written and verbal consent to participation in the research, to meet with ethical requirements for the study.	(a) Unable to understand the purpose of the group and their involvement if they are unaware of their dementia diagnosis (b) Unable to fully participate in the group discussion on P-CAD without being able to examine the test and stimulus booklet (c) Unable to communicate consent or assent
Focus Group 2 **Communication partners (CPs) of people with dementia**	(a) CPs with responsibility for the care of the person have first-hand experience of the communication changes that occur due to dementia. (b) well known to the person with dementia and has contact with the person at least twice a week. Experienced in providing supported communication as well as understanding the impacts of communication breakdown.	(a)CP does not regularly communicate with the person with dementia (b) Not experienced in supporting the communication of a person with dementia

Focus Group 3 **Speech and language Therapists**	(a) at least 3 years post graduate experience in the assessment and management of people with communication impairment associated with dementia, as experienced therapist opinion is being sought. (b) working in acute, rehabilitation, community and palliative care. The inclusion of a range of working settings will provide a broader scope for feedback on the P-CAD.	(a) Less than 3 years post graduate clinical experience working with people with dementia
Focus Group 4 **HSPCs, nurses and medical physicians**	(a) member of interdisciplinary team involved in the management of people with dementia, as experienced opinion is being sought. (b) working in acute, rehabilitation, community and palliative care settings. The inclusion of a range of working settings will provide a broader scope for feedback on the P-CAD.	(a) not a member of an interdisciplinary team working with people with dementia

7.4.2.3 Phase 1: Data Collection Procedure

Focus Group Logistics

Discussions were held in a relaxed, non-threatening environment to allow all the participants to share their perspectives on the P-CAD. The number of focus group attendees in each group can be seen in Table 7.2.

Table 7.2 Participant demographics

Focus Group	**No. of participants**	**Gender of participants**		**Work Setting**		
		Male	**Female**	**Community Hospital**	**Acute Hospital**	**Community Care**
Focus Group 1 People with dementia	3	3	-			
Focus Group 2 Communication Partners	4	1	3			
Focus Group 3 SLTs	9	-	9	3	3	3
Focus Group 4 HSCPs	9	2	7	6	36	
Totals	25	6	19	9	6	3

Focus Group Process

Facilitation of the groups was carried out by the researcher and research assistant. The discussion was audio recorded using a laptop (Lenovo Yoga 500) with an external microphone (Sony: Electret Condenser Microphone). Research instruments used were; the P-CAD assessment tool and topic guides (see Appendix 7.13). Notes were also taken manually by the researchers at the time as the discussions progressed.

Focus Groups 1 and 2 were given accessible information by the researcher e.g. documents with large and clear formatting, including a topic guide and consent forms. The participants gave written consent before group discussions began. The individual topic guides were used to facilitate each focus group discussion on the P-CAD. A copy of the P-CAD administration and stimulus booklets were available to the participants during the session.

Following the focus groups the audio files were transferred from the laptop to a password protected computer in the Department of Clinical Speech and Language studies for storage in compliance with the Data Protection Act (DPA 2018). Audio recordings were then transcribed in the subsequent days.

Focus Group Timelines

All the focus groups were conducted over a period of two weeks. Focus Group 1 lasted for 1 hour and all 3 participants with dementia contributed to the discussion. Some facilitation was needed at times to help keep the conversation on track and to ensure that all key topics were explored. All the other focus groups took approximately 90 minutes.

7.4.2.4 Data Analysis

The analysis of data was carried out after each focus group was completed. TA was used and is defined as a method for identifying, analysing and reporting patterns within data (Braun and Clarke, 2006) (see Table 7.3). This involved; becoming familiar with the data (TA: Phase 1) through analysis, transcription and the generation of codes (TA: Phase 2). This systematic identification and organisation of themes identifies shared meaning across the data (TA: Phase 3) in relation to the research question, of specific interest in the data was feedback on the face, ecological and content validity of P-CAD. The transcripts were reviewed throughout the process, a sample transcript is provided (see Appendix 7.14).

Inductive analysis facilitated the emergence of codes in the data where none were pre-existing. A bottom-up approach was taken where the codes and themes were derived from the data. Descriptive themes based on participants' responses were developed to give meaning to the experiences and opinions of the participants, reflecting the actual opinions of the focus

group participants. All data emerging from the focus groups was accounted for in the analysis.

Table 7.3 Thematic Analysis (Braun and Clarke 2006)

Phase 1	familiarising with the data
Phase 2	generating initial codes
Phase 3	searching for themes
Phase 4	reviewing potential themes
Phase 5	defining and naming themes
Phase 6	producing the report

A randomly selected sample (20%) of transcripts was coded blindly and analysed by the research assistant, an experienced SLT, to ensure reliability of the analysis. Any discrepancies in coding and categorisation into themes were resolved through discussion. Recommended revisions to the P-CAD were identified and collated into an Excel document.

7.4.3 Phase 1 Focus Group: Results

Focus group feedback was categorised following analysis. Dominant focus group themes are presented here along with suggested P-CAD revisions.

7.4.3.1 Dominant Focus Group Themes

Two predominant themes emerged from the focus group data (see Figure 7.4), they were *Communication* and *Care*.

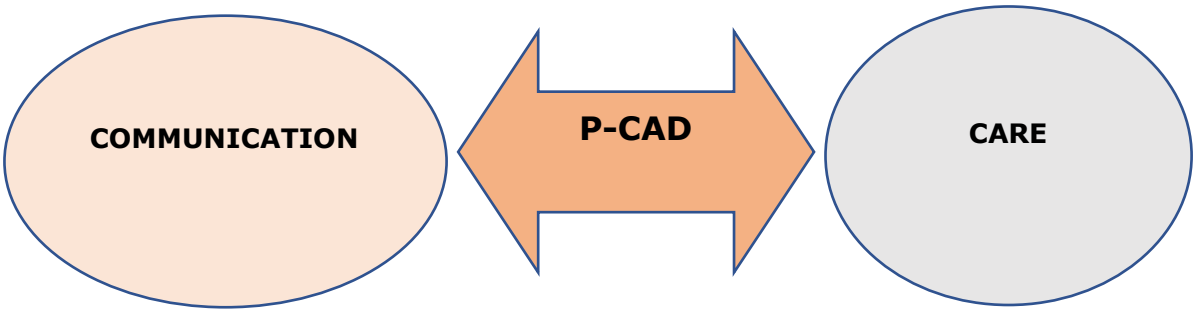


Figure 7.4 P-CAD Thematic Map

These overarching themes were identified across all 4 focus group discussions. These themes were frequently referenced and expressed as fundamental to the P-CAD assessment and are described below (Table 7.4).

Table 7.4 Focus Groups: Thematic Analysis

Selected Themes
Theme 1 *Communication: "Hearing what the person has to say":* This theme of communication was a common thread throughout group discussions. It is at the centre of this research project also as the P-CAD was designed to profile the person with dementia's communication ability. There was a consensus that the P-CAD communication profile is "*everybody's business".* All groups acknowledged the value of measuring and documenting a person's communication profile so that it can be used to guide care and intervention. There was a clear message that the P-CAD Communication Profile (see Appendix 8.6) needs to be readily accessible to the interdisciplinary team and family in an easy to use format. Team members want to communicate successfully with the person with dementia and the P-CAD's recommended communication support strategies enable this. This theme was underpinned by a theme of *"knowing and understanding the communication support":* the facilitation of communication in everyday, clinical and decision-making conversations. Profiling functional communication abilities and the inclusion of conversational analysis was "breaking new ground" in communication assessment of people with dementia. CPs were interested in the idea of focusing on retained skills*: "it is helpful to look at (husband's) communication in a different way, he can read you know",* CP acknowledging retained skills and how this might support everyday communication. This theme of communication encapsulates the view that P-CAD "*captures communication ability"* and will highlight communication strengths. Acknowledging the person with dementia as an active participant in the assessment process is important and was emphasised by HSCPs*, "they can mention their abilities in reading and writing"*. The P-CAD Communication

Profile facilitates a more holistic approach to communication and care discussions.

Theme 2: *Care: "Facilitation of smooth management of their care".* This theme encompasses the sub themes of consenting, care pathways and quality care. Easy access to the person's P-CAD communication profile will impact on the person, their family, the interdisciplinary team and care planning, "*that's my patient*. As discussed in Chapter 1, diagnosis of communication problems in early dementia facilitates care planning. Within the focus groups there was a positivity and a sense of relief about knowing how best to communicate with the person with dementia; *"It is my favourite part, I love it",* an SLT commenting on the Profile Summary Form. HSCPs said "*P-CAD is useful in facilitating conversations about capacity*" and "*it is important to know and understand the communication support strategies before you see your patient*". The use of support strategies can improve communication, impact on "*smooth management*" and assist care decisions and care planning. Data from the focus groups indicated that improved communication with the person with dementia has the potential to *"enhance rehab potential and prevent roadblocks in care"*. There was a clear narrative within the groups that better communication is empowering for all stakeholders, enabling quality service provision and enhanced engagement in decision making conversations. The P-CAD was acknowledged by SLTs, HSCPs and the participants with dementia as a care resource.

Participants agreed that the P-CAD can be used to monitor the progression of dementia *"as a measure of baseline communication"* which will contribute to quality care and care planning. Developing a tool that is sensitive to change was identified as challenging "*achieving clear definitions for levels of impairment*" by the SLTs and HSCP group participants.

The *Care* theme encompasses issues of consent. The availability of the P-CAD Communication Profile will support decision making discussions for all: *"using this information facilitates conversation around decisions".* Consenting to video recording was discussed in detail by the people with dementia and the CP groups. There was a consensus among people with dementia that "*there's nothing wrong with being videoed"* and that video

recording is an important assessment tool once the person with dementia has an awareness that it is happening. Participants agreed that informed consent/assent to be videoed is an important concern. Some positive experiences of receiving video feedback in clinics were discussed by people with dementia.

7.4.3.2 Focus Group Feedback on the face, ecological and content validity of P-CAD

Data was further analysis to review participant feedback on the different aspects of P-CAD validity. Comments on the face, ecological and content validity of P-CAD were identified and organised accordingly.

Face Validity

Feedback regarding face validity from across all focus groups (see Table 7.5), reinforces the relevance of P-CAD, it' s appropriateness for use with people with dementia and for assessing communication ability in dementia.

Table 7.5 Face Validity of P-CAD

Focus Group	Participant Feedback
1	*"once you have a reasonable sense of what is going on" (re being videoed)* *"this gives you a score(P-CAD), monitors your progress and gives you strategies to use at home"* *"Validation is very important throughout this whole structure(test)"*
2	*"Good communication is so important when he is in respite, this is a very important part for us as carers"* *"I think it's comprehensive "* *"was diagnosed with dementia two years ago so his whole issue is around communication really and eh… he was seeing a speech therapist one-on-one"*

3	*"P-CAD will facilitate smooth management of care while an inpatient"* *"Supporting communication may prevent roadblocks in care"* *"Having this information available will inform therapist before they meet the client"*
4	*The group liked the title of the P-CAD, "it fits well with other communication assessments"* *"Profile Summary Form is really useful; you can see your client's profile at the end! "that's my patient"* *"The profile summary form is text heavy, but it is my favourite part, I love it!"* *"Knowing the person's communication abilities is important to be able to hear what the person has to say especially in terms of facilitating communication "*

Participant feedback reinforces the strong face validity of P-CAD, its suitability for use with people with dementia, it's value in identifying the communication difficulties associated with dementia and how this can impact on the person with dementia's health care and communication.

Ecological Validity

Results confirm that P-CAD could be a useful and appropriate tool for cognitive communication tool for people with dementia. Participant feedback from all focus groups referred to the usability of P-CAD in clinical practice and it's potential to impact positively on communication function as well as facilitating the MDT in their interactions with the person with dementia. Some direct quotes from each focus group are presented below (Table 7.6) Participants identified that P-CAD provides guidance on individualised communication support which can impact health care delivery.

Table 7.6 Ecological Validity of P-CAD

Focus Group	Participant Feedback
1	*"This can be shared with other health professionals; strategies help us at home"* *"No problem with testing time of 30mins to one hour "* *"Once the person is aware it is happening" (videoing)* *"Partners support conversation, they know us well"* *"It helps people to relax and talk about how to overcome the barriers of communication"*
2	*"Weaker things he'd find hard but others he'd fly through, the key is that the person doing it with him makes it feel like a conversation"*
3	*"It helps people to relax and talk about how to overcome the barriers of communication"* *"The graph is very useful, a good visual representation of the communication profile, as a PT the graph will help me deliver my intervention, I would definitely use it"* *"It allows for individualised feedback"* *"Having the information available will inform the therapist before they meet the client"*
4	*"Can be administered in an acute setting on the ward with environmental modifications"* *"The strategies are very useful but need to be simplified a bit"*

Content Validity

Focus group feedback on P-CAD's content validity was identified in the data. Comments relating to how P-CAD evaluates important aspects of cognitive communication difficulties associated with dementia are presented below (see Table 7.7). Phases 2 and 3 of P-CAD development provide more in-depth feedback from SLT participants particularly on content validity of the P-CAD subsections that are relevant for cognitive communication assessment in dementia.

Table 7.7 Content Validity of P-CAD

Focus Group	Participant Feedback
1	*"The pictures are clear, but they must be culturally appropriate"*
2	*"I'm thinking now – just looking at (husband)'s communication in a different way. He can read you know. It's the auditory and that, he doesn't get"*
3	*"Knowing the person's communication abilities is important to be able to hear what the person has to say especially in terms of facilitating communication"* *"Using this information, like strong reading comprehension to facilitate the conversation around decisions"* *"Might be used in facilitating conversations about capacity"* *"Consent form will be useful but needs to be at the front of the assessment"* *"Communication assessments like P-CAD could identify a potential dementia"*
4	*"Evaluating attention in the context of communication is appropriate"* *"PSF is useful, you can see your client's profile at the end! "that's my patient"* *"The group concluded that modifying the language used in the questions would be adequate. It was felt that this section (Section 6) will help identify subtle areas of communication ability"* *"The writing section will elicit functional ability"* *"Having qualitative notes is so important"*

7.4.4 Phase1: Recommended P-CAD Revisions

All four focus groups recommended specific changes to P-CAD. These recommendations were categorised and collated to facilitate the process of refinement. P-CAD revisions included; improvements to the administration, the layout, design and content of the P-CAD (see Table 7.8.1 and 7.8.2).

Groups 1 and 2 were particularly interested in the administration of the P-CAD, time involvement, the use of video recordings to analyse conversational ability and the role of the CP in supporting the person with dementia in conversation. Groups 3 and 4 gave more detailed feedback on the face and content validity of the P-CAD. These included the need to use graphic representation of P-CAD scores and specific revisions of the clinician's instructions. Initial revisions were applied after Phase 1 of P-CAD development.

7.4.5 Phase 1 P-CAD: Summary and conclusions

Each focus group gave unique feedback representing their specific opinions and experiences in the context of cognitive communication assessment. There was positive feedback about P-CAD content and its potential to enhance communication ability and facilitate clinical conversations, contributing to improvements in the person with dementia's care experience and the creation of a better communication environment. The overarching themes of "*Communication"* and "*Care"* fit well with the purpose of the P-CAD and reinforce its clinical value as a functional communication assessment.

Recommendations were synthesised and used to guide P-CAD amendments, improving the face, content and ecological validity of the P-CAD. Phase 2 of P-CAD development involved a pilot study carried out by SLTs working with people with dementia. This is described in the next chapter.

Table 7.8.1 Recommended P-CAD Revisions (Phase 2: SLT Focus Group)

Areas for Revision	**Sub-sections for revision**	**Recommend changes**	**Rationale**
P-CAD Administration	Introductory notes Gaining content for videoing	*"Move the consent form to the front of the P-CAD administration and scoring booklet. The following information should be included in the instructions for the test".* Group 4	*"Give an opt out option at the beginning of the assessment"*
		"It is not always appropriate to use video recording, the P-CAD can be completed without videoing the conversation ability section (Section 6). Analysis can be done online in clinical setting" Group 4	*"For clients with advanced dementia videoing may not be appropriate"*
	Sections 1,3 and 5 Clinician's instructions	**Section1:** *"Add a reminder to score the attention section at end of the P-CAD"* Group 3	To improve standardisation
		Section 3: *"Add a written prompt for clinician at the end of the test to score Goodbyes"* (Section 4 Verbal Expression) Group 3	To improve standardisation
		Section 5: *"Improve the instructions and include an administration time"* Group 4	*"The Shopping list is a writing task not a memory task, the instruction should reinforce this"* (see Appendix 7.20)
	Section 6 Conversation Ability	"*Evaluation of the communication partners skills and their impact on the conversation in more detail"* Group 4	*"Analysing the communication of both partners"* (dyadic analysis)

Table 7.8.2 Recommended P-CAD Revisions (Phase 2: SLT Focus Group)

Areas for Revision	**Sub-sections for revision**	**Recommend changes**	**Rationale**
P-CAD layout and design	Test Layout	A range of suggested minor amendments to design and layout were made Group 4	Improve usability for SLTs Increase objectivity
	Profile Summary Form (PSF)	*"Improve cognitive communication level descriptors"* Group 4	
	P-CAD Graph	*"Improve size and locate beside the PSF"* Group 3	*"So that it can easily be copied for the health care record and easily available to the MDT"*
	Picture Stimulus Book	Black and white pictures only Group 3 and Group 4	*"Improve accessibility for those with visual perceptual impairments"*
P-CAD Content	Section 2 Auditory Comprehension Ability	Test Language: remove "Cineplex" from the text in Section 3 and replace with Cinema Group 4 *"Improve how the communication support strategies are written by simplifying the wording and giving examples"* Group 3	Improve accessibility *"Use more culturally neutral language"* *"Improve usability by MDT and family"*

Chapter 8
Phase 2 and 3 P-CAD Development and Refinement

8.1 Introduction

This chapter describes the further development and refinement of P-CAD in Phase 2 and 3. Phase 2 involved a pilot study by SLTs working in dementia care. The research objectives were to obtain feedback on P-CAD from SLTs therefore opinions were sought on; the appearance, design, content and appropriateness of the P-CAD. A further objective of this research phase was to determine its usefulness in the environment for which it was devised. In Phase 3, the assessment underwent final revisions in preparation for the validation process.

8.2 Phase 2: Methodology

A prospective design was used, seeking qualitative information from SLTs on the P-CAD assessment using a questionnaire (see Appendix 8.1). The purpose of this phase of the research was to gain further feedback from SLTs in practice, on the face, ecological and content validity of P-CAD for people with dementia. The researcher was particularly interested in the extent to which P-CAD was subjectively viewed as being appropriate for use as a communication assessment in dementia care (face validity). As well as how useful P-CAD is for use in clinical practice settings (ecological validity) and if P-CAD evaluates the relevant aspects of communication ability in people with dementia (content validity) and if there were any omissions. Ethical approval was obtained from the Research Ethics Committee of the School of Linguistic, Speech and Communication Sciences, TCD (see Appendix 8.2).

8.2.1 Participants and Recruitment

SLTs were recruited via purposive sampling and had at least 3 years clinical experience working in dementia care. These SLTs (n=12) were emailed by a gatekeeper (SLT Department secretary) and provided with information on the

research (see Appendix 8.3). These SLTs had been members of a dementia working group and national dementia research projects, that the research student was also involved in. It was anticipated that at least 5 SLTs would agree to participate in a pilot study. Inclusion and exclusion criteria were applied (see Table 8.1).

SLTs were asked to contact the researcher by email or phone to indicate interest in participation. Initially eight SLTs committed to piloting the P-CAD, subsequently one recruited SLT withdrew due to personal commitments. All the SLT participants (n=7) were working in services for older persons at the time of the pilot study.

Table 8.1 Inclusion and Exclusion criteria

Inclusion Criteria	**Exclusion Criteria**
1. 3 years SLT post-graduation experience	1. SLTs not experienced in dementia
2. Currently working with people with dementia as part of their clinical remit.	3. Inability to complete the P-CAD with people with dementia and their CPs.

8.2.2 Research Instruments

There were 2 research instruments; the P-CAD (Appendix 8.6) and a feedback questionnaire (Appendix 8.1) which contained 16 questions.

8.2.3 Procedure

SLT participants (n=7) were provided with the P-CAD along with instructions on scoring and administration, the anonymous questionnaire and a stamped addressed envelope for return of the questionnaire. The average number of years clinical experience was 16 years (range 3-30 years). Once the SLTs had familiarised themselves with the P-CAD and the stimulus materials, they identified 3 clients with dementia from their caseload who had a known CP and who would benefit from assessment. They administered the P-CAD with the person with dementia (n=3) and their CPs as part of their routine

communication assessment. Completed P-CAD test sheets were not required by the researcher and were held by the SLTs as part of the clinical record.

SLTs were given 4 weeks to complete the P-CAD pilot and questionnaire. They received a reminder e-mail (see Appendix 8.4) 2 weeks before the expected return date. The total time taken to participate in the research per clinician was estimated at 5 hours. This included administration of P-CAD with 3 people with dementia and questionnaire completion.

8.2.4 Data analysis

The returned questionnaires were analysed qualitatively. The data was collated by the researcher onto an Excel spreadsheet for data extraction and then coded to identify areas for P-CAD refinement. Descriptive statistics was used to measure the frequency of SLT responses to questions on appropriateness, ease of use and ability to guide intervention. Content analysis was also used to review open questions and comments representing the views and perspectives of the SLT participants.

8.3 Phase 2: Results

All 7 questionnaires were completed on the P-CAD and returned by the SLT participants. The P-CAD was administered with 19 people with dementia. There were fewer (n=21) P-CAD pilot tests than expected carried out, but each SLT participant administered P-CAD at least twice before completing the questionnaire. This data was then synthesised and thematically coded.

SLT responses to P-CAD were grouped into three key themes along with the underpinning validity type:

1) P-CAD is appropriate for use with people with dementia

2) P-CAD is easy to use

3) P-CAD guides SLT intervention

Feedback was coded according to validity type; face validity (F), ecological validity (E) and content validity (C). SLT feedback also contained some recommendations for P-CAD revisions, that are categorised and described in Section 8.4. Overall feedback on the use of P-CAD for the assessment and

management of functional communication in people with dementia was positive and will be explored in the following sections.

8.3.1 P-CAD is appropriate for use with people with dementia

All SLT participants reported that P-CAD is a useful assessment for people with dementia and their CPs in different clinical practice settings (7/7) (see Table 8.2). P-CAD was identified as a versatile functional cognitive communication assessment by all seven participants. Comments relating to the face, ecological and content validity of P-CAD were identified (see table 8.2). P-CAD communication support strategies are a useful communication therapy resource for SLTs providing conversation therapy.

Table 8.2 P-CAD is appropriate for use with people with dementia

Questions	Responses	Supporting comments
Q 4. Where there any unnecessary items in P-CAD?	No 6/7 Not sure 1/7	
Q12. Usefulness of P-CAD as an assessment tool for PwD?	7/7 rated as quite to extremely useful	*"really practical" (F)* *"specific strategies were helpful" (C)* *"Might be useful for facilitating decision making conversations" (C)* *"It profile's the person with dementia's communication skills" (C)*
Q13. Usefulness of the P-CAD as an assessment tool for the CP?	7/7 quite to extremely useful	*"Section 6 has great potential" (F)* *"Section 6 particularly useful for guiding family members" (E)*
Q15. Is it appropriate for use in a range of settings?	7/7 agreed that it could	*"but more difficult to administer in acute care settings" (E)* *"maybe difficult to find a suitable communication partner" (E)*

8.3.2 Ease of use

All participant feedback commented on how straightforward the P-CAD was to administer (See Table 8.3). Questions 1,2,3,7,8 and 9 all relate to the ecological validity of P-CAD. All seven SLT participants reported that P-CAD was easy or very easy to use (Question 1). Positive responses to Questions

7 and 8 about clear administration instructions and support strategies reinforced that P-CAD is easy to use in clinical practice. Three SLTs reported that they administered and scored P-CAD (Question 2) in less than 60 mins, three other participants administered P-CAD in 30-40 mins and one participant in 20 mins. SLT participants reported that the P-CAD could be completed in 20 to 60 mins in all cases and on subsequent trials administration time was reduced. P-CAD is an "appropriate length" (5/7 responses), however some participants (2/7) felt it was "too long" for use in the acute care setting.

Table 8.3 Ease of use

Questions	**Responses**	**Comments**
Q1. How easy/difficult was the P-CAD to administer?	Quite easy 6/7 Very easy 1/7	"fine once I had done it once" (E) "needed to read through it"
Q2. How long on average did it take you to complete and score each individual P-CAD?	30 to 60 mins 6/7 20 mins 1/7	"with each use I got quicker with administration" (E) "appropriate length" (E) "too long for acute care" (E)
Q3. Rate the P-CAD in terms of length of time to administer?	Appropriate 5/7 too long 2/7	
Q7. Were there any skills or support strategies which you found to be unclear?	No 7/7	
Q8. Were there any parts of the P-CAD you felt were difficult to understand?	No 7/7	
Q9. Please rate how easy or difficult it was to score the P-CAD?	4/7 quite or very easy 3/7 quite difficult	"No sectional sub scores, lots of going backwards and forwards" (E) "be good to have sub totals in each section" (E)

Participants suggested some revisions to the scoring system (Question 9), specifically to include subsection score tables to improve efficiency. All SLT participants reported that the they had no difficulties understanding the test format and sequence of the assessment tasks.

8.3.3 Ability of P-CAD to direct SLT intervention

Questions 5, 11 and 14 sought primarily to explore SLTs views on the content validity of P-CAD. In Question 5, responses were positive (6/7) in relation to the Summary Profile Form and how it can guide management. All participants reported that P-CAD has the potential to detect change in cognitive communication ability in dementia (Question 11).

Participants were asked in Question 14, "Did the P-CAD impact on your clinical decision making or case management?". More specifically participants commented that P-CAD guides therapy planning and intervention, "highlights subtle strengths" and "individualises intervention", as well as providing appropriate communication supports (see Table 8.4). One participant commented that "information elicited and summarised in the P-CAD assessment can be used to identify therapy goals and support clinical decision making", again referring to the relevance of P-CAD in assessing cognitive communication impairments in dementia and how this might guide intervention.

Table 8.4 P-CAD guides intervention

Intervention related questions	**Responses**	**Supporting comments**
Q5. Do you think the Summary Profile Form captures the person's individual communication profile to guide management?	Yes 6/7 No 1/7	"easy to highlight certain areas" (C) "reduced sensitivity at each end of the scale" (C)
Q11. Do you believe that the P-CAD has potential to detect change in communication ability as dementia progresses?	Yes 7/7	"helps with fine tuning strategies" (C)
Q14. Did the P-CAD impact on your clinical decision-making regarding case management?	Yes 4/7 No 3/7	"highlights subtle strengths" (C) "focuses and individualises intervention" (C) "No, but clarified goals" (C) "guides therapy planning" (C)

There were a range of suggestions made to improve P-CAD. The following section describes these amendments.

Research outcomes from Phase 2 of P-CAD development and refinement were in line with Phase 1 findings, reinforcing the face, ecological and content validity of P-CAD.

In the following section, Phase 3 of this research, outlines P-CAD revisions.

8.4 Phase 3 Refinement

Focus group, SLT pilot and expert group feedback was synthesised (see Results section 8.3) to identify areas for refinement. This feedback was grouped into different categories;

1. Artwork revisions
2. Scoring revisions
3. Content revisions

8.4.1 Artwork revisions

Some of the artwork was redrawn by the illustrator to address some ambiguity in the action pictures. The composite picture of a classroom scene (Figure 8.1) was replaced with an original drawing of an everyday family scene in the garden. This alternative composite picture (Figure 8.2) is likely to be more suitable for a wider age range of people. The picture depicts everyday outdoor activities; cutting the grass, pushing a pram and cycling a bicycle. It provides stimulus for some inferential thinking and extended verbal description with 1) a dog chasing a ball onto the road and 2) rain on the horizon.

VE7

Figure 8.1 Initial P-CAD composite picture

VE10

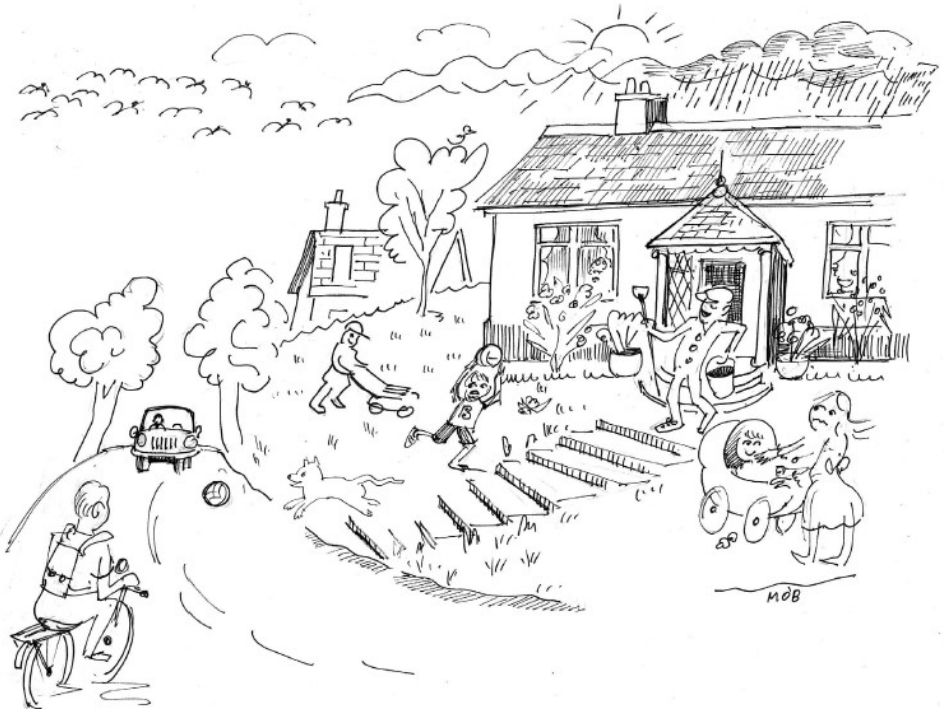


Figure 8.2 P-CAD composite picture final version

Other drawings in the picture stimulus booklet were redrawn also. Picture stimulus cards VE1-6 were improved in terms of scale and the characterisation of the figure (see Appendix 8.5).

8.4.2 Scoring revisions

The scoring system was revised to address specific anomalies that were identified in the scoring summary tables at the end of each section. A new sub test grid was inserted at the end of each section to improve ease of use, so that subtotalling scores might be more efficient for the clinician. These inconsistencies in scoring were identified by the SLT focus group as well as the expert group. These revisions improve the process of scoring up the assessment as well as enabling the SLT to analyse and record the subsection scores as the assessment is being administered. (see Appendix 8.6).

8.4.3 Content revisions

Revision of the initial P-CAD content involved the most significant changes in the refinement phase. The purpose of these revisions was to:

1. increase the focus on non-verbal communication across the test
2. improve language neutrality
3. revise P-CAD Section 6 Conversation Ability to include analysis of the CPs communication skills

1. Increasing the focus on non-verbal communication

SLT participant feedback suggested a greater focus on non-verbal communication in P-CAD. *Section 3, Verbal Expression* was amended and guided by evaluation of non-verbal communication in the FLCI (Bayles and Tomoeda, 1994). The evaluation of non-verbal communication such as pointing, gestures and head nodding was included. Non-verbal responses to a greeting, a compliment and goodbyes will be scored in line with verbal responses.

The focus on non-verbal communication in P-CAD was reviewed and enhanced (see Table 8.5). These changes were applied across the assessment

as well as in the communication support strategies section provided in P-CAD. Non-verbal communication strategies in the facilitation of both auditory comprehension and verbal expression were included.

These P-CAD amendments were made in order to facilitate clinicians in evaluating non-verbal communication. This increased focus on non-verbal communication will enhance the assessment of functional communication skills. Promoting non-verbal communication to enhance everyday interactions will be a part of P-CAD recommendations.

Table 8.5 Inclusion of non-verbal communication

P-CAD Pg. No.	Revised areas
Pg. 10	Note and record communication support strategies and non-verbal communication in the comment section
Pg. 23	Appropriate verbal or non-verbal response such as saying "Thank you" "Goodbye" or a wave of the hand or appropriate natural gesture
Pg. 23	Are you/ Is _____ able to express their/your needs verbally? If no does _____ communicate mainly non-verbally?
Pg. 24	Only communicates effectively with maximum support Unable to consistently express/ demonstrate basic care needs like thirst, pain or express choice Communication is difficult to interpret Mainly non-verbal communication
Pg. 25	Communication partner uses more gesture and non-verbal communication to facilitate comprehension
Pg. 26	Communication partner validates non-verbal communication by responding verbally or non-verbally, such as using mirroring or reflecting techniques

2. Improving the cultural-linguistic neutrality of P-CAD

The influence of language and culture in cognitive assessment has been examined (Ng et al., 2018, Pearson, 2004). P-CAD was developed for use

with English speaking populations. The aim is for P-CAD to be dialect neutral; this was highlighted by the expert group. As part of the refinement process P-CAD was screened for culturally biased language, removing all dialect specific words/phases. For example, in *Section 2 P-CAD*, paragraph level auditory comprehension (see Appendix 8.6) the words "join the queue" were replaced with "join the line". This screening was undertaken in conjunction with Professor Hopper, Speech Pathologist, from Canada. A few problematic words were identified. Alternative options were given for clinicians (see Table 8.6) in the administration and scoring booklet following amendment.

Table 8.6 Language screening for cultural bias

P-CAD Section	Page no.	Initial P-CAD	Final P-CAD
Section 2 Auditory Comprehension	9	"joined the queue"	"joined the line/ queue"
	9	"cinema"	"cinema/movie theatre"
Section 4: Reading Comprehension	19	"Was there loss of life in the accident?"	"Did someone die in the accident?"

3. Revision of Section 6: Conversational Ability

Following Phase 2 and 3 of P-CAD development and refinement, revisions of *Section 6 Conversation Ability* were indicated. Feedback from across the focus groups and the expert group pointed to the importance of assessing functional communication and including non-verbal communication. Focus Group 4 (SLTs) suggested changes specifically to this section including increased attention being paid to the role of the CP in the conversation.

This section of the P-CAD (see Appendix 8.6, Pg.20-22) evaluates an everyday conversation between the person with dementia and their CP. They are invited to have a short conversation on a topic of interest. The clinician uses a discourse grid (see Figure 8.3) to document their clinical notes. This conversation is then videoed with consent and replayed as part of the assessment and subsequent therapy sessions. The initial P-CAD discourse analysis grid evaluated turn-taking, topic initiation and maintenance as well

as communication breakdown and repair. This discourse grid did not incentivise objective analysis and there was little guidance provided on how to rate the person with dementia and the CP as collaborators in the conversation.

A dyadic approach to conversation analysis is well evidence and discussed in Chapters 1 and 2. It is acknowledged that the CP can reveal the communication competence of the person with dementia by adapting their communication style and acknowledging communication potential. This type of communication profiling is important and will measure baseline conversational ability as well as guiding management. Revising the content and design of this section was guided by participant feedback as well as similar scales and approaches used in the analysis of conversation and communication support in aphasia (Kagan et al., 2004, Lock et al., 2001, Perkins et al., 1997). Section 6 revisions may provide clinicians with a more objective tool to facilitate therapy planning.

Firstly, the discourse grid (see Figure 8.3) has been replaced with 2 profiling scales; *Profile 1* is developed to analyse the communication skills of the person with dementia and *Profile 2* analyses the communication skills of their CP (see Figure 8.4 and 8.5). These profiling forms have a similar layout and rating system but evaluate conversation skills from two different perspectives.

***Profile 1*:** Evaluates 5 aspects of conversation ability of the person with dementia. These are comprehension, engagement, expression, resolving breakdown and sharing responsibility for conversation management.

***Profile 2*:** Evaluates 3 aspects of CP communication support. These are recognising communication potential, adjusting communication style and resolving communication breakdown.

Discourse Analysis Grid

	Clinician's notes
Turn-taking	
Topic initiation	
Topic maintenance	
Communication breakdown *Note who signals breakdown	
Communication repair *Note who attempts repair and its effectiveness	

Score	Discourse Skills
3	Evidence of dynamic turn-taking by the client and their PCP. Some initiation by the client. Effective topic management. No evidence of word finding difficulty.
2	Less dynamic turn-taking and topic management communication breakdown is dealt with efficiently and effectively and does not interrupt the conversational flow. Mild word finding difficulty.
1	Some disruption to turn-taking, one partner may dominate. Difficulty transitioning between topics and/or reduced topic maintenance. Communication breakdown is not always resolved efficiently or effectively. Some disruption to the conversational flow. Moderate word finding difficulty.
0	Significant disruption to turn-taking and topic management. Communication breakdowns are frequently unresolved. Severe word finding difficulty.

Total Conversation Ability Score	

Figure 8.3 Discourse Analysis Grid

Profile 1: The Conversation Abilities of the Person with Dementia

Conversation Abilities	0	1	2	3	Score
Attends to and **comprehends** the conversation	Does not attend to and/or seem to comprehend the conversation	Attends to and comprehends less than half of the conversation	Attends to and comprehends more than half of the conversation	Attends to and comprehends all of the conversation	
Engages and **participates** in the conversation with non-verbal communication through use of facial expression, gesture, vocalisations and postural positioning	Does not engage in the conversation through either verbal or non-verbal modalities	Engages in the conversation up to half of the time through either verbal or non-verbal communication	Engages is the conversation over half of the time through either verbal or non-verbal communication	Engages in this conversation all of the time through either verbal or non-verbal communication	
Expresses his/her message verbally/non-verbal effectively (use of greeting, requesting, expresses feelings, commenting, & protesting).	Verbal or nonverbal communicative attempts are ineffective in this conversation	Expresses his/her message effectively less than half of the time during the conversation	Expresses his/her message effectively more than half of the time during the conversation	Expresses his /her message effectively all of the time during the conversation	
Resolving communication breakdown	No attempt to resolve communication breakdown	Tries to resolve miscommunication in less than half of the instances of communication breakdown, even if the conversational flow is not restored in the conversation	Tries to resolve miscommunications in more than half of the instances of communication breakdown even if the conversational flow is not restored in the conversation	Tries and successfully resolves communication breakdown nearly all of the time in the conversation	
Shares the responsibility for conversation management, with their communication partner by establishing, maintaining and progressing the conversation.	No attempts to share, establish, maintain or progress the conversation	Minimal attempts (1-2 within conversation observed) to share, establish, maintain or progress the conversation	Some attempts (more than 5 within the conversation observed) to share, establish, maintain or progress the conversation	Shares equally in the conversation by establishing, maintaining and progressing the conversation	
				Total score(/15) **PCAD Score 12-15=3, 8-11=2, 4-7=1, 0-3=0**	
			Person with dementia Sub score		

Figure 8.4 Conversation Ability Profile 1

Profile 2: The Communication Abilities of their Communication Partner

Ability to acknowledge and support the person with dementia in conversation	0	1	2	3	Score
Recognises the communication **potential** of the person with dementia by trusting their inherent competence to participate in the conversation. This is evidenced by: • Verbal and nonverbal communication that is respectful, inclusive and expectant of engagement • Explicitly or implicitly acknowledging verbal & non-verbal communication attempts • Following their lead in conversation	Does not recognise the communication potential of the person with dementia in the conversation	Recognises the communication potential of the person with dementia less than half of the time	Recognises the communication potential of the person with dementia more than half of the time	Recognise the communication potential of the person with dementia nearly all of the time	
Supports the person with dementia in conversation by **adjusting** their communication style: • slowing down their rate of speech • allowing extra time for the person to respond • avoiding test questions • using communication aids e.g. photos, pen & paper, picture symbols	No helpful adjustments to communication style observed	Adjusts communication style by using appropriate conversational support strategies/aids less than half of the time	Adjusts communication style by using appropriate conversational support strategies/aids more than half of the time	Adjusts communication style by using appropriate conversational support strategies/aids effectively nearly all of the time	
Resolves communication breakdown by: • Clarifying • Repeating • Rephrasing • Simplifying • Using humour	Does not attempt to resolve communication breakdown	Tries to resolve communication breakdown, less than half of the time even if the conversational flow is not restored in the conversation	Tries to resolve miscommunication in more than half of the instances of communication breakdown even if the conversational flow is not restored in the conversation	Tries and successfully resolves communication breakdown nearly all the time in the conversation	
Total Score (_/9) **Observational PCAD Score; 8-9=3,5-7=2, 2-4=1, 0-1(not added to the section score)**					

Figure 8.5 Conversation Ability Profile 2

The video recorded conversation is rated using Profiles 1 and 2. Both conversation ability profiles are rated across 4 levels, scored from 0-3, (0= skill not observed to 3= skill always present). Only the Profile 1 (The conversation abilities of the person with dementia) score is incorporated into the subsection score for the overall P-CAD score. Section 6 Conversation Ability has developed into an objective conversation profiling tool. It has potential to be used as a standalone tool to evaluate the conversational ability of the person with dementia but will require further testing in this regard. This will be discussed further in Chapter 10 (section 10.5).

The new communication profiling scale was developed to evaluate the communication skills of both CPs. This major revision acknowledges the important role the CP plays in providing a framework for conversation.

8.5 P-CAD development and refinement summary

Feedback from all the key stakeholders shaped the final P-CAD assessment. Recommendations from the expert group, user groups and SLTs in clinical practice guided the development and refinement process. The final P-CAD a more user-friendly and objective assessment for use with people with dementia. Participant feedback affirmed that the P-CAD has clinical value, is easy to administer and guides intervention. The P-CAD was revised over a 12-month period. The following section will describe the final version of P-CAD that will be used in the validation study.

8.6 The Final P-CAD

The P-CAD (see Appendix 8.6) assessment profiles the functional communication ability of the person with dementia.

The purpose of the P-CAD is to help clinicians to achieve the following:

1. To evaluate comprehensively the communication abilities of individuals with dementia

2. To develop a profile of the communication strengths and weaknesses of the person with dementia

3. To measure change in communication abilities of the person with dementia over time

4. To directly guide intervention.

The P-CAD assessment evaluates the individual's functional communication ability by screening eight cognitive communication domains.

Table 8.7. P-CAD Domains

Section 1: Attention ability	**Section 5: Writing ability**
Section 2: Auditory comprehension ability	**Section 6: Conversation ability**
Section 3: Verbal expression ability	**Section 7: Communication support strategies ability**
Section 4: Reading ability	**Section 8: Functional communication ability**

The P-CAD uniquely combines the assessment of language, functional communication ability and ability to compensate for declining cognitive–linguistic skills. Communication between the person with dementia and their CP is video recorded in Section 6 and then evaluated to inform the overall communication profile. Total administration and scoring of the P-CAD takes approximately 30 minutes. P-CAD. Picture and Reading Stimulus Book (see Appendix 8.5) is provided and used throughout the assessment. It contains stimulus pictures and the reading comprehension subtests.

Once completed the assessment is reviewed and scored by the SLT. The maximum total P-CAD score is 24 (higher being better). Some individualised communication support strategies can then be selected and recommended from those provided in the back of the assessment booklet. For clients who communicate non-verbally the focus of the assessment is Sections 6, 7 and 8. Full instructions for administration and scoring are in the administration and scoring booklet.

Section 1: Attention ability

Attention is the ability to focus on certain aspects of the environment that one finds interesting and to flexibly manipulate this information. It is important to note that alertness and arousal are prerequisites for attention. A model of attention is provided to guide the clinician (Sohlberg and Mateer, 1989).

The attention score is determined by the clinician's subjective assessment, based on observation, of how the individual's attention capacity is affecting their communication ability over the course of testing. The section has been placed at the beginning of the assessment to remind the clinician to evaluate attention throughout the test. Observe for the person's ability to stay on task, to respond to verbal instructions, the level of redirection required, their ability to focus and keep track in the conversation section and any CP feedback regarding attention skills.

The level at which attention impacts on communication is rated as; consistently impacts, frequently impacts, occasionally impacts or no impact within normal limits. This section of the evaluation should be completed at the end of the assessment.

Section 2: Auditory comprehension ability

Auditory comprehension is screened at four different levels. These graduated auditory comprehension tasks reflect existing language batteries in assessment in acquired brain injury the Western Aphasia Battery (WAB) (Kertesz, 2006) and the Measure of Cognitive Linguistic Ability (Ellmo et al., 1995b). These tasks scale up from auditory single word comprehension to auditory paragraph comprehension. The clinician is guided to discontinue testing if the client stops responding in tasks or is having marked difficulty.

Item 1: Word picture matching: matching 3 heard words and pictures

Item 2: Following verbal instructions: response to one stage and two stage verbal instructions

Item 3: Answering questions: response to 3 questions of increasing syntactic complexity and length

Item 4: Paragraph level auditory comprehension: answer yes/no questions having listened to a short story entitled "A Night Out". There are factual questions (Questions 1,2, and 3) and inferential questions (Questions 4 and 5) in this sub section.

Section 3: Verbal expression ability

This section has three subsections evaluating verbal expression. The difficulty level increasing as this section progresses and the clinician can discontinue testing when required. Black and white picture drawings are used to facilitate visual processing.

Greetings and Goodbyes (Item 1) this section allows for the evaluation of verbal and non-verbal interaction, including greeting and leave taking. Confrontation naming of nouns and verbs (Item 2) using drawn objects and action pictures. Low, medium and high frequency words are represented along with action pictures e.g. walking, reading.

The picture description task (Item 3) allows for expanded verbal expression in response to a black and white drawing of a busy family scene in the country. Similar stimulus pictures used in other language focused assessments are those in the Boston Diagnostic Aphasia Examination (Goodglass et al., 2001) and the WAB (Kertesz, 1982). The black and white high contrast image was chosen to support those with visual perceptual deficits This task evaluates sentence formation, syntax, language content, narrative cohesion, word finding difficulty, use of compensatory strategies and non-verbal communication. The client's verbal response to the picture is graded with scores from 0-4; no meaningful attempt (0 points) to a comprehensive picture description (4 points). The scoring here is guided by the scoring descriptions given on the test form and the judgement of the clinician.

Section 4: Reading ability

Reading comprehension is evaluated at word, sentence and paragraph level. The development of this section was guided by a well-established reading comprehension assessment, the Reading Comprehension Battery of Aphasia (LaPointe and Horner, 1998). A short functional reading task is included

which involves reading the label of a tablet box as well as a newspaper article. Importantly the person with dementia can reread and review all the stimulus cards including the newspaper article to find their answer, this is a reading comprehension assessment and is not designed to specifically test memory.

Section 5: Writing ability

Five sections that review functional writing ability. Tasks difficulty ranges from writing their name, a shopping list and a birthday card. The shopping list (5 items) is written down item by item when called out by the clinician, to facilitate reduced short-term memory loading. There is a birthday card template included on the testing form to be completed.

The focus is on retained writing skills, so there are partial marks given when there are errors such as spelling errors or poorly formed letters.

Section 6: Conversation ability

A short conversation between the person with dementia and their CP is video recorded and analysed using the P-CAD conversation ability profiles 1 and 2. This video can be recorded in clinic or by the CP at home. The analysis examines the conversation abilities of the dyad, evaluating the communication skills of the communication partner also and their ability to adjust their communication style to facilitate the conversation. This section provides an opportunity to observe the functional communication skills of the person with dementia.

Section 7: Communication support strategies

This final section examines how the person with dementia, with his/her CP uses compensatory strategies to support communication. The video recording gives the clinician an opportunity to evaluate their communication in more detail. The clinician reviews; awareness of communication breakdown, communication support strategies used and their effectiveness. The client's awareness of communication challenges and evidence of adaptation in conversation. The clinician rates the use of strategies as occasional, frequent or consistently used. When a recorded conversation is not possible the clinician can observe and evaluate the use of communication support

strategies between the CP and the person with dementia while conversations are taking place, during the assessment session.

Section 8: Functional communication ability

The client's functional communication ability and the required level of support will have been assessed on an ongoing basis throughout the assessment. This section of P-CAD investigates the person with dementia's participation in everyday communication activities. Reviewing the person with dementia and CP perspectives on communication strengths and challenges. The development of this section was influence by a wide range of tools such as the Communication Disability Profile (Swinburn et al., 2006), the Communication Effectiveness Index (Lomas et al., 1989) and the ASHA FACS (Fratalli et al., 1995)guided. The score given is based on the clinician's subjective opinion of the client's functional communication ability along with feedback from the CP.

Clinical decisions will be informed by:

- Discussion with the client and their CP as to how dementia is impacting on the person's ability to function independently in a range of communication situations.
- Some questions are provided to facilitate this conversation e.g. What are your greatest communication strengths? and What helps you?
- How the client and their CP communicated with each other and the clinician during the evaluation.

8.6.1 P-CAD Profile and Summary Forms

There are a set of P-CAD forms included in the assessment booklet which are used to chart communication profiles. These are described and included in the following section:

1. P-CAD Scoring Form
2. P-CAD Total Communication Profile
3. P-CAD Summary Profile Form (with graph)

1. P-CAD Scoring Form

The raw scores are inserted into the subsection grids at the end of each P-CAD section and then transferred to the scoring form (see Figure 8.6) in the booklet. The clinician can then determine the level of communication support that the client requires for the eight cognitive communication domains. For example, a score of 4- 6 is attained in reading comprehension ability section then this is an impairment score of 1, which is classified as a moderate reading impairment.

2. P-CAD Total Communication Profile

This form profiles functional communication ability and level of communication support required (see Figures 8.7.1 and 8.7.2). It contains descriptions of communication abilities across cognitive communication parameters and guides selection of communication support strategies. This form can be made available along with the P-CAD Summary Profile Form to health care and speech and language therapy records.

3. P-CAD Summary Profile Form

Communication between the person with dementia and their CP is evaluated and used to inform the overall communication profile. Having completed the scoring form, transfer the P-CAD score and the complete the graph on the summary profile form (see Figures 8.8 and 8.9). It will show the client's individual communication profile. The clinician documents the communication abilities and communication support strategies on the summary profile form.

P-CAD Scoring Form

Cognitive Communication Skills		Normal Function	Mild Impairment	Moderate Impairment	Severe Impairment	P-CAD Grading Score
Grading Score		**3**	**2**	**1**	**0**	
1. Attention Ability						
Impact of impaired attention on Communication Ability		No impact on communication	Occasionally impacts on communication	Frequently impacts on communication	Consistently impacts on communication	
Total Grading Score		3	2	1	0	**/3**
2. Auditory Comprehension Ability						
Word picture matching	3					
Following verbal instructions	3					
Answering questions	3					
Paragraph comprehension	5					
Total Raw Score	/14	13-14	9-12	5-8	0-4	
Total Grading Score						**/3**
3. Verbal Expression Ability						
Greetings & Goodbyes	3					
Naming: Confrontation	4					
Picture description	4					
Total Raw Score	/11	10-11	7-9	4-6	0-3	
Total Grading Score						**/3**
4. Reading Comprehension Ability						
Word level reading	3					
Sentence level reading	3					
Functional level reading	3					
Paragraph level reading	3					
Total Raw Score	/12	11-12	7-10	4-6	0-3	
Total Grading Score						**/3**
5. Writing Ability						
Writing name	1					
Writing a shopping list	3					
Writing a sentence	2					
Completing birthday card	4					
Total Raw Score	/10	9-10	6-8	3-5	0-2	**/3**
6.Conversation Ability (Profile 1: Person with Dementia)		3 Normal function	2 Mild impairment	1 Moderate impairment	0 Severe impairment	**/3**
7. Communication Support Strategies		3 Normal function	2 Minimum Communication Support	1 Moderate Communication Support	0 Maximum Communication Support	**/3**
8. Functional Communication Ability		3 Normal function	2 Mild impairment	1 Moderate impairment	0 Severe impairment	**/3**
				Total P-CAD Score		**/24**

Figure 8.6 P-CAD Scoring Form

Profiling Communication Ability in Dementia P-CAD
Total Communication Profile Form

Client_____

MRN_____

AFFIX HOSPITAL LABEL HERE

Date of Assessment _____

Speech & language Therapist _____

COGNITIVE COMMUNICATION ABILITIES	NORMAL RANGE OF FUNCTION SCORE=0	MINIMUM COMMUNICATION SUPPORT SCORE=1	MODERATE COMMUNICATION SUPPORT SCORE=2	MAXIMUM COMMUNICATION SUPPORT SCORE=3	SCORE 0-3
1.Attention Ability	**No reported change from baseline attention and concentration skills**	Reduced attention impacts **occasionally** on communication ability • Stable focused and sustained attention throughout the evaluation • Lapses of selective and alternating attention observed during evaluation	Reduced attention impacts **frequently** on communication ability • Sustained attention of periods up to 10-15 minutes observed during the evaluation • External cuing needed to support attention beyond this level	Reduced attention **consistently** impacts on communication ability • Can focus attention with stimulation • Fluctuating levels of alertness observed during the evaluation • May be drowsy	
2.Auditory Comprehension Ability	**Auditory Comprehension skills are within the normal range**	**Understands all but the most complex conversations** • Can understand verbal communication in a range of interactions • Has subtle auditory comprehension difficulties with lengthy & complex information • Clarifies meaning occasionally	**Understands everyday conversations** • Can understand spoken words and follow verbal instructions most of the time. • Will have some difficulty with two - three stage verbal instructions • Clarifies meaning frequently	**Basic understanding is inconsistent** • May understand some everyday spoken words and phrases • Gets most meaning from the speaker's intonation, visual and situational clues • Pictures enhance verbal comprehension	
3.Verbal Expression Ability	**Verbal explanatory skills are within the normal range**	**Mild reduction in verbal expression** • May experience mild word-finding difficulty in conversation but can self-cue • Can give verbal explanations but they may lack detail • Can express a wide range of opinions and ideas but these may lack some cohesion	**Moderate reduction in verbal expression** • Word finding difficulties more obvious in spontaneous speech • Vocabulary is restricted but he/she will use circumlocution. • Verbal expression can be repetitious, incomplete or contain "empty" words	**Little or no verbal communication** • May respond appropriately to a greeting or compliment • May produce automatic and/or imitative words and phrases • Uses pointing, voice or use gesture to express needs	
4.Reading Comprehension Ability	**Normal Function** No reading comprehension difficulties identified or reported	**Competent Reader** • Requires extra time to process written material • Understands written factual information at paragraph level (250 words) but increased difficulty with more complex material • Reads a wide range of print material	**Functional Reader** • Understands familiar written words and sentences for meaning but increased difficulty beyond level. • Understands newspaper headlines, calendars, bank statements, prescriptions etc. • Needs to re-read text for comprehension	**Non-Reader** • Unable to read meaningfully • May visually scan a newspaper, letter or greeting card if supported • May occasionally read words aloud	
5.Writing Ability	**Normal Function** No writing difficulties identified or reported	**Competent Writer** • Writes sentences but will have increasing spelling errors • Mechanics of writing and spelling are mildly impaired • Will text and/or send e-mails	**Functional Writer** • Writing restricted to name, address and everyday words • Mechanics of writing and spelling ability will be significantly impaired	**Non Writer** • Unable to write meaningfully	

Figure 8.7.1 P-CAD Total Communication Profile

6. Conversation Ability	**Normal function and Communication load is balanced** both partners contribute equally to the conversation	**Communication is slightly imbalanced** • Minor imbalance in turn taking and topic management in conversation • Miscommunications are quickly resolved • The PCP carries a little more than half of the communication load/responsibility for the conversation	**Communication is moderately imbalanced** • A moderate imbalance in turn-taking and topic management in conversation • Miscommunications not always resolved • The PCP carries most of the communication load	**Communication is totally imbalanced** • A significant imbalance to turn-taking and topic management in conversation • Communication breakdown frequently unresolved • The PCP carries nearly all of the communication load	
7. Functional Communication	**Communication ability is within the normal range**	• **Communicates independently** in a range of communication situations with familiar and unfamiliar communication partners • Converses **freely** in most situations • May be challenged by group conversations	• **Engages competently** in social exchanges with familiar communication partners • Consistently able to make needs known and conveys more information than this • Copes with one: one conversations most of the time with support	**Dependant Communicator** • Unable to consistently express/ demonstrate basic care needs like thirst, pain or express choice • Communication is difficult to interpret • Mainly non-verbal communication	
8. Communication support strategies	**Communication support strategies not required**	• The client is aware of and will cover up communication errors • **Occasional** use of support strategies required to facilitate communication • Both partners use communication support strategies effectively to facilitate communication	• The client is not always aware of communication breakdowns • **Frequent** use of support strategies required to facilitate communication • Both partners use communication support strategies inconsistently to facilitate communication	• No evidence of awareness of communication errors • **consistent** use of support strategies required to facilitate communication • Client has limited or no use of effective compensatory strategies	
				P-CAD Total Score	
			Level of communication support required	**0-6 None** **7-12 Minimum** **13-18 Moderate** **19-24 Maximum**	

Communication Abilities	**Communication Support Strategies**
1.	**1.**
2.	**2.**
3.	**3.**

DO NOT COPY

Figure 8.7.2 P-CAD Total Communication Profile

P-CAD Summary Profile Form

Date of Assessment _____ Date of Re-assessment _____ P-CAD SCORE _____

Level of communication support required: **Minimum Moderate Maximum SLT _____**

COGNITIVE COMMUNICATION ABILITIES		**NO COMMUNICATION SUPPORT REQUIRED**	**MINIMUM COMMUNICATION SUPPORT**	**MODERATE COMMUNICATION SUPPORT**	**MAXIMUM COMMUNICATION SUPPORT**
1	Attention Ability	No reported change from baseline attention and concentration skills	Reduced attention impacts occasionally on communication ability	Reduced attention impacts frequently on communication ability	Reduced attention consistently impacts on communication ability
2	Auditory Comprehension Ability	No auditory comprehension difficulties identified or reported	Understands all but the most complex conversations	Understands everyday conversations	Basic understanding is inconsistent
3	Verbal Expression Ability	No verbal language difficulties identified or reported	Mild reduction in verbal language	Moderate reduction in verbal language	Little or no verbal communication
4	Reading Comprehension Ability	No reading comprehension difficulties identified or reported	Reads all but the most complex material	Basic reading ability is intact	Little or no reading comprehension
5	Writing Ability	No writing difficulties identified or reported	Writes all but the most complex	Basic writing ability is intact	Little or no writing ability
6	Conversation Ability	Conversation is dynamic in relation to initiation, turn-taking and topic maintenance.	Conversation is mostly dynamic	Conversation is sometimes dynamic	Conversation is rarely dynamic
7	Functional Communication Abilities	Communication ability is within the normal range	Communicates independently almost always	Communicates independently frequently	Communicates independently occasionally
8	Communication support strategies	Communication support strategies not required	Occasional use of support strategies required to facilitate communication	Frequent use of support strategies required to facilitate communication	Consistent use of support strategies required to facilitate communication

Communication Abilities	**Communication Support Strategies**

Figure 8.8 P-CAD Summary Profile Form

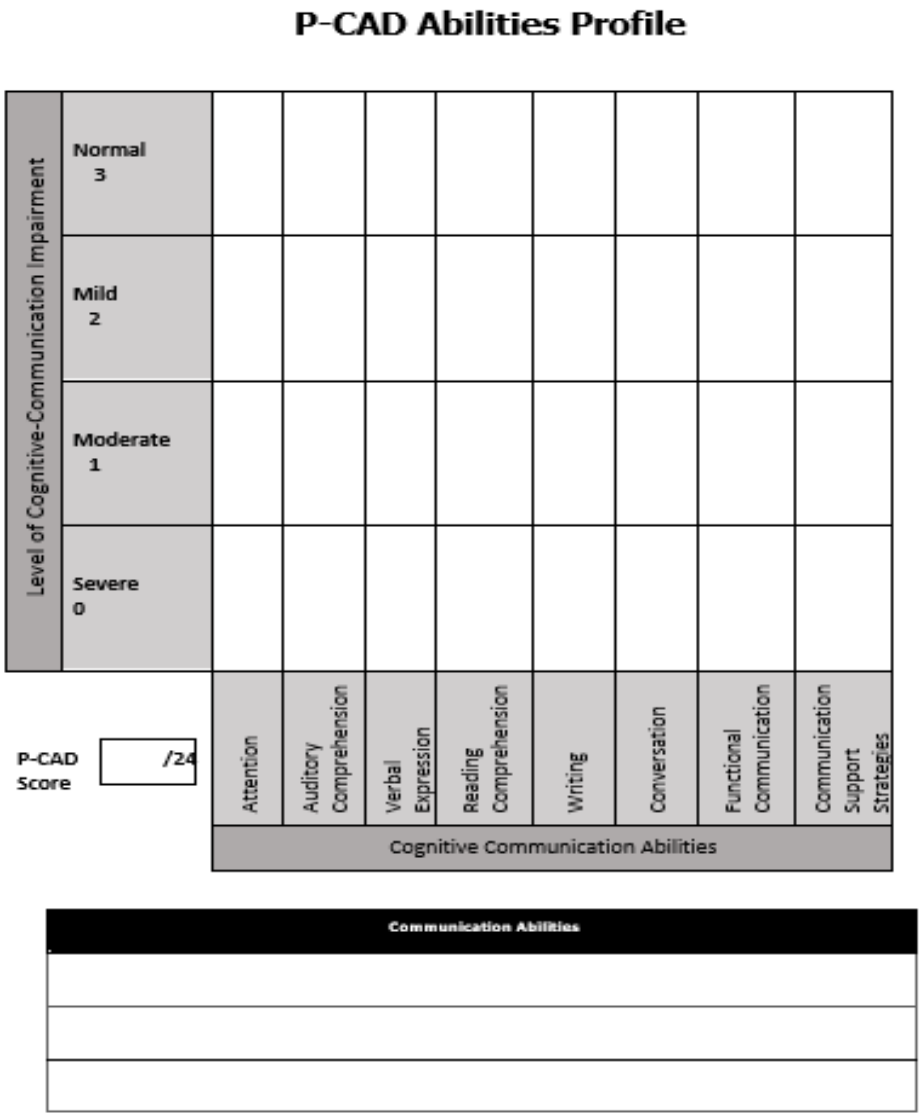


Figure 8.9 P-CAD Summary Profile Graph

3. P-CAD Summary Profile Form and Graph

Communication between the person with dementia and their CP is evaluated and used to inform the overall communication profile. Having completed the scoring form, transfer the P-CAD score and the complete the graph on the summary profile form (see Figures 8.8 and 8.9). It will show the client's individual communication profile. The clinician documents the communication abilities and communication support strategies on the summary profile form.

8.7 P-CAD Refinement and development has been completed

This revised and improved assessment was now ready for validation with people with dementia and their CPs. There is an administration and scoring booklet and a picture stimulus book (see Appendices 8.5 and 8.6). The complete validation study will be described in the following chapter.

Section 4: P-CAD Validation and Implications for Research and Clinical Practice

Chapter 9
Validation of the Profiling Communication Ability in Dementia Tool

9.1 Introduction

In the previous chapters the phases of P-CAD development and refinement were described. These phases were the foundation of the P-CAD validation study. The current research questions are as follows:

1. What is the validity and reliability of the P-CAD?

2. Is it sensitive to change in the person with dementia's communication ability over time?

This chapter describes the validation of the P-CAD involving 100 people with dementia and their CPs in Ireland. The reliability of the P-CAD was tested for consistency of scoring between SLTs and sensitivity to change in communication ability over time. At the end of this process, the goal is that the P-CAD will be a reliable and functional cognitive communication assessment for people with dementia.

9.2 Methods

This was a prospective cross-sectional study examining the concurrent validity of the scale, inter rater reliability and its sensitivity to detect change overtime. Validity and reliability testing were conducted concurrently. Ethical approval was sought and granted from the Ethics Committee of the School of Linguistics, Speech and Communication Science, Trinity College Dublin (TCD) and the Joint SJH/AMNCH Research Ethics Committee (see Appendix 9.1). Methods employed to evaluate validity and reliability were quantitative.

A sample size of one hundred participants with dementia and CPs was calculated for 5% level of significance and 80% power to detect a meaningful statistical difference in a given sample size. There was a conservative assumption of equal percentage of responses across 3 categories of severity

of dementia (mild, moderate and severe). Convenience sampling was used at the outset to recruit people at different stages of dementia. Purposive sampling was used later in the project to specifically recruit people missing from the population profile.

9.2.1 Participants

There were two groups of participants;

1. **People with dementia:** One hundred people with dementia were recruited. It was planned to have a minimum of 10 people across each stage of dementia and a range of sub types of dementia (AD, EOAD, VaD, LBD, DPD, FTLD and mixed dementia).

2. **CPs:** One hundred CPs/carers of the people with dementia participating in the study were recruited. Each person with dementia in the study had an assigned CP.

A balance of male and female participants was sought. Potential hospital-based participants were current in-patients and outpatients. Community-based participants were clients of the *Living Well with Dementia* services (community-based pilot projects to support people with dementia to continue to live at home and participate in their own communities) and their CPS. Those living in residential units affiliated with level 1 and 2 hospitals in HSE Community Units were included. CPs were family members and professional carers. Inclusion/exclusion criteria (see Table 9.1) were applied.

9.2.2 Recruitment

9.2.2.1 Research sites

Recruitment took place across the Health Service Executive (HSE). The research recruitment sites were:

- 3, Level 1 Hospitals in Dublin
- 2, Level 2 Hospitals in Dublin/ Wicklow
- 4, HSE community residential units in Dublin
- 2, Living Well with Dementia communities in Dublin and Southern Ireland

Table 9.1 P-CAD Inclusion and Exclusion Criteria

People with dementia (n=100)	Communication partners (n=100)
Inclusion Criteria	
Confirmed diagnosis of dementia	Person who is well known to the person with dementia and has contact with at least twice per week.
18 years +	18 years +
High proficiency of English as the tests used in the validation of the P-CAD are validated on English speakers. English as a first language.	High proficiency of English Ability to converse easily in English with the research student
If unable to provide written or verbal informed consent, then person must either be able to indicate assent or have a nominated person who can provide consent on their behalf.	Ability to give written and verbal consent to participate.
Medically stable	
Exclusion Criteria	
Premorbid conditions associated with cognitive linguistic impairment that differ from those associated with dementia (e.g. traumatic brain injury, intellectual disability). People with primary progressive aphasia (PPA) were also excluded, as language is the primary impairment in early PPA with preserved cognition.	
Medically unstable	
Presence of severe visual impairment (E.g. macular degeneration)	
Profound hearing loss	
Severe motor speech disorder that may elicit a different communication profile.	

9.2.2.2 Recruitment Process

The planning and co-ordination of the recruitment process was guided by feedback from the expert group. Early expressions of interest to facilitate recruitment were made by the team leaders from the *Living Well with Dementia* community projects and the SLT managers at the research sites. The gatekeepers were then formally invited to participate in the project and a letter seeking access was sent to them (see Appendix 9.2).

The recruitment process involved emailing potential participants. Accessible versions of the introductory letter, the PIL and consent forms were made available to potential participants. They were provided with study details in an introductory letter (see Appendices 9.3.1 and 9.3.2), a participant information leaflet (PIL) (see Appendices 9.4.1 and 9.5.1) and a consent form (see Appendices 9.4.2 and 9.5.2). Potential participants were given the opportunity to discuss the study with a member of the research team to inform the consent process.

Different approaches to recruitment were undertaken depending on the research site and community service. For the *Living Well with Dementia* groups, the gatekeepers disseminated the PIL by email to carers and people with dementia on their mailing lists who met the P-CAD inclusion criteria. The researcher was available on request to provide further information about the project at a carers' meeting. In other settings gatekeepers distributed the research information to people with dementia and their CPs linked in with their speech and language therapy service, memory or residential services.

9.2.3 Ethical Considerations

9.2.3.1 Anonymity

A participant study number was issued ensuring non-disclosure of identifying information for the participant dyad (person with dementia and their CP). All personal and potentially identifiable information was linked to this study number and stored in a password-protected folder on a secure TCD server. Access to this folder was restricted to the researchers (research student and an SLT colleague). This folder was located separately from the study data which was identified by a study number only.

If a participant wanted to withdraw from the study at any point or if he/she were unable to participate for any reason it was possible for the researchers to trace the relevant information and delete it from the folder. This occurred with two participants with dementia during data collection. One person became unwell and the other withdrew consent to participate during communication assessment. All data for these two individuals was removed by the researcher from the database and not included in data analysis phase.

Digital data (i.e. audio and video files) from the P-CAD (sections 3 and 6) were transferred from the portable recording device to a password-protected folder on a secure TCD server in the Department of Clinical Speech and Language Studies. This study followed **EU Directive 95/46/EC** http://www.dataprotection.ie/docs/EU-Directive-95-46-EC/89.htm to ensure that personal data was treated in line with that legal directive. In terms of protection of personal data this research project enforced the EU Regulation 2016/679, (Directive 95/46/EC) on General Data Protection Regulation on privacy, electronic communications and data storage. All portable media storage devices were encrypted.

9.2.3.2 Autonomy

Gatekeepers facilitated recruitment of people with dementia and their CPs. SLT managers, Clinical Nurse Managers (CNMs), medical consultants and department secretaries in these locations acted as gatekeepers for the people with dementia and their family carers. None of the SLT Managers appointed as gatekeepers had previous direct contact with the potential participants, all the other gatekeepers would have clinical or administrative contact with potential participants.

An accessible version (simplified and visually enhanced) of the PIL and Consent forms (see Appendices 9.3 -9.4) were provided to the participants with dementia. These documents were formatted according to the guidelines for accessible documents used in TCD, https://www.tcd.ie/about/policies/accessible-info-policy.php#print.

Opportunities for discussion and further information were also offered where needed. The researcher obtained written and/or verbal consent from the participants in advance. This process was guided by the Assisted Decision-Making (Capacity) Act 2015 (Oireachtas, 2015). The service user's agreement to participate in the research study was documented by their signature (or mark if unable to write) on the consent form (appendix 9.4). As anticipated some participants were unable to give written consent but gave their consent verbally and/or non-verbally. The researcher documented that they had given consent through verbal and/or non-verbal means, for example through use

of an augmentative-alternative communication system such as a Yes/No chart.

When participants with dementia were unable to give consent due to reduced decision-making ability, the researcher contacted their registered decision-making representative or person with enduring power of attorney. The CP decided on participation based on the will and preferences of the person with dementia. The researcher reiterated to participants that participation involved being video recorded in short conversation with a conversation partner. Specific consent was requested in this regard as some clients may not agree to being video recorded. Those who did not consent to video recording were still included in the study. If the person with dementia was unable to consent and did not have a legal decision-making representative appointed, then participation in the research was not sought.

9.2.4 Research Instruments

A proforma and seven research instruments were used. The research instruments were chosen in consultation with the expert group. These were used to screen for study inclusion, measure concurrent validity and recording equipment (see Table 9.2).

A proforma (see Appendix 9.6) cataloguing the person with dementia's unique participant code, age, gender, type of dementia, stage of dementia, the presence of co-morbid conditions such as hearing impairment, visual deficit, level of education and depression was recorded at the beginning of the data collection session. Years of education were calculated based on 7 levels of education outlined on the proforma and ranged from primary school (Level 1) to completing post graduate studies (Level 7).

9.2.4.1 The Single Word Speech Recognition Screening Test (SWSRT)

The Single Word Speech Recognition Screening Test (SWSRT) (Boothroyd, 1985). This test was used to screen for significant hearing loss that may impact on test administration and scoring. People with dementia who achieved 50% accuracy or higher on the word test were included in the study.

Those with severe hearing loss were excluded, as this level of hearing deficit would impact on the validation process.

9.2.4.2 The 2-Question Test

This 2-Question test (Whooley, 2016) was used to screen for depression, which may impact on test administration and scoring. Presence of comorbid conditions such as depression would not exclude a participant, but a history of their depression and treatment were noted for the data analysis phase to determine potential impacts on test performance. The participants with dementia were asked two yes/no questions. These were "During the last month, have you often been bothered by feeling down, depressed or hopeless?" and "During the last month, have you often been bothered by having little interest or pleasure in doing things?".

9.2.4.3 The Mini-Mental State Examination (MMSE-2)

The Mini-Mental State Examination (MMSE-2) (Folstein et al., 2010) was used to rate the severity of the dementia and to evaluate the diagnostic accuracy and sensitivity to change in cognitive function independent of the P-CAD over time. The MMSE-2 takes 5-8 minutes to complete and comprises of subtests to evaluate attention, orientation and short-term memory primarily. It is widely used as a research instrument in dementia studies.

9.2.4.4 Profiling Communication Ability in Dementia (P-CAD)

This newly developed cognitive communication tool evaluates the individual's functional communication ability by screening eight cognitive communication domains. A full description of the P-CAD was provided in Chapter 8.

9.2.4.5 The Functional Linguistic Communication Inventory (FLCI)

The FLCI (Bayles and Tomoeda, 1994) evaluates the functional communication of people with dementia. It was validated with people with Alzheimer's disease with moderate to severe cognitive decline as defined by the Functional Assessment of Staging in Alzheimer's disease (Sclan & Reisberg 1991). The scoping review in Chapter 5 included the FLCI. It assesses functional aspects of communication including; greeting/naming,

answering questions, writing, auditory and reading comprehension, following commands, reminiscing, gesture/pantomime. The FLCI takes approximately 30 minutes to complete and it is the only published test available that examines similar domains to the MMSE-2. It was validated with people with moderate to severe dementia but can be used in early stage dementia.

Table 9.2 Summary of Research Instruments

Research Instruments		**Purpose**	**Rationale**
Screening Measures	**1.Single Word Speech Recognition Screening Test (Boothroyd, 1985)**	To screen for significant hearing loss	Hearing loss would impact on test administration and scoring
	2.The 2-Question Instrument (Whooley et al., 1997)	To screen for depression	Depression may impact on test administration and test outcomes
	3.Global Deterioration Scale (Reisberg et al., 1985)	To determine stage of dementia	To guide participant recruitment and inform P-CAD testing
Outcome measures	**4.MMSE-2 (Folstein et al., 2010)**	To evaluate cognition	Determine level of cognitive impairment (unless completed in the previous 2 weeks and where the person with dementia is medically stable)
	5.P-CAD Assessment	To evaluate functional cognitive communication ability	To test validity as well as generate communication support strategies
	6. FLCI (Bayles and Tomoeda, 1994)	To evaluate functional communication ability	To establish concurrent validity
Recording equipment	**7. Video recorder (Sony FDR-AX53)**	To audio and video P-CAD Sections 3 and 6	Record a conversation for discourse analysis (Section 6) and transcribe the picture description narrative (Section 3)

9.2.4.6 The Global Deterioration Scale (GDS)

The GDS (Reisberg et al., 1985) is an observational-based scale that defines seven stages of cognitive decline associated with dementia (see Appendix 4.6). This scale was selected to measure the progression of the dementia and to identify which stage of dementia the person had reached. This staging guided participant recruitment and validation of the concurrent validity of the P-CAD (see section 9).

9.2.5 Data Collection

Assessments were administered in the participants with dementia's place of residence or in the outpatient department of the research hospital. All testing was done in a quiet well-lit room. The researcher and an SLT colleague collected the data. This SLT colleague was involved in the inter rater assessment sessions (n=20) only, the researcher carried out all other aspects of data collection in this validation study.

Participants with dementia completed the cognitive and communication screening and assessments described below (research instruments 1-6). The assessment process took approximately 1½ hours and was undertaken in one sitting for most participants (n=98). The assessment protocol (see Figure 9.1) describes the data collection procedure carried out over one session with a refreshment break. Where indicated, assessments were administered over two sessions: for example, if the participant was fatigued or became unwell during data collection. There were only two participants in the study that required two separate assessment sessions and the data collection protocol for these two participants was the same, in every other respect.

There were 15 participants with dementia with self-identified hearing difficulties. Fourteen of these participants wore hearing aids for the assessment and 1 person who reported having a hearing loss participated in assessment without any amplification. CPs were present during data collection and had direct involvement in the completion of the GDS and the P-CAD. The SLT research colleague was involved in the retesting sessions of 12 participants at the 3-month time point.

The participant's biographical information, testing dates and details were inserted onto the Proforma and then the hearing and depression screening tools were administered. The tests were administered in the following sequence; MMSE-2, P-CAD, FLCI, GDS. A voice recorder (Sony ICDUX-580) was used to record the Picture description in P-CAD Section 3.3. Section 6 Conversational Abilities of the P-CAD was video recorded (with consent) using a handheld Sony HDR CX450. The participants were asked to have a short conversation for approximately 3-5 minutes about something happening in their day, hobbies or pets. They were invited to watch the video recording during the assessment session with the researcher. Initial conversation analysis was done at this time during data collection to enable preliminary feedback to be given to the participants at the end of the session. This feedback related to communication support strategies and suggestions on modifying communication. Recommendations on communication support strategies were given verbally and written feedback provided to the participants (see Appendix 9.10) at the end of the assessment session. The assessment feedback did not form part of the validation study. It was an opportunity for the participants to receive some advice regarding communication challenges. The videoed conversation (P-CAD, Section 6 Conversation Ability) was reviewed and scored at the end of data collection when all the assessments were being scored.

9.2.6 Validity testing

Development and refinement of P-CAD (Chapters 6,7 and 8) focused on improving the face, content and the ecological validity of the tool.The term validity refers to whether the test measures what it claims to measure (Wade, 1992) and is arguably the most important criteria for the quality of a test. Criterion-related validity was tested by calibrating the P-CAD against known measures used in communication and cognitive testing in dementia, the FLCI (Bayles and Tomoeda, 1994)and the MMSE-2 (Folstein et al., 2010). The P-CAD was concurrently tested against two reference standards: The FLCI (Bayles and Tomoeda, 1994) (reviewed in Chapter 5) and the MMSE-2.

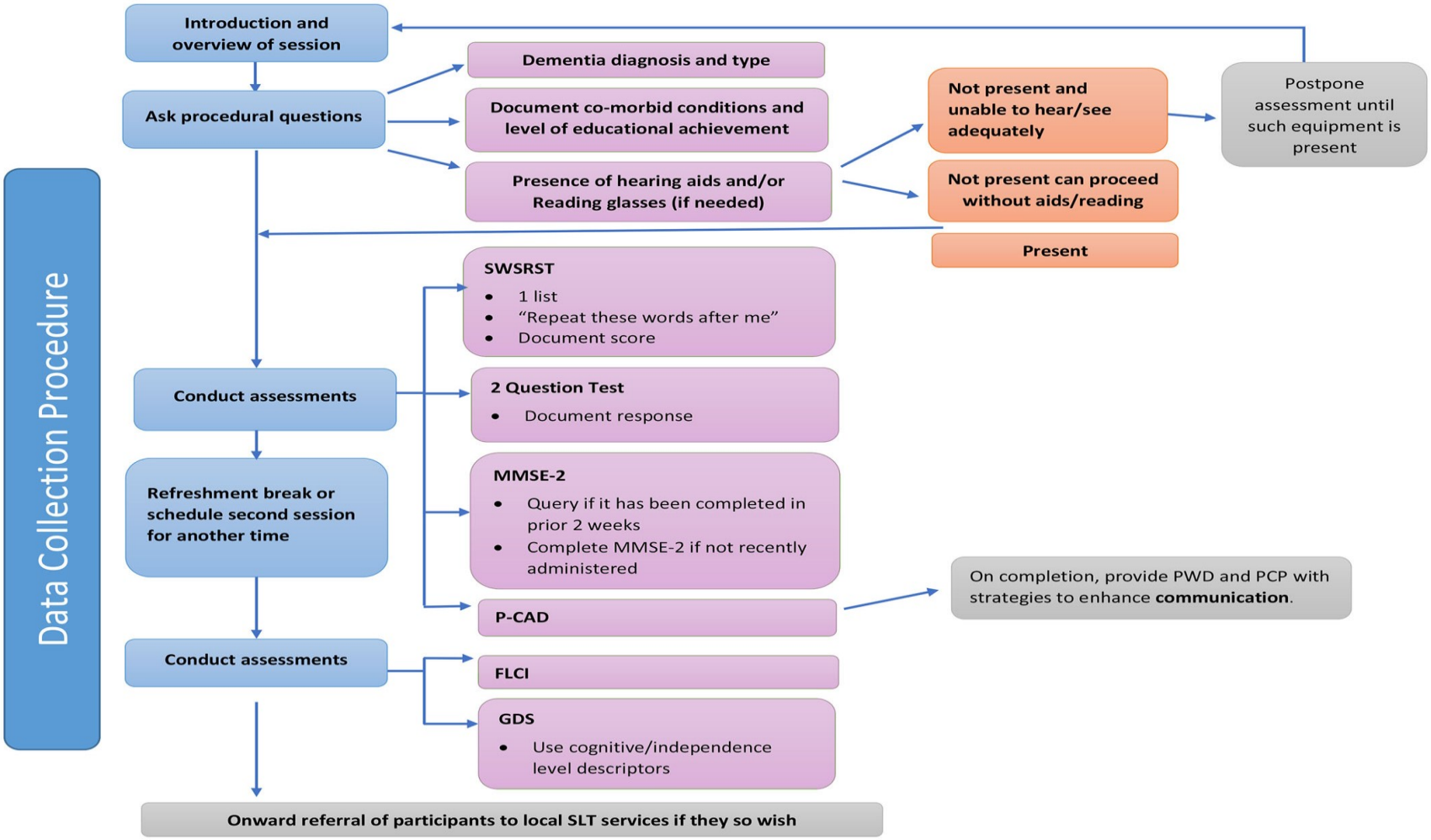


Figure 9.1 Data Collection Protocol

Independent t-tests were performed to test for differences between those with AD (n=56) and VAD (n=26) for the scores of the P-CAD, MMSE-2, and FLCI. Tests for correlation on the participants with AD and VaD, were also performed between P-CAD and the other measures, for each diagnosis.

9.2.7 Reliability Testing

Both inter-rater reliability and sensitivity to change over time were examined.

9.2.7.1 Inter-Rater Reliability

Inter-rater reliability was necessary to demonstrate consistency in the administration and scoring of the P-CAD. To test the degree in which different examiners would independently evaluate an individual's performance in the same way using the 3 outcome measures; the P-CAD, MMSE-2 and FLCI.

Observational ratings by two raters (the researcher and a SLT colleague) were carried out to test inter-rater reliability, the researchers completed the tests on a random sample (20%, n=20) of people with dementia and their CPs. Random identification of the person with dementia and their CP was achieved using the participants identification codes and an online random number generator (https://www.random.org/integers/). The SLT colleague had reviewed P-CAD, MMSE-2 and the FLCI assessments and was familiar with administration instructions.

The researchers took alternate roles of "tester" and "observer" for each administration session, both were blinded to the other person's rating on the tests. Both sets of test results were independently coded and compared for agreements. Inter-rater reliability was tested and performed for the two raters on the P-CAD, MMSE-2 and the FLCI tests to evaluate the strength of agreement between the sets of data (see Section 9.3.2.1). Further subtest analysis of the scoring and scoring agreement by the SLT raters on P-CAD was completed and will be presented with the results.

9.2.7.2 Sensitivity to change

Twelve people with dementia and their CPs who participated in the initial P-CAD study at Time Point 1, were randomly selected and invited by the

researcher to be retested at a second time point, 3 months later, Time Point 2. Three measures were used, the P-CAD, FLCI and MMSE-2 assessments were administered. All three measures were re-administered in order to determine any changes in cognition (MMSE-2) and cognitive communication ability (P-CAD and FLCI) at Time 2 and to evaluate variance and correlations in test results within and across measures over time. Both sets of assessment results from Time 1 and Time 2 were statistically analysed to check if changes in participant performance was identified. Due to the low number of participants retested (n=12) nonparametric tests (Wilcoxon Signed Rank tests) were used to compare results to identify any significant change in scores in any one test over time. It was expected that low participant number would impact on outcomes and reliability.

The MMSE-2, FLCI and P-CAD scores were collated for each person and the results inputted into SPSS. Changes between baseline scores and those taken at 3 months were examined using the Wilcoxon Signed-Rank test. It was a suitable statistical measure as there were three or more correlated and repeated outcomes whose distribution was not normal.

9.2.8 Data Analysis

In preparation for data analysis the distribution of test scores was reviewed. Test scores on the MMSE-2, FLCI and the P-CAD were not normally distributed therefore, nonparametric tests were used to analysis results (see Appendix 9.7).

This analysis phase tested concurrent validity and examined inter-rater reliability and sensitivity to change over time. Significance is tested at the 5% level. Data to be analysed was extracted from the proforma (see Appendix 9.6). All relevant medical and demographic data and three sets of assessment results (sub scores and total scores) were inputted into Excel for export into SPSS and to facilitate descriptive analysis. The data was anonymised, coded and charted using an Excel data report. The total data set for the P-CAD, MMSE 2 and FLCI were collated for each person and results transferred from Excel document and inputted into SPSS for analysis.

9.3 Results

The following section describes participant characteristics (sociodemographic characteristics, dementia stage and subtype) and the results of validity (concurrent) and reliability (inter rater and sensitivity to change over time) testing of P-CAD.

9.3.1 Sociodemographic characteristics of participants

Most of the 100 participants with dementia were female (64%) with 36% male participants. Sociodemographic characteristics of participants are displayed in Tables 9.3 and 9.4. Participants with dementia had an average age of 85 years (range 58-95 years). Years of education ranged from 8-18 years with a median age of 12 years, which is equivalent to completing the Irish Junior Cycle programme, second level education. The majority (73%) of CP participants were female, with 27% male CPs. Nearly half (48%) of the CP participants were professional carers and the rest were spouses (32%) and children (18%) of the participants with dementia (see Table 9.3).

Table 9.3 Characteristics of CP Participants

Sociodemographic Characteristics			**Relationship to the person with dementia**				
Frequency	Male	Female	Professional Carer	Spouse	Sister	Child	Friend
N=	27	73	48	32	1	18	1
%	27	73	48	32	1	18	1

9.3.2 Prevalence of dementia subtypes and hearing impairment

The distribution of dementia subtypes can be seen in Table 9.4.and reflects the typical rates found in published studies (Brunnetrom et al 2008, Lobo et al 2000), Over half (55%) the participants had a diagnosis of AD, three of this group had EOAD. Approximately a quarter of those recruited had vascular dementia (28%) and 9% of participants presented with mixed dementia. The

other participants represented other less common dementia subtypes such as FTLD, LBD and DPD. Fifteen percent of the participants with dementia also had a self-identified hearing loss.

9.3.3 Prevalence of Stage and Severity of Dementia

About half (48%) of the participants had mild dementia (GDS level 4) (see Table 9.5) and the other participants had GDS levels of, 5,6, and 7. There were few participants (6%) in the late stages of dementia (GDS level 7), as recruitment of individuals in this group was difficult.

Table 9.4 Characteristics of Participants with Dementia

Sociodemographic Characteristics					**Prevalence of Dementia Subtypes**					
Frequency	Female	Male	Age (Years) and range	Years of Education	Alzheimer's Disease	Vascular Dementia	Lewy Body Dementia	Dementia with Parkinson's Disease	Frontotemporal Dementia	Mixed Dementia
N=	64	36			55	28	3	4	1	9
Mean Range			85 (58-95)	12 (8-18+)						
%	64	36			55	28	3	4	1	9

Table 9.5 Prevalence of dementia stages and severity

GDS Levels and Severity of Dementia		**Frequency**	**Percentage**
Level 4 Mild dementia	Moderate cognitive decline	48	48%
Level 5 Moderate Dementia	Moderately severe cognitive decline	31	31%
Level 6 Moderate to Severe Dementia	Severe cognitive decline	15	15%
Level 7 Severe Dementia	Very severe cognitive decline	6	6%
Total		100	100%

9.3.4 Assessment Settings

Data was collected across a range of settings where SLTs work and people with dementia live. There were 17 different research sites visited for data collection; acute hospitals, care homes and residential homes (see Table 9.6). The versatility of P-CAD for use by SLTs in different settings was important to establish as part of this large research study.

Table 9.6 Assessment Settings

Locations	**Acute Hospital**	**Care homes**	**Home-Domiciliary**
No. of participants	15	31	54

9.3.5 Outcome Measures Comparison

Test scores for P-CAD, MMSE-2 and FLCI were compared based on mean and standard deviation SD. Further analysis across levels of the GDS (levels 4-7) was also carried out (see Table 9.7). These results were then scaled (to a maximum value of 100) to enable direct comparison (see Appendix 9.8). The three outcome measures performed similarly across each GDS level (Figure 9.2), as the mean score falls for each test as the GDS levels increase.

Table 9.7 Mean and Standard Deviation of Outcome Measures

GDS Levels	**P-CAD** Mean(SD)	**MMSE-2** Mean(SD)	**FLCI** Mean(SD)
4	16.08 (4.01)	18.23 (5.90)	68.63 (13.56)
5	11.58 (4.43)	12.35 (4.03)	55.00 (18.40)
6	4.33(3.05)	4.80 (4.09)	24.31 (19.76)
7	1.00(1.15)	0.50 (1.12)	6.50 (4.57)
Total	**12.02 (6.28)**	**13.33 (7.55)**	**54.03 (24.97)**

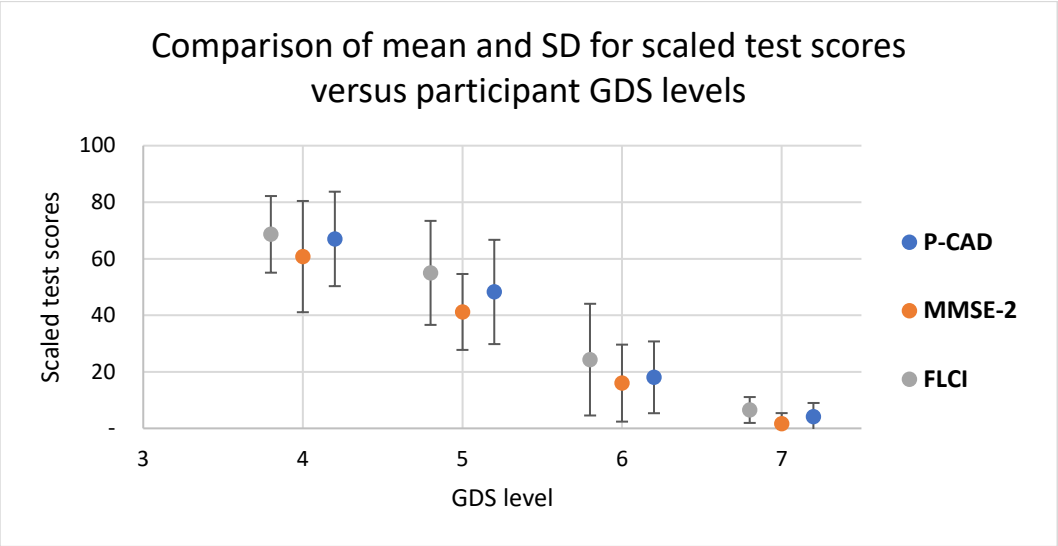


Figure 9.2 Scaled Comparison of P-CAD, MMSE-2 and FLCI

9.4 Validity of the P-CAD

Testing the concurrent validity of P-CAD was a key research question. To test the concurrent validity of P-CAD it was examined against the MMSE-2 a cognitive screening tool and the FLCI a cognitive communication test.

9.4.1 Concurrent validity of the P-CAD with the MMSE-2

The maximum score attainable on the MMSE-2 is 30 and on the P-CAD it is 24. Higher scores on the MMSE-2 and P-CAD are closer to the norm. A Spearman's rank-order correlation was used to determine the relationship between the P-CAD and the MMSE-2 raw scores as the scores were not normally distributed (Appendix 9.7). There is a strong, positive correlation between these raw scores, which is statistically significant (rho=0.812, $p<0.001$) (see Figure 9.3).

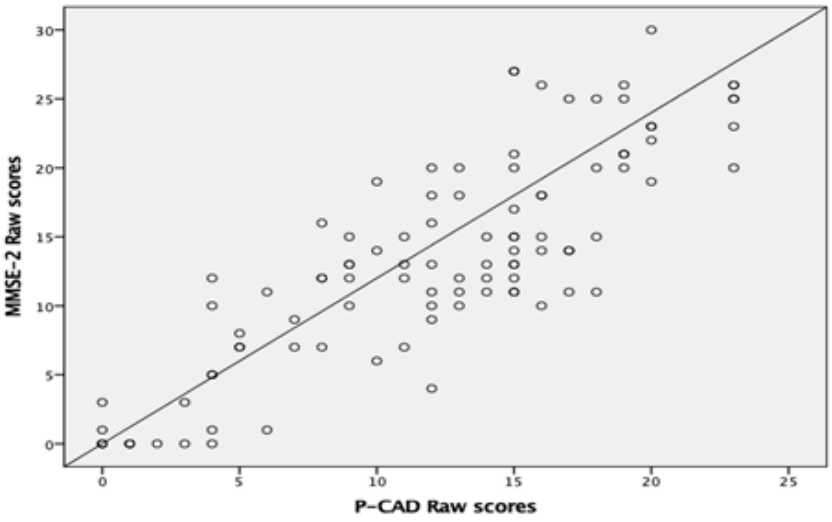


Figure 9.3 Correlation showing concurrent validity of P-CAD with MMSE

9.4.2 Concurrent validity of the P-CAD with the FLCI

Normal cognitive communication function is indicated by higher scores on the FLCI and P-CAD. A Spearman's rank-order test was used to determine the correlation between the P-CAD and the FLCI raw scores (see Figure 9.4). Non-parametric statistics was used since neither the P-CAD nor the FLCI raw scores are normally distributed (see Appendix 9.7). There is a strong, positive correlation between the raw scores, which is statistically significant (rho=0. 828, p<0.001).

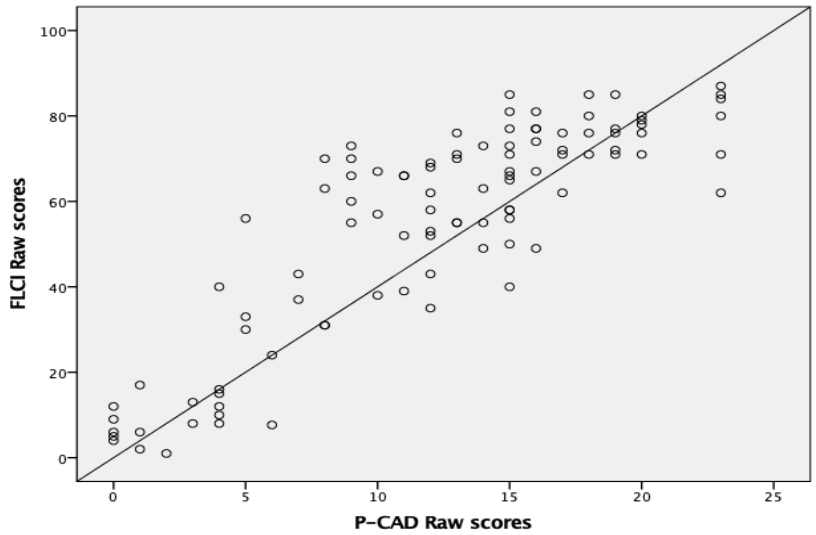


Figure 9.4 Correlation showing concurrent validity of P-CAD with FLCI

9.4.3 Comparing P-CAD scores with the GDS levels

P-CAD scores were plotted across GDS levels to analyse distribution of scores (Figures 9.5 and 9.6). It was found that P-CAD scores, in line with the FLCI and MMSE-2 scores, fall as GDS levels increase. Participants with GDS levels 4 and 5 rarely attain a P-CAD score less than 7 and those with GDS levels of 6 and 7 rarely attain a P-CAD score greater than 6.

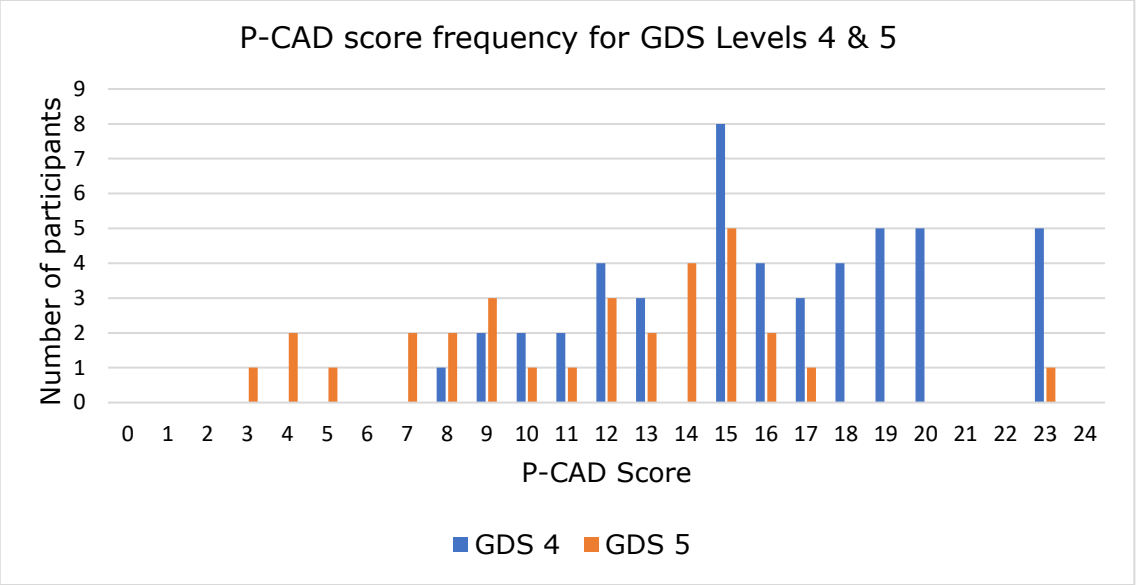


Figure 9.5 P-CAD Scores with GDS Levels 4 & 5

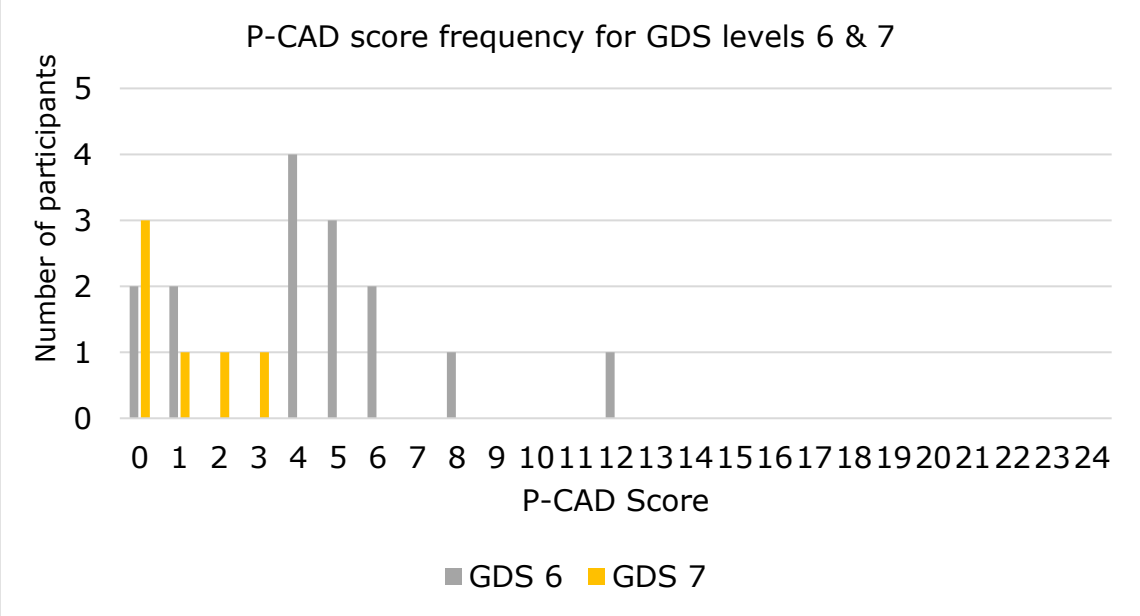


Figure 9.6 P-CAD Scores with GDS Levels 6 & 7

A Kruskal- Wallis test was applied to compare the P-CAD raw scores across GDS levels (Figure 9.7). Nonparametric statistics were used as the P-CAD raw scores were not normally distributed (see Appendix 9.7). There is a statistically significant ($p<0.001$) difference between P-CAD raw scores at different GDS levels. P-CAD scores were lower with each advancing stage of dementia, tracking the decline in both communication and cognitive skills.

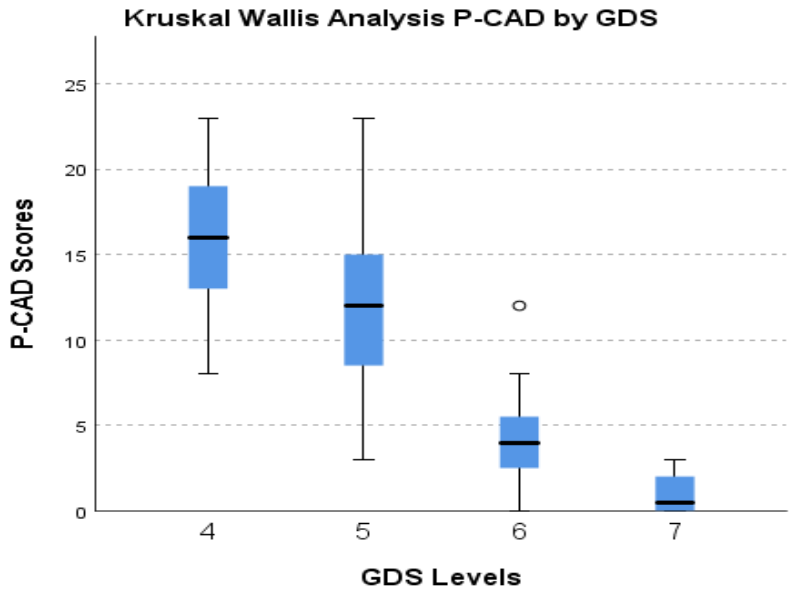


Figure 9.7 Comparing P-CAD Scores across GDS Levels

9.4.4 Comparing P-CAD Communication Support levels with MMSE-2 scores

Additional review of specific P-CAD outcomes, *level of communication support* needed was analysed with the MMSE-2 (cognition measure). P-CAD levels of communication support, see Section 8.6.8, are subdivided into three levels (none=0, minimum=1, moderate=2 and maximum=3). P-CAD communication support levels were compared with MMSE-2 raw scores to determine if there was a relationship between level of cognitive impairment and level of communication support required.

A one-way ANOVA test (Kruskal- Wallis) was used to compare the MMSE-2 test scores across P-CAD levels of communication support (Figure 9.8) (categorical data), as MMSE-2 distribution was normal (see Appendix 9.7). Findings confirm a statistically significant difference ($P<0.001$) in MMSE-2

scores (the participant's cognitive level) across the different P-CAD communication support levels. Participants with lower MMSE-2 scores needed higher levels of communication support. P-CAD determination of levels of communication support are sensitive to the level of cognitive impairment as measured by the MMSE-2. Increasing levels of communication support are required as the dementia progresses. Communication support was required with all but one of the participants (n=99).

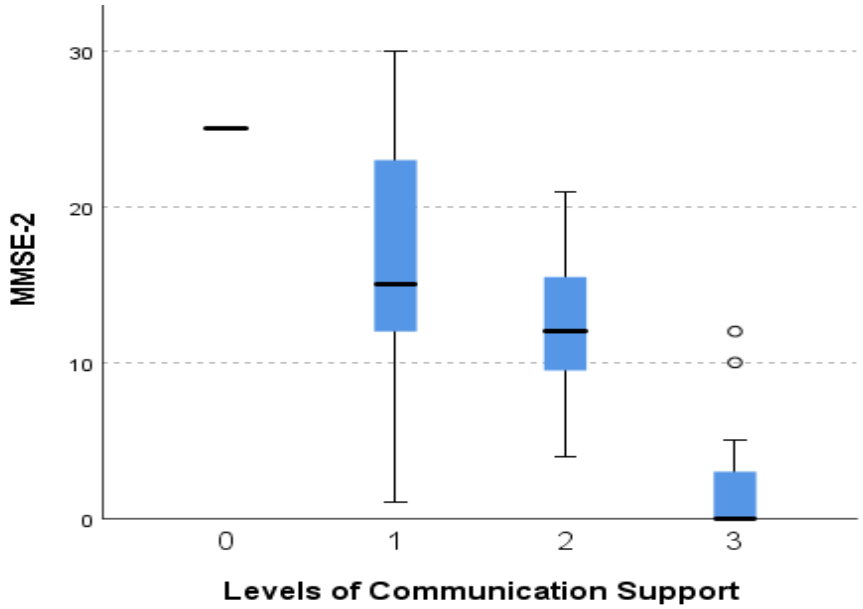


Figure 9.8 Comparing P-CAD Support levels with MMSE-2 Scores

A Spearman's rank-order was also used to determine the relationship between P-CAD Level of communication support and MMSE-2 score. There is a strong, positive correlation ($rh0=0.628$ $p<0.001$) between the MMSE-2 and P-CAD support scores, confirming that increased communication support is required as dementia progresses.

9.4.5 Dementia Subtype Outcome Measure Comparisons

Independent t-tests were performed to test for differences between participants with AD and VaD for the scores of the P-CAD, MMSE-2, and FLCI (see Table 9.8). Significance was tested at 5%. No significant differences were found between diagnoses.

Pearson correlations were also performed between P-CAD test scores and the other measures, for each diagnosis. All correlations were found to be highly significant ($p<0.001$). See Table 9.9 for correlation coefficients.

Table 9.8 Descriptive statistics by diagnosis

	AD (n=56)	VAD (n=26)
P-CAD	11.73 (6.37)	12.35 (6.22)
MMSE-2	12.73 (7.78)	14.62 (6.38)
FLCI	53.04 (26.61)	55.41 (23.16)
GDS	4.80 (0.96)	4.69 (0.93)

Values given in mean (SD)

Table 9.9 Correlations with P-CAD by diagnosis

	P-CAD	
	AD (n=56)	VAD (n=26)
MMSE-2	0.828	0.839
FLCI	0.884	0.820
GDS	-0.735	-0.792

Values given are Pearson correlation coefficient

Participant sample sizes within some of the dementia subgroups (individuals with FTD, DPD and LBD) were not large enough to analyse in this manner. The positive correlations between outcome measures and the P-CAD for these two larger subtypes (AD and VaD) demonstrates the validity of P-CAD for use with these subgroups.

9.5 P-CAD Reliability

Both interrater reliability on the P-CAD and sensitivity of the P-CAD to change over time were examined.

9.5.1 Interrater agreement for P-CAD, MMSE-2 and FLCI

Twenty participants were randomly selected for retesting (see Table 9.10). A range of dementia stages and subtypes and were represented. A Spearman's correlation analysis was performed for the two raters (the researcher and SLT colleague) in each of the four measures to test the strength of agreement.

Table 9.10 Participant characteristics (n=20)

Gender	GDS LEVEL	No. of participants	Dementia Subtype	No. of participants
Female n=11	4	5	AD	11
Male n=-9	5	7	VaD	5
	6	5	DPD	2
	7	3	Mixed	2
			Total	20

There were highly significant correlations for all four measures; GDS (rho=0.969, p<0.001), MMSE-2 (rho=0.992, p<0.000), FLCI (rho=0.999, p<0.000), P-CAD (rho=0.982, p<0.000) between the two raters (see Figure 9.9 and Appendix 9.9).

These finding suggest that P-CAD is a reliable measure of cognitive communication ability when administered by different testers.

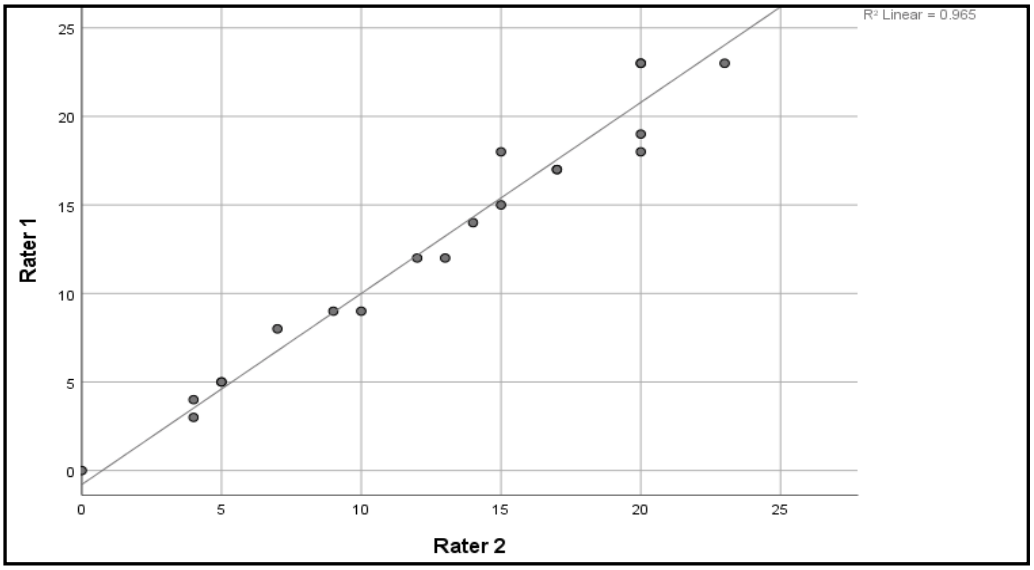


Figure 9.9 Inter rater correlation for P-CAD

9.5.2 Inter rater agreement for P-CAD subsections

Further analysis of inter rater agreement was carried out on P-CAD subsections 1-8 (see Appendix 9.9). A Spearman's rank-order correlation was used to compare two raters' scoring for P-CAD subsections (see Table 9.11). There was good agreement between raters across all P-CAD subsections.

Table 9.11 Correlational Analysis for Raters on P-CAD Subsections

	Section 1	**Section 2**	**Section 3**	**Section 4**	**Section 5**	**Section 6**	**Section 7**	**Section 8**	**Total**
rho	.69	.99	.959	.969	.994	.816	.903	.938	.983
P	.001	.000	.000	.000	.000	.000	.000	.000	.000

9.5.3 P-CAD Sensitivity to Change Over Time

To address the accuracy of P-CAD to measure change in cognitive communication ability over time (see Section 9.1), a preliminary study to investigate changes in P-CAD, MMSE-2, and FLCI raw scores over a 3-month interval were tested for significance (see Appendix 9.9).

In the preliminary study, it was possible to sample 12 participants at both 0 months and 3 months, therefore nonparametric tests (Spearman's rho and Wilcoxon Signed Rank test) were used to analyse the change in scores over a 3-month interval. Nonparametric correlation was calculated using Spearman's rho, to assess if changes in P-CAD total scores compare to changes in MMSE-2 or FLCI scores. Wilcoxon Signed Rank tests were also performed (see Table 9.12), to test whether the change over the 3-month interval was significant for each of the P-CAD, MMSE-2, and FLCI.

Correlations between the change in P-CAD scores over three months were insignificant for both the change in MMSE-2 scores (rho= -0.130, p=0.704) and the FLCI scores (rho=0.221, p=0.513).

Table 9.12 Test statistics for change over time analysis

	P-CAD_T2 - P-CAD_T1	**MMSE-2_T2 - MMSE-2_T1**	**FLCI_T2 - FLCI_T1**
Z	-1.190[b]	-1.663[b]	-1.380[b]
Asymp. Sig. (2-tailed)	0.234	0.096	0.168

a. Wilcoxon Signed Ranks Test b. Based on positive ranks.

There were no significant changes over time in any of the three assessment outcomes (see Figures 9.10 and 9.11) for the 12 participants.

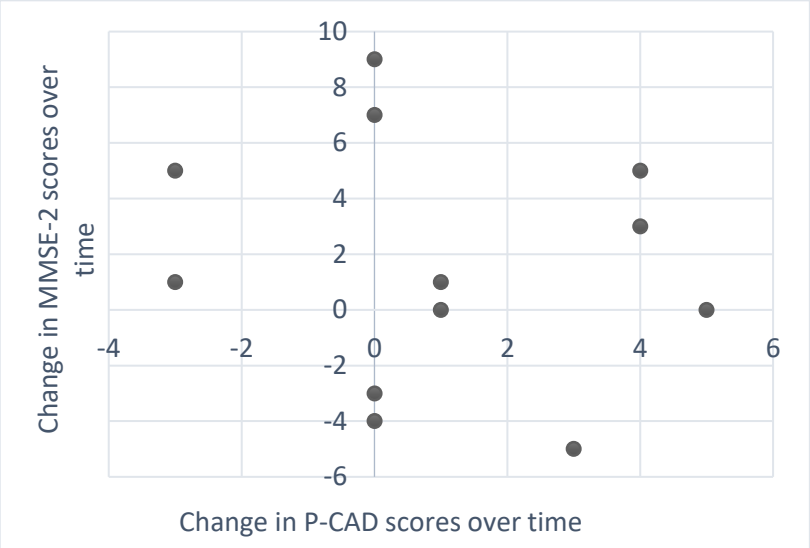


Figure 9.10 Change over time P-CAD and MMSE-2 raw scores

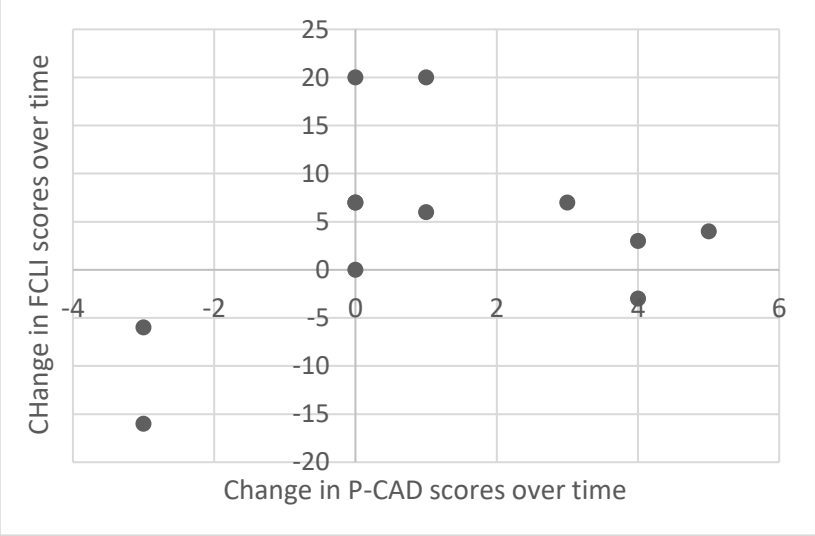


Figure 9.11 Change over time P-CAD and FLCI raw scores

It is important to note that this sample size was small and the time-lapse of three months between Time 1, test and Time 2, retest was short. Using the differences seen between timepoints, a sample size calculation was conducted to determine an appropriate sample size for future studies to evaluate change over time.

Sample size was calculated for each of P-CAD, MMSE-2, and FLCI using G*Power 3.1.9.2 software (Table 9.13). For a two-tailed test for differences in paired samples, to achieve 80% power at a 5% significance level, 84 samples are required in order to detect any significant changes in all three measures.

Table 9.13 Sample size calculations for change over time

	Change Over Time (n=11)		
	MMSE-2	FLCI	P-CAD
Time 1(Mean)	18.55 (8.64)	71.55 (19.91)	16.18 (5.81)
Time 2(Mean)	16.36 (8.25)	67.73 (17.69)	15.36 (4.57)
Correlation	0.886	0.851	0.898
Effect Size	0.54	0.36	0.31
Total N Required	29	62	84

9.6 Discussion

The P-CAD is now validated at a preliminary level providing clinicians with an alternative cognitive communication assessment for use with people with dementia. The main research findings, and their implications will be discussed in the following sections.

9.6.1 P-CAD participants representative of people with dementia

P-CAD has been validated with people with different dementia subtypes: AD (55%), VaD (28%), MD (9%), DPD (4%), LBD (3%) and FTD (1%). The largest sample groups were those with AD and VAD, which was representative of population prevalence (Section 1.6.2), the other subtypes (mixed dementia, DPD, LBD and FTD) accounted for 17% of the total participants

with dementia, which indicates the versatility of P-CAD for use with people with different dementia subtypes. Further exploration is required, as some of the subtype group were small. Other available cognitive communication assessments reviewed (Chapter 5) are validated primarily with people with AD. The ABCD included had 8 people with DPD and the SIB included 1 person with VAD.

It is argued that P-CAD has been validated with a more representative dementia sample than those cognitive communication assessments reviewed in the scoping review (Study 2). This initial validation study indicates that P-CAD can be used with people with the more commonly occurring dementia sub types (AD, VaD and MD). Some of the sub groupings (FTD, LBD and DPD) tested were small, but their inclusion along with the three larger subgroups of people with AD, VaD and MD strengthens the test.

P-CAD has been validated with people with early, mid and late stage dementia (Table 9.5) again this reinforces the test, providing clinicians with a tool that can be used in the early, middle or late stages of dementia. Cognitive communication assessments reviewed in Study 2 did not include the full range of dementia stages (Table 5.3) in their standardisation studies.

The participants with dementia were assessed in a variety of setting and locations (n=17). These clinical settings included, acute care hospitals, out-patient departments, care homes and domiciliary home settings representative of where people with dementia interface with SLTs. The communication profiles for each individual with dementia will be unique, however certain communication strengths and weakness will be more prevalent across subtypes and different stages (Bourgeois and Hickey, 2011). P-CAD will facilitate an individualised approach to assessment and guide intervention.

9.6.2 Concurrent Validity of P-CAD

P-CAD is important given the growing need for communication interventions for people with dementia. The P-CAD validation study found positive and strong correlations with the MMSE-2 ($rho=0.812$, $p<0.001$) a measure of cognition and the FLCI ($rho=0.828$, $p<0.001$) a cognitive communication

assessment. It was found that P-CAD scores, in line with the FLCI and MMSE-2 scores, fall as GDS levels increase, indicating parallels between cognitive decline and reduced communication ability in dementia. Further analysis (Section 9.4.4) of P-CAD support levels indicated that a pattern of increased levels of communication support are needed as dementia advances.

The scoping review in Chapter 5 (Study 2) emphasised the lack of cognitive communication assessments available for use with people with dementia. Reviewed assessments were outdated, time consuming to administer and had limited focus on functional communication. The concurrent validity testing of the P-CAD establishes that it's can reliably be used to evaluate the cognitive communication abilities of people with dementia.

9.6.3 Inter rater reliability

The inter-rater reliability of P-CAD was tested by two raters. The other outcome measures were also rated during this phase to compare results across test measures. Participants involved in this phase of the research had a range of dementia subtypes (AD, VaD, DPD and mixed). All four GDS Levels were represented as the participants were at different stages of dementia (see Table 9.10). Rater 2 (SLT colleague) was familiar with all the research instruments prior to data collection, as would be normal clinical practice with using any new assessment measure.

There were highly significant correlations between the two raters on the P-CAD. These strong correlations were also evident on the other measures GDS MMSE-2 and FLCI. Inter rater reliability for the all eight P-CAD subtests were also examined and found to be strong (see Table 9.11). Good inter rater reliability for the P-CAD has been established and will facilitate it's use by SLT clinicians. Only two of the previously reviewed cognitive communication assessments in Study 2, the scoping review, reported strong inter rater reliability. The number of participant's tested here was small (n=20), a larger test group could be used in future P-CAD testing to expand this research.

Establishing the inter rater reliability of the P-CAD is an important research outcome which strengthens the P-CAD as an assessment of cognitive communication ability in dementia.

9.6.4 P-CAD's Sensitivity to change over time

P-CAD's ability to measure change in cognitive communication ability was not established fully in this study. A small sample size (n=12) and a short time period (3 months) between testing periods impacted on research findings. There was also some difficulty in assuring the availability of participants for a second assessment session.

Due to research time limitations it is was not possible to reassess a large cohort of the participants, resulting in a restricted number of participants being retested. To test P-CAD sensitivity to changes in cognitive communication a larger research sample is required. The time interval between test and retest assessments was too short (3 months) to determine if there was a change in participants' cognitive communication ability. This was not a long enough time interval for changes in cognitive communication ability to have occurred. It is possible also that this group of participants remained medically and cognitively stable during the testing intervals.

A sample size calculation was conducted to determine an appropriate sample size for future studies to evaluate change over time. Sample size was calculated for each of P-CAD, MMSE-2, and FLCI using G*Power 3.1.9.2 software. For a two-tailed test for differences in paired samples, to achieve 80% power at a 5% significance level, 84 samples are required to detect any significant changes in all three measures (see Table 9.14).

Table 9.14 Sample size calculations for change over time

Change Over Time (n=12)			
	MMSE-2	FLCI	P-CAD
Time 1 (Mean)	18.55 (8.64)	71.55 (19.91)	16.18 (5.81)
Time 2 (Mean)	16.36 (8.25)	67.73 (17.69)	15.36 (4.57)
Correlation	0.886	0.851	0.898
Effect Size	0.54	0.36	0.31
Total N Required	29	62	84

9.7 Limitations of the Study

The P-CAD validation had a short time frame of 24 months to achieve the goals of the research. Studies 1 and 2 (Chapters 4 and 5) were completed outside of this time frame. The primary goals of P-CAD validation were met within this time frame but there were some limitations to the design and scope of the research as a result. These were establishing P-CAD sensitivity to change over time and intra rater reliability. Research time constraints meant that P-CAD retesting could not be conducted on a large scale. Only 12 participants were retested with P-CAD after a 3-month interval to investigate its sensitivity to change over time, a larger research sample was desirable. Retesting cognitive communication abilities with P-CAD after 12 months, would have been a more suitable timeframe to profile cognitive communication changes related to dementia progression. In addition, it was not logistically possible in this research study to retest participants with dementia at a shorter time interval (one week) to examine the intra rater reliability of the P-CAD. Access to full medical records would also have been required to record medical stability and was not included in this research design.

There were some lessons learnt throughout the validation project. Gaining ethical approval across the various recruitment sites for inclusion of participants with dementia was time consuming and there were some ethical concerns that need to be resolved prior to data collection in one main recruitment site. The required clarifications about the ability of people with dementia to consent to participate in the research were presented to the ethics committee. These ethical considerations will be discussed further in the final chapter (see section 10.8).

9.8 Conclusions

The findings from this validation study suggest that the P-CAD is a valid reliable cognitive communication assessment for people with dementia. P-CAD demonstrates strong and reliable validity with the FLCI, a communication reference measure. It correlates with the MMSE-2, a cognitive screening measure frequently used in dementia management

P-CAD profiles communication and tracks parallel changes in cognitive function as measured by the MMSE-2. It has good interrater reliability which emphasises its value as an objective measure of communication in dementia management. It provides an up to date alternative for the assessment of communication in people dementia. The clinical and research implications will be discussed in Chapter 10.

Chapter 10
Implications for Research and Clinical Practice

10.1 Introduction

This research established the need for a new cognitive communication assessment tool for people with dementia. The development and validation of P-CAD has addressed this gap in assessment. This final chapter will explore the potential for P-CAD research to positively influence SLT practice in the context of evolving services for people with dementia and enhance their role as experts in the assessment and management of those communication deficits presenting in dementia.

10.2 Implementation of the INDS: changes in SLT policy and practice

This research was initiated soon after the publication of the INDS in 2014. From then to research completion, there have been significant developments in the involvement of SLTs in INDS implementation. The development of a position paper by the professional body IASLT (2015), to guide SLTs in clinical practice in dementia has been achieved and establishes a framework for the full practice guidelines to follow. Over the past two years, the National Dementia Office (NDO) has involved SLTs in the Dementia Diagnostic and Post Diagnostic Steering Committees, of which the researcher is a member, showing a growing awareness among policy makers that SLTs play an important and integrated role in dementia management.

A National Dementia Office SLT working group is developing a specific speech and language therapy E-Learning module for SLTs working with people with dementia. This module will provide a valuable resource for all qualified SLTs to build and expand their competencies in this area. *The Next Steps* (NDO, 2019) guidance document acknowledges the importance of supporting communication as part of dementia care. These recent developments in policy implementation will contribute to improvements in speech and language therapy clinical practice and service delivery for people with

dementia in the coming years. SLTs are aware of current gaps in service (Chapter 4) and are reprioritising the management of cognitive communication disorders in dementia. The development of the P-CAD tool is timely and can assist SLTs in establishing increased practice in assessment and direct individualised advice, support and therapy for people with dementia. P-CAD has been recommended as one of a range of resources for communication assessment by the SLT working group for the SLT E-Learning module being launched in 2020.

10.2.1 Recalibration of Speech and Language Therapy in Dementia Care

Changes in relevant dementia policy as detailed above, impacts on SLT practice and service provision for people with dementia. This has motivated SLTs to emphasise their role in the management of cognitive communication difficulties in dementia. The lack of understanding of the role of the SLT was identified as a primary barrier to SLT service provision in Study 1. This barrier is also identified in the literature (O'Reilly and Walshe, 2015, Volkmer et al., 2018a, Moloney and Walshe, 2019). The initial pilot study (Chapter 3, Phase 2), focus group feedback (Chapter 6) and the researcher's clinical experience have shown that the P-CAD outcomes are readily understood by other members of the MDT.

Survey findings (Study 1) emphasised the dominance of dysphagia management in SLT practice in dementia. Dysphagia management by SLTs has been well established and recognized (Logemann, 1988) for over 30 years. The effective management of eating, drinking and swallowing difficulties is fundamental to medical management, especially in the acute care setting (Groher and Crary, 2015). In addition to dysphagia management, SLTs are aware of the need to prioritise cognitive communication assessment (see section 3.3.5) and improve access to a range of communication therapies for people with dementia as is current practice in other areas of SLT practice as was previously discussed (see section 4.4.4).

P-CAD fills a gap in cognitive communication assessment availability for SLTs, it efficiently and effectively identifies retained skills and evaluates functional communication.

10.3 Expanding SLT current assessment practice with P-CAD

P-CAD correlates strongly with FLCI, a similar cognitive communication assessment used by SLTs. It has good inter rater reliability within subtests between raters. P-CAD was tested across care settings and can guide cognitive communication management. P-CAD communication support levels correlate with MMSE-2 outcomes and levels of cognitive ability. It can be used with dementia subtypes and at all stages of dementia and has been shown to be useful in the assessment of those with AD and VaD (Chapter 9) unlike currently available cognitive communication assessments (Study 1).

P-CAD has been developed from the shared lived experience of people with dementia, their families and the health care professionals providing their care. It provides an ability-based approach to assessing and supporting cognitive communication disorders in dementia. It focuses on the communication abilities of the person with dementia, evaluates the communication support skills of the CP and guides cognitive communication interventions to improve social engagement and quality of life.

Communication assessment is the first step to tailoring intervention by informing clinical decision making and facilitating an integrated care approach. Research objectives to refine and validate the P-CAD against other measures and establish its reliability for use with people with dementia were achieved

10.3.1 The unique features of the P-CAD

As well as assessing linguistic abilities the P-CAD evaluates the person's functional communication ability and explores the impact of communication impairment on their everyday lives. Three communication perspectives are reviewed; everyday communication tasks, conversational ability (both partners) and the level of communication support routinely needed. P-CAD

targets communication breakdown by evaluating the communication skills of the CP to enhance conversations.

P-CAD assesses the person with dementia's communication ability to participate in a range of life activities for social participation and independence. The person-centred interview (Section 7 Functional Communication) evaluates communication activity, ability and limitations. Many of the communication activities in P-CAD correspond to the examples of communication-related activities of daily living (ADLs) (Hickey and Bourgeois, 2018). P-CAD can guide communication interventions across the stages of dementia.

The P-CAD differs from other functional communication measures such as the ASHA -FACS (Fratalli et al., 1995) and the CETI (Lomas et al., 1989) as it aims to classify the degree of language impairment and the impact on interpersonal communication functioning. The P-CAD profiles baseline language levels providing a context for improving functional conversational effectiveness and efficiency within the dyad. The SLT can evaluate both interactional and transactional aspects of communication. P-CAD moves beyond traditional definitions of functional communication (Worrall et al., 2002) where the focus is mainly on transactional exchanges such as using the telephone, offering a greeting. Section 6 of the P-CAD facilitates analysis of the interaction; recognition of competence and levels of engagement.

The P-CAD can capture conversation skills and participation in conversation, providing a useful measure for conversation therapy. The Rating Support and Participation in Conversational measure (Kagan et al., 2004) adopts a similar approach to analysing conversation in aphasia. The *P-CAD Section 6: Conversational Ability*, has two profiles (see Appendix 8.6); one for the person with dementia and one for their CP. These conversation profiles are further informed by the SLT's understanding of the cognitive linguistic abilities of the person with dementia.

10.4 P-CAD Section 6: a useful conversation analysis tool

P-CAD Section 6 Conversation Ability was refined following feedback from focus group participants (Chapter 6). The revised conversation profiling scales were developed to evaluate the communication skills of both CPs, addressing the collaborative nature of conversations. The role of the CP in co-constructing the conversation has already been discussed (Perkins et al., 1998) in the literature review (see section 2.1). The person with dementia and their CP initiate repair sequences (Samuelsson and Hydén, 2017) and compensate for cognitive linguistic errors, therefore, it is important to evaluate both their interactions in conversation as a basis for intervention.

The P-CAD research study has established the usefulness of the CAPs in evaluating conversation. This subsection had good inter rater reliability (rho= .816, $p<0.000$) between two SLT raters. It was used with one hundred people with different types, of dementia, at different stages of dementia and across clinical setting.

CAPS can be completed in approximately 10 mins, it is not interdependent on any other P-CAD subtests for analysis or scoring. It provides a useful and quick review of conversation ability and identifies the type and frequency of communication support strategies being used. This information can then guide communication intervention.

It does not aim to provide a comprehensive evaluation of the person's cognitive communication skills like P-CAD. It screens conversation between the person with dementia and their CP, this type of tool can help identification of everyday commutation problems including the communication skills of the CP. Further research is required to establish if CAPs is a sensitive and appropriate conversation evaluation tool for use with people with dementia when used as a standalone subtest of P-CAD.

10.5 P-CAD guides cognitive communication intervention, supporting communication and relationships

P-CAD analyses dynamic communication which can direct and guide speech and language therapy planning. Approaches to communication intervention (previously discussed in Section 1.9) will be influenced by the preferred approach taken by the SLT to meet the communication needs of the client in the context of the best available evidence (Egan et al., 2010). P-CAD informs specific approaches to intervention and facilitates individualised therapy programmes such as conversation therapy.

10.5.1 P-CAD as a basis for conversation therapy

Conversation therapy activities focus on changing behaviours within the context of genuine conversation and can be considered a life participation approach focusing on building conversational participation and relationships (Simmons-Mackie et al., 2014). It has a defined basis and purpose to enhance conversation skills and confidence. Conversation therapy can focus on the verbal and non-verbal aspects of communication in the dyad and this can be measured by P-CAD.

Supported conversation (Kagan et al., 2001) is widely used in aphasia management and involves training CPs. There is a large evidence base also for this approach in dementia management (Ripich et al., 1995, Conway and Chenery, 2016, Eggenberger et al., 2013). These methods enhance communication between the person with dementia and their CP. For example, if the CP was not allowing the person with dementia to initiate a conversational turn then this might be a therapy target. Training "good communication skills" contributes to better conversations. P-CAD uses appreciative enquiry to review everyday communication skills enabling the person with dementia and their CP to identify what is working well in the videoed conversations and to explore areas for behavioural change. Building awareness of individual communication styles and troublesome behaviours is a foundation step achieving behaviour change. Communication support strategies are included in the back of the P-CAD test booklet and include a

range of specific strategies to enhance communication (see Appendix 8.6). Typically, useful strategies for people with dementia include; introducing one idea at a time, a reduced pace of conversation and avoiding testing questions. CP adaptation in everyday communication situations with the person with dementia will enhance communication function and support relationships.

10.5.2 P-CAD guides conversation coaching intervention for people with dementia

P-CAD provides a basis to plan communication intervention. It is a repeatable measure that can profile functional communication ability and rehabilitation-related improvements or a deterioration in communication capability due to a progression of the dementia. *Conversation Coaching for People with Dementia (CCPD)* (Dooley and Conway, April 2016) (see Appendix 10.1) is a P-CAD based intervention that was developed by the researcher, however, it was not part of this PhD research.

CCPD was initially developed to meet a growing need in service delivery for intervention programs to address communication difficulties in dementia. It combines conversation therapy and training for people with dementia and their CPs. The SLT provides education and supported conversation training to people with dementia and their CPs in a one to one and group therapy setting. A P-CAD feasibility study based on a coaching intervention is currently being conducted (see Appendix 10.4) by the researcher. P-CAD is being used as part of this cognitive communication intervention study to measure outcomes along with other research tools. Clinical practice has indicated P-CAD's potential in this regard. However, further research is required to confirm P-CAD's usefulness as an intervention outcome measure.

10.6 Canadian Validation Study

The scope of this research has expanded to include a validation of the P-CAD assessment with participants in Canada; but that study does not form part of this dissertation. The researcher travelled to Canada in June 2017, to establish a P-CAD research site in collaboration with SLT colleagues from the

University of Alberta, Edmonton. Professor Tammy Hopper, an international expert in communication and dementia led the Canadian study. Research methods used were the same as those in the Irish validation study. P-CAD research protocols were discussed with the research team and a plan for data collection was drawn up.

Data was collected on 24 people with dementia and their CPs between September 2018 and May 2019. Data analysis will be carried out in 2020 to determine the validity of P-CAD in this population. The Irish and Canadian data sets will then be compared for analysis and results published in the final validation data for the P-CAD assessment.

There were some research challenges experienced obtaining ethical approval for the validation of P-CAD in Ireland and Canada. The following section describes these issues and how they were managed.

10.7 Challenges in Dementia Research

Involving people with dementia in this P-CAD research raised some practical and ethical issues. It is widely acknowledged that a person-centered approach to dementia care implies that people with dementia should actively participate in dementia research (Dewing, 2002). The legal, governance and ethical frameworks for dementia research is rapidly changing (Sherratt et al., 2007) and there is debate about how these changes will affect social research that needs to involve people with advancing dementia. The validation of the P-CAD would not have been achieved without the participation of people with dementia and their CPs.

P-CAD research involved the participation of people with cognitive communication impairments that needed communication support to engage in the consent process. Requesting consent involved their decision-making representatives, accessible participant information leaflets and face to face discussion (discussed in Chapters 6 and 7). Ethical approval had been granted by the School of Communication and Speech Sciences and all protocol for gaining consent and legal requirements were adhered to (Kelly, 2017). As this was a large-scale study the research proposal needed approval

from 4 different ethics committees. One ethics committee challenged the ethics application based on their opinion that "people with dementia would not be able to consent to participation". The researcher was not in agreement with this view and was able to defend the involvement of people with dementia to the ethics committee on the basis that; people with dementia have capacity for decision making particularly in the early to mid-stages of dementia. Those in the advanced stages of dementia may be unable to give consent so their decision-making representative would decide on their behalf, based on their will and preferences and strict adherence to the Assisted Decision-Making Act (2015) was observed.

During P-CAD data collection there were two individuals that withdrew from the research during the assessment process, consent was revisited, and they chose to decline any further involvement in the research, their wishes were immediately acknowledged and acted upon. An important consideration in research participation is the level to which it can be achieved while not cognitively and emotionally out-pacing the person with dementia (Dewing, 2007). Equal opportunity for people with dementia to be involved in research is an important ethical consideration and therefore solutions to some of these ethical challenges must be found.

10.8 Final thoughts

P-CAD is a valid and reliable cognitive communication assessment tool for cognitive communication assessment in dementia, that can guide intervention. It has been validated for use with people with dementia (primarily AD and VaD) at different stages of dementia. It will be published in English in 2020 and give SLTs a psychometrically sound communication assessment for people with dementia. Research outputs to date include presentations, published abstracts and a journal article (see Appendix 10.5).

P-CAD has developed from the shared lived experience of people with dementia, their families and the health care professionals providing their care. The combination of cognitive-linguistic baselines, conversational analysis and guidance for conversation coaching are all uniquely addressed by the P-CAD. It takes an ability-based approach to assessing cognitive

communication disorders, reinforcing retained communication skills with a recommended level and type of communication support. The development of P-CAD for clinical use addresses an identified gap in cognitive communication assessment in dementia management.

References

AKATSU, H., TAKAHASHI, M., MATSUKAWA, N., ISHIKAWA, Y., KONDO, N., SATO, T., NAKAZAWA, H., YAMADA, T., OKADA, H. & YAMAMOTO, T. 2002. Subtype analysis of neuropathologically diagnosed patients in a Japanese geriatric hospital. *Journal of the Neurological Sciences,* 196**,** 63-69.

ALAGIAKRISHNAN, K., BHANJI, R. A. & KURIAN, M. 2013. Evaluation and management of oropharyngeal dysphagia in different types of dementia: a systematic review. *Archives of Gerontology and Geriatrics,* 56**,** 1-9.

AMERICAN SPEECH HEARING ASSOCIATION 2016. Scope of practice in speech-language pathology.

ARKSEY, H. & O'MALLEY, L. 2005. Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology,* 8**,** 19-32.

ASHA 2011. SLP health care survey: Caseload characteristics. *American Speech-Language-Hearing Association, Rockville, MD*.

BAHAR-FUCHS, A., CLARE, L. & WOODS, B. 2013. Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia. *Cochrane Database of Systematic Reviews,* 6.

BAKER, K. & IRVING, A. 2016. Co-producing approaches to the management of dementia through social prescribing. *Social Policy & Administration,* 50**,** 379-397.

BARKER, W. W., LUIS, C. A., KASHUBA, A., LUIS, M., HARWOOD, D. G., LOEWENSTEIN, D., WATERS, C., JIMISON, P., SHEPHERD, E. & SEVUSH, S. 2002. Relative frequencies of Alzheimer disease, Lewy body, vascular and frontotemporal dementia, and hippocampal sclerosis in the State of Florida Brain Bank. *Alzheimer Disease and Associated Disorders,* 16**,** 203-212.

BARNLUND, D. C. 2017. A transactional model of communication. *Communication theory.* Abingdon, UK: Routledge.

BAYLES, K. & TOMOEDA, C. 1993. *Arizona battery for communication disorders of dementia(ABCD),* Tucson, AZ, Canyonlands Publishing Inc.

BAYLES, K. A., KIM, E., CHAPMAN, S. B., ZIENTZ, J., RACKLEY, A., MAHENDRA, N., HOPPER, T. & CLEARY, S. J. 2006. Evidence-based practice recommendations for working with individuals with dementia: Simulated presence therapy. *Journal of Medical Speech Language Pathology,* 14**,** xiii-xxi.

BAYLES, K. A. & TOMOEDA, C. K. 1994. *The Functional Linguistic Communication Inventory,* Tucson AZ, Pro-Ed.

BAYLES, K. A. & TOMOEDA, C. K. 2007. *Cognitive-communication disorders of dementia,* Tucson AZ, Plural Pub.

BAYLES, K. A., TOMOEDA, C. K., CRUZ, R. F. & MAHENDRA, N. 2000. Communication abilities of individuals with late-stage Alzheimer disease. *Alzheimer Disease & Associated Disorders,* 14**,** 176-181.

BOOTHROYD, A. 1985. Evaluation of speech production of the hearing impaired: Some benefits of forced-choice testing. *Journal of Speech, Language, and Hearing Research,* 28**,** 185-196.

BOURGEOIS, M. S. 1991. Communication treatment for adults with dementia. *Journal of Speech, Language, and Hearing Research,* 34**,** 831-844.

BOURGEOIS, M. S. & HICKEY, E. 2011. *Dementia: From diagnosis to management-A functional approach,* New York, Taylor & Francis.

BOYLE, M., MAHENDRA, N., HOPPER, T., BAYLES, K. A., AZUMA, T., CLEARY, S. & KIM, E. 2006. Evidence-based practice recommendations for working with individuals with dementia: Montessori-based interventions. *Journal of Medical Speech-Language Pathology,* 14**,** xv-xxv.

BPS 2010. A NICE-SCIE guideline on supporting people with dementia and their carers in health and social care. *National Collaborating Centre for Mental Health.* London: British Psychological Society.
BRADY, M. C., KELLY, H., GODWIN, J., ENDERBY, P. & CAMPBELL, P. 2016. Speech and language therapy for aphasia following stroke. *Cochrane Database of Systematic Reviews.*
BRAUN, V. & CLARKE, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3**,** 77-101.
BRAUN, V., CLARKE, V., HAYFIELD, N. & TERRY, G. 2019. Thematic analysis. *Handbook of Research Methods in Health Social Sciences***,** 843-860.
BROOKER, D. & LATHAM, I. 2015. *Person-centred dementia care: Making services better with the VIPS framework*, Jessica Kingsley Publishers.
BROUGHTON, M., SMITH, E. R., BAKER, R., ANGWIN, A. J., PACHANA, N. A., COPLAND, D. A., HUMPHREYS, M. S., GALLOIS, C., BYRNE, G. J. & CHENERY, H. J. 2011. Evaluation of a caregiver education program to support memory and communication in dementia: A controlled pretest–posttest study with nursing home staff. *International Journal of Nursing Studies,* 48**,** 1436-1444.
BRUCE, C., BRUSH, J. A., SANFORD, J. A. & CALKINS, M. P. 2013. Development and evaluation of the environment and communication assessment toolkit with speech-language pathologists. *Seminars in Speech and Language,* 34**,** 042-052.
BRUNNSTRÖM, H., GUSTAFSON, L., PASSANT, U. & ENGLUND, E. 2009. Prevalence of dementia subtypes: a 30-year retrospective survey of neuropathological reports. *Archives of Gerontology and Geriatrics,* 49**,** 146-149.
BRUSH, J. A., CALKINS, M. P., BRUCE, C. & SANFORD, J. A. 2012. *Environmental & Communication Assessment Toolkit for Dementia Care,* Baltimore,USA, Health Professions Press.
BRUSH, J. A. & CAMP, C. J. 1999. Effective interventions for persons with dementia: Using spaced retrieval and Montessori techniques. *Perspectives on Neurophysiology and Neurogenic Speech and Language Disorders,* 9**,** 27-32.
BRYAN, K., BINDER, J., DANN, C., FUNNELL, E., RAMSEY, V. & STEVENS, S. 2001. Development of a screening instrument for language in older people (Barnes Language Assessment). *Aging & Mental Health,* 5**,** 371-378.
BURGIO, L., LICHSTEIN, K. L., NICHOLS, L., CZAJA, S., GALLAGHER-THOMPSON, D., BOURGEOIS, M., STEVENS, A., ORY, M., SCHULZ, R. & INVESTIGATORS, R. 2001. Judging outcomes in psychosocial interventions for dementia caregivers: The problem of treatment implementation. *The Gerontologist,* 41**,** 481-489.
BURGIO, L., STEVENS, A., GUY, D., ROTH, D. L. & HALEY, W. E. 2003. Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia. *The Gerontologist,* 43**,** 568-579.
BUTLER, E. A. & RANDALL, A. K. 2013. Emotional coregulation in close relationships. *Emotion Review,* 5**,** 202-210.
CAHILL, S., O'SHEA, E. & PIERCE, M. 2012. Creating excellence in dementia care: A research review for Ireland's national dementia strategy. Dublin, Ireland: HSE.
CHERTKOW, H., FELDMAN, H. H., JACOVA, C. & MASSOUD, F. 2013. Definitions of dementia and predementia states in Alzheimer's disease and vascular cognitive impairment: consensus from the Canadian conference on diagnosis of dementia. *Alzheimer's Research & Therapy,* 5**,** 2.
CLEARY, S., DONNELLY, M. J., ELGAR, S. & HOPPER, T. Service delivery for Canadians with dementia: A survey of speech-language pathologists. Clinical Aphasiology Conference, 2003 Orcas Island, WA.
CONWAY, A. & WALSHE, M. 2015. Management of non-progressive dysarthria: practice patterns of speech and language therapists in the Republic of Ireland. *International Journal of Language & Communication Disorders,* 50**,** 374-388.

CONWAY, E. R. & CHENERY, H. J. 2016. Evaluating the MESSAGE Communication Strategies in Dementia training for use with community-based aged care staff working with people with dementia: a controlled pretest–post-test study. *Journal of Clinical Nursing,* 25**,** 1145-1155.
DATA PROTECTION COMMISSION 2018. GDPR and you.
DAVIDSON, B., HOWE, T., WORRALL, L., HICKSON, L. & TOGHER, L. 2008. Social participation for older people with aphasia: The impact of communication disability on friendships. *Topics in Stroke Rehabilitation,* 15**,** 325-340.
DAY, C. R. 1997. Validation therapy: A review of the literature. *Journal of Gerontological Nursing,* 23**,** 29-34.
DENSCOMBE, M. 2007. The good research guide. Berkshire. *England: McGraw-Hill Education*.
DEPARTMENT OF HEALTH 2014. The Irish National Dementia Stratey. Ireland: Minister for Health
DEWAR, B. & NOLAN, M. 2013. Caring about caring: developing a model to implement compassionate relationship centred care in an older people care setting. *International Journal of Nursing Studies,* 50**,** 1247-1258.
DEWING, J. 2002. From ritual to relationship: a person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia,* 1**,** 157-171.
DEWING, J. 2007. Participatory research: a method for process consent with persons who have dementia. *Dementia,* 6**,** 11-25.
DOOLEY, S. & CONWAY, A. April 2016. Conversation Coaching Group for People with Dementia. *31st International Conference of Alzheimer's Disease International.* Budapest, Hungary: Alzheimer's Disease International.
DOOLEY, S. & WALSHE, M. 2018. Speech and Language Therapy Practice in the Management of Cognitive Communication Difficulties in People with Dementia in Ireland. *Un published.* Dublin: Trinity College Dublin.
DOOLEY, S. & WALSHE, M. 2019. Assessing Cognitive Communication Skills in Dementia: A scoping review. *International Journal of Language & Communication disorders,* 0**,** 1-13.
DROST, E. A. 2011. Validity and reliability in social science research. *Education Research and Perspectives,* 38**,** 105.
EGAN, M., BÉRUBÉ, D., RACINE, G., LEONARD, C. & ROCHON, E. 2010. Methods to enhance verbal communication between individuals with Alzheimer's disease and their formal and informal caregivers: A systematic review. *International Journal of Alzheimer's Disease,* 2010.
EGGENBERGER, E., HEIMERL, K. & BENNETT, M. I. 2013. Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics,* 25**,** 345-358.
EKSTRÖM, A., FERM, U. & SAMUELSSON, C. 2015. Digital communication support and Alzheimer's disease. *Dementia***,** 1471301215615456.
ELFRINK, T. R., ZUIDEMA, S. U., KUNZ, M. & WESTERHOF, G. J. 2017. The effectiveness of creating an online life story book on persons with early dementia and their informal caregivers: a protocol of a randomized controlled trial. *BMC Geriatrics,* 17**,** 95.
ELLMO, W., GRASER, J., KRCHNAVEK, B., HAUCK, K. & CALABRESE, D. 1995a. *Measure of cognitive-linguistic abilities* Florida, The Speech Bin.
ELLMO, W., GRASER, J., KRCHNAVEK, B., HAUCK, K. & CALABRESE, D. 1995b. Measure of Cognitive-Linguistic Abilities (MCLA). *Norcross, GA: The Speech Bin, Incorporated*.
ENDERBY, P. & PETHERAM, B. 2002. Has aphasia therapy been swallowed up? *Clinical Rehabilitation,* 16**,** 604-608.

ETTERS, L., GOODALL, D. & HARRISON, B. E. 2008. Caregiver burden among dementia patient caregivers: a review of the literature. *Journal of the American Academy of Nurse Practitioners,* 20**,** 423-428.
FEIL, N. 1993. *The validation breakthrough: Simple techniques for communicating with people with" Alzheimer's-type dementia."*, Health Professions Press.
FERRIS, S., IHL, R., ROBERT, P., WINBLAD, B., GATZ, G., TENNIGKEIT, F. & GAUTHIER, S. 2009. Severe Impairment Battery Language scale: A language-assessment tool for Alzheimer's disease patients. *Alzheimer's & Dementia,* 5**,** 375-379.
FLYNN, E., SMITH, C. H., WALSH, C. D. & WALSHE, M. 2018. Modifying the consistency of food and fluids for swallowing difficulties in dementia. *Cochrane Database of Systematic Reviews*.
FOGEL, A. 2017. Two principles of communication: Co-regulation and framing. *New perspectives in early communicative development.* Abingdon, UK: Routledge.
FOLSTEIN, M. F., FOLSTEIN, S. E. & MCHUGH, P. 2010. *Mini-mental state examination: MMSE-2,* USA, Psychological Assessment Resources.
FOLSTEIN, M. F., FOLSTEIN, S. E. & MCHUGH, P. R. 1975. “Mini-mental state”: a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research,* 12**,** 189-198.
FOX, C., EBERSBACH, G., RAMIG, L. & SAPIR, S. 2012. LSVT LOUD and LSVT BIG: behavioral treatment programs for speech and body movement in Parkinson disease. *Parkinson’s Disease,* 2012**,** 12.
FRATALLI, C., THOMPSON, C., HOLLAND, A., WOHL, C. & FERKETIC, M. 1995. *Functional assessment of communication skills for adults (ASHA FACS),* Rockville,MD, American Speech-Language-Hearing Association.
FRIED-OKEN, M. 2008. Augmentative and alternative communication treatment for persons with primary progressive aphasia. *Perspectives on Augmentative and Alternative Communication,* 17**,** 99-104.
FU, C., CHUTE, D. J., FARAG, E. S., GARAKIAN, J., CUMMINGS, J. L. & VINTERS, H. V. 2004. Comorbidity in dementia: an autopsy study. *Archives of Pathology and Laboratory medicine,* 128**,** 32-38.
GALVIN, J. E., KUNTEMEIER, B., AL-HAMMADI, N., GERMINO, J., MURPHY-WHITE, M. & MCGILLICK, J. 2010. “Dementia-friendly hospitals: Care not crisis” an edcuational program designed to improve the care of the hospitalized patient with dementia. *Alzheimer Disease and Associated Disorders,* 2**4,** 372.
GAUGLER, J. E., GALLAGHER-WINKER, K., KEHRBERG, K., LUNDE, A. M., MARSOLEK, C. M., RINGHAM, K., THOMPSON, G. & BARCLAY, M. 2011. The memory club: Providing support to persons with early-stage dementia and their care partners. *American Journal of Alzheimer's Disease & Other Dementias®,* 26**,** 218-226.
GOODGLASS, H., KAPLAN, E. & BARRESI, B. 2001. *BDAE-3: Boston Diagnostic Aphasia Examination–Third Edition*, Lippincott Williams & Wilkins Philadelphia, PA.
GORNO-TEMPINI, M. L., HILLIS, A. E., WEINTRAUB, S., KERTESZ, A., MENDEZ, M., CAPPA, S. F., OGAR, J. M., ROHRER, J., BLACK, S. & BOEVE, B. F. 2011. Classification of primary progressive aphasia and its variants. *Neurology,* 76**,** 1006-1014.
GROHER, M. E. & CRARY, M. A. 2015. *Dysphagia: clinical management in adults and children*, Elsevier Health Sciences.
HABERSTROH, J., NEUMEYER, K., KRAUSE, K., FRANZMANN, J. & PANTEL, J. 2011. TANDEM: Communication training for informal caregivers of people with dementia. *Aging & Mental health,* 15**,** 405-413.
HABERSTROH, J., NEUMEYER, K., SCHMITZ, B. & PANTEL, J. 2009. Development and evaluation of a training program for nursing home professionals to improve

communication in dementia care. *Zeitschrift fur Gerontologie und Geriatrie,* 42**,** 108-116.
HABERSTROH, J., NEUMEYER, K., SCHMITZ, B., PERELS, F. & PANTEL, J. 2006. Communication training for family caregivers of dementia patients. *Zeitschrift fur Gerontologie und Geriatrie,* 39**,** 358-364.
HARADA, C. N., LOVE, M. C. N. & TRIEBEL, K. L. 2013. Normal cognitive aging. *Clinics in Geriatric Medicine,* 29**,** 737-752.
HARCIAREK, M. & COSENTINO, S. 2013. Language, executive function and social cognition in the diagnosis of frontotemporal dementia syndromes. *International Review of Psychiatry,* 25**,** 178-196.
HARRIS, J. L., KIRAN, S., MARQUARDT, T. P. & FLEMING, V. B. 2008. Communication Wellness Check-Up©: Age-related changes in communicative abilities. *Aphasiology,* 22**,** 813-825.
HELM-ESTABROOKS, N. 2001. *Cognitive linguistic quick test: CLQT,* USA, Psychological Corporation.
HICKEY, E. & BOURGEOIS, M. S. 2011. *Dementia: From diagnosis to management-A functional approach*, Psychology Press.
HICKEY, E. & BOURGEOIS, M. S. 2017. *Dementia: Person-centered Assessment and Intervention,* New York, Routledge.
HICKEY, E. & BOURGEOIS, M. S. 2018. *Dementia: Person-centered Assessment and Intervention,* New York, USA, Routledge.
HOLLAND, A. L., FRATTALI, C. & FROMM, D. 1999. *Communication activities of daily living: CADL-2,* USA, Pro-Ed.
HOLLAND, A. L., WOZNIAK, L. & FROMM, D. 2018. *CADL-3: Communication Activities of Daily Living*, Pro-ed.
HOLT-LUNSTAD, J., SMITH, T. B. & LAYTON, J. B. 2010. Social relationships and mortality risk: a meta-analytic review. *PLOS medicine,* 7**,** e1000316.
HOPPER, T., BAYLES, K. A. & KIM, E. 2001. Retained Neuropsychological Abilities of individuals with Alzheimer's disease. *Seminars in Speech and Language,* 22**,** 261-274.
HOPPER, T., BOURGEOIS, M., PIMENTEL, J., QUALLS, C. D., HICKEY, E., FRYMARK, T. & SCHOOLING, T. 2013. An evidence-based systematic review on cognitive interventions for individuals with dementia. *American Journal of Speech-Language Pathology,* 22**,** 126-145.
HOPPER, T., HOLLAND, A. & REWEGA, M. 2002. Conversational coaching: Treatment outcomes and future directions. *Aphasiology,* 16**,** 745-761.
HOPPER, T. L. 2003. “They’re just going to get worse anyway”: perspectives on rehabilitation for nursing home residents with dementia. *Journal of Communication Disorders,* 36**,** 345-359.
IASLT 2016. IASLT Position Statement. Speech and Language Therapy Provision for People with Dementia. Dublin, Ireland: Irish Association of Speech and Language Therapists,.
ICGP 2014. Dementia:Diagnosis and Management in General Practice. Dublin, Ireland: ICGP.
IRWIN, D. J., WHITE, M. T., TOLEDO, J. B., XIE, S. X., ROBINSON, J. L., VAN DEERLIN, V., LEE, V. M. Y., LEVERENZ, J. B., MONTINE, T. J. & DUDA, J. E. 2012. Neuropathologic substrates of Parkinson disease dementia. *Annals of Neurology,* 72**,** 587-598.
JACK, C. R., ALBERT, M. S., KNOPMAN, D. S., MCKHANN, G. M., SPERLING, R. A., CARRILLO, M. C., THIES, B. & PHELPS, C. H. 2011. Introduction to the recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's & Dementia,* 7**,** 257-262.
JELLINGER, K. 1996. Structural basis of dementia in neurodegenerative disorders. *New Trends in the Diagnosis and Therapy of Non-Alzheimer’s Dementia.* Springer.

JONES, D. 2015. A family living with Alzheimer's disease: The communicative challenges. *Dementia,* 14**,** 555-573.
JONES, D., DREW, P., ELSEY, C., BLACKBURN, D., WAKEFIELD, S., HARKNESS, K. & REUBER, M. 2016. Conversational assessment in memory clinic encounters: interactional profiling for differentiating dementia from functional memory disorders. *Aging & Mental Health,* 20**,** 500-509.
KAGAN, A., BLACK, S. E., DUCHAN, J. F., SIMMONS-MACKIE, N. & SQUARE, P. 2001. Training volunteers as conversation partners using *Supported Conversation for Adults With Aphasi*a (SCA). *Journal of Speech, Language, and Hearing Research*.
KAGAN, A., SIMMONS-MACKIE, N., ROWLAND, A., HUIJBREGTS, M., SHUMWAY, E., MCEWEN, S., THREATS, T. & SHARP, S. 2008. Counting what counts: A framework for capturing real-life outcomes of aphasia intervention. *Aphasiology,* 22**,** 258-280.
KAGAN, A., WINCKEL, J., BLACK, S., FELSON DUCHAN, J., SIMMONS-MACKIE, N. & SQUARE, P. 2004. A set of observational measures for rating support and participation in conversation between adults with aphasia and their conversation partners. *Topics in Stroke Rehabilitation,* 11**,** 67-83.
KANE, J. P., SURENDRANATHAN, A., BENTLEY, A., BARKER, S. A., TAYLOR, J.-P., THOMAS, A. J., ALLAN, L. M., MCNALLY, R. J., JAMES, P. W. & MCKEITH, I. G. 2018. Clinical prevalence of Lewy body dementia. *Alzheimer's Research & Therapy,* 10**,** 19.
KAPLAN, E., GOODGLASS, H. & WEINTRAUB, S. 2001. *Boston naming test,* Texas, USA, Pro-ed.
KAY, J., LESSER, R. & COLTHEART, M. 1992. PALPA: psycholinguistic assessment of language performance in aphasia. London: Erlbaum.
KELLY, B. 2017. The Assisted Decision-Making (Capacity) Act 2015: what it is and why it matters. *Irish Journal of Medical Science (1971-),* 186**,** 351-356.
KERTESZ, A. 1982. *Western aphasia battery test manual,* USA, Psychological Corp.
KERTESZ, A. 2006. Western Aphasia Battery–Revised (WAB-R) Pro-Ed. *Austin, TX*.
KIM, E. S., CLEARY, S. J., HOPPER, T., BAYLES, K. A., MAHENDRA, N., AZUMA, T. & RACKLEY, A. 2006. Evidence-based practice recommendations for working with individuals with dementia: Group reminiscence therapy. *Journal of Medical Speech-Language Pathology,* 14**,** xxiii-xxiii.
KINDELL, J., KEADY, J., SAGE, K. & WILKINSON, R. 2017. Everyday conversation in dementia: a review of the literature to inform research and practice. *International Journal of Language & Communication Disorders,* 52**,** 392-406.
KINDELL, J., SAGE, K., KEADY, J. & WILKINSON, R. What does the biopsychosocial model have to offer in the management of communication in semantic dementia: evidence from a family case study. DEMENTIA AND GERIATRIC COGNITIVE DISORDERS, 2012. KARGER ALLSCHWILERSTRASSE 10, CH-4009 BASEL, SWITZERLAND, 113-114.
KITWOOD, T. M. 1997. *Dementia reconsidered: The person comes first*, Open university press Buckingham.
KOVALEVA, M., SPANGLER, S., CLEVENGER, C. & HEPBURN, K. 2018. Chronic stress, social isolation, and perceived loneliness in dementia caregivers. *Journal of psychosocial nursing and mental health services,* 56**,** 36-43.
KRUGER, R. & CASEY, M. 2015. *Focus groups: A practical guide for applied research* New Delhi, India SAGE Publications, Inc.
LANGMORE, S. E., SKARUPSKI, K. A., PARK, P. S. & FRIES, B. E. 2002. Predictors of aspiration pneumonia in nursing home residents. *Dysphagia,* 17**,** 298-307.
LAPOINTE, L. L. & HORNER, J. 1998. *Reading comprehension battery for aphasia: RCBA-2,* Texas, USA, Pro-Ed.
LEVAC, D., COLQUHOUN, H. & O'BRIEN, K. K. 2010. Scoping studies: advancing the methodology. *Implementation Science,* 5**,** 1-9.

LEVY, J. A. & CHELUNE, G. J. 2007. Cognitive-behavioral profiles of neurodegenerative dementias: beyond Alzheimer's disease. *Journal of Geriatric Psychiatry and Neurology,* 20**,** 227-238.
LIDDLE, J., SMITH-CONWAY, E. R., BAKER, R., ANGWIN, A. J., GALLOIS, C., COPLAND, D. A., PACHANA, N. A., HUMPHREYS, M. S., BYRNE, G. J. & CHENERY, H. J. 2012. Memory and communication support strategies in dementia: Effect of a training program for informal caregivers. *International Psychogeriatrics,* 24**,** 1927-1942.
LOCK, S., WILKINSON, R., BRYAN, K., MAXIM, J., EDMUNDSON, A., BRUCE, C. & MOIR, D. 2001. Supporting partners of people with aphasia in relationships and conversation (SPPARC). *International Journal of Language & Communication Disorders,* 36**,** 25-30.
LOGEMANN, J. A. 1988. The role of the speech language pathologist in the management of dysphagia. *Otolaryngologic Clinics of North America,* 21**,** 783-788.
LOMAS, J., PICKARD, L., BESTER, S., ELBARD, H., FINLAYSON, A. & ZOGHAIB, C. 1989. The communicative effectiveness index: Development and psychometric evaluation of a functional communication measure for adult aphasia. *Journal of Speech and Hearing Disorders,* 54**,** 113-124.
LUXENBERG, J. Environmental Modifications Tailored for the Dementia Patient. Seminars in Clinical Neuropsychiatry, 1997. 132-137.
LYKETSOS, C. G., STEELE, C., BAKER, L., GALIK, E., KOPUNEK, S., STEINBERG, M. & WARREN, A. 1997. Major and minor depression in Alzheimer's disease: prevalence and impact. *Journal of Neuropsychiatry and Clinical Neurosciences,* 9**,** 556-561.
MACDONALD, S. 2017. Introducing the model of cognitive-communication competence: A model to guide evidence-based communication interventions after brain injury. *Brain Injury,* 31**,** 1760-1780.
MAHENDRA, N., KIM, E. S., BAYLES, K. A., HOPPER, T., CLEARY, S. J. & AZUMA, T. 2005. Evidence-based practice recommendations for working with individuals with dementia: Computer-assisted cognitive interventions (CACIs). *Journal of Medical Speech-Language Pathology,* 13**,** xxxv-xxxv.
MALONE, M. L. & CAMP, C. J. 2007. Montessori-based dementia programming®: Providing tools for engagement. *Dementia,* 6**,** 150-157.
MAMO, S. K., NIEMAN, C. L. & LIN, F. R. 2016. Prevalence of untreated hearing loss by income among older adults in the United States. *Journal of Health Care for the Poor and Underserved,* 27**,** 1812-1818.
MARSHALL, C. R., HARDY, C. J., VOLKMER, A., RUSSELL, L. L., BOND, R. L., FLETCHER, P. D., CLARK, C. N., MUMMERY, C. J., SCHOTT, J. M. & ROSSOR, M. N. 2018. Primary progressive aphasia: a clinical approach. *Journal of Neurology,* 265**,** 1474-1490.
MATTIS, S. 1988. Dementia rating scale (DRS). *Psychological Assessment Resources :Odessa, FL.*
MCCALLION, P., TOSELAND, R. W., LACEY, D. & BANKS, S. 1999. Educating nursing assistants to communicate more effectively with nursing home residents with dementia. *The Gerontologist,* 39**,** 546-558.
MCCARRON, M., MCCALLION, P., REILLY, E. & MULRYAN, N. 2014. A prospective 14-year longitudinal follow-up of dementia in persons with D own syndrome. *Journal of Intellectual Disability Research,* 58**,** 61-70.
MCKEOWN, J., CLARKE, A., INGLETON, C., RYAN, T. & REPPER, J. 2010. The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing,* 5**,** 148-158.
MERCY, L., HODGES, J., DAWSON, K., BARKER, R. & BRAYNE, C. 2008. Incidence of early-onset dementias in Cambridgeshire, United Kingdom. *Neurology,* 71**,** 1496-1499.

MESULAM, M. M. 2001. Primary progressive aphasia. *Annals of neurology,* 49**,** 425-432.
MILLER, N. & BLOCH, S. 2017. A survey of speech–language therapy provision for people with post-stroke dysarthria in the UK. *International Journal of Language & Communication Disorders,* 52**,** 800-815.
MILLER, N., DEANE, K. H., JONES, D., NOBLE, E. & GIBB, C. 2011. National survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: therapists' practices. *International Journal of Language & Communication Disorders,* 46**,** 189-201.
MILNE, A. 2010. The 'D'word: Reflections on the relationship between stigma, discrimination and dementia. *The Journal Of Mental Health,* 19(3)**,** 227–233.
MOK, Z., STEEL, G., RUSSELL, C. & CONWAY, E. 2019. Measuring the interactions of people with dementia and their conversation partners: a preliminary adaption of the Kagan measures of support and participation in conversation. *Aging & mental health***,** 1-9.
MOLONEY, J. & WALSHE, M. 2019. Managing and supporting quality-of-life issues in dysphagia: A survey of clinical practice patterns and perspectives in the UK, Ireland and South Africa. *International Journal of Language & Communication Disorders,* 54**,** 41-49.
MOON, H. & ADAMS, K. B. 2013. The effectiveness of dyadic interventions for people with dementia and their caregivers. *Dementia,* 12**,** 821-839.
NASREDDINE, Z. S., PHILLIPS, N. A., BÉDIRIAN, V., CHARBONNEAU, S., WHITEHEAD, V., COLLIN, I., CUMMINGS, J. L. & CHERTKOW, H. 2005. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society,* 53**,** 695-699.
NDO 2019. The Next Steps Dementia Post Diagnostic Support Guidance. Dublin, Ireland: National Dementia Office Health Service Executive.
NEAL, M. & BRIGGS, M. 2003. Validation therapy for dementia. *Cochrane Database Syst Rev,* 3.
NG, K. P., CHIEW, H. J., LIM, L., ROSA-NETO, P., KANDIAH, N. & GAUTHIER, S. 2018. The influence of language and culture on cognitive assessment tools in the diagnosis of early cognitive impairment and dementia. *Expert Review of Neurotherapeutics,* 18**,** 859-869.
NÓBREGA, J., LOUSADA, M. & FIGUEIREDO, D. 2016. Exploring the Clinical Practice of Speech and Language Therapists with Adults with Dementia: A Cross-Sectional Survey in Portugal. *Folia Phoniatrica et Logopaedica,* 68**,** 216-221.
NOONE, P. 2015. Addenbrooke's cognitive examination-III. *Occupational Medicine,* 65**,** 418-420.
NORTHCOTT, S. & HILARI, K. 2011. Why do people lose their friends after a stroke? *International Journal of Language & Communication Disorders,* 46**,** 524-534.
O'BRIEN, J. T., ERKINJUNTTI, T., REISBERG, B., ROMAN, G., SAWADA, T., PANTONI, L., BOWLER, J. V., BALLARD, C., DECARLI, C. & GORELICK, P. B. 2003. Vascular cognitive impairment. *The Lancet Neurology,* 2**,** 89-98.
O'REILLY, A. C. & WALSHE, M. 2015. Perspectives on the role of the speech and language therapist in palliative care: An international survey. *Palliative Medicine,* 29**,** 756-761.
OIREACHTAS 2015. Assisted Decision Making (Capacity) Act. Ireland: Department of the Attorney General.
ORANGE, J. & COLTON-HUDSON, A. 1998. Enhancing communication in dementia of the Alzheimer's type. *Topics in Geriatric Rehabilitation,* 14**,** 56-75.
ORANGE, J. B., KERTESZ, A. & PEACOCK, J. 1998. Pragmatics in frontal lobe dementia and primary progressive aphasia. *Journal of Neurolinguistics,* 11**,** 153-177.
PALMER, A. D., CARDER, P. C., WHITE, D. L., SAUNDERS, G., WOO, H., GRAVILLE, D. J. & NEWSOM, J. T. 2019. The Impact of Communication Impairments on the

Social Relationships of Older Adults: Pathways to Psychological Well-Being. *Journal of Speech, Language, and Hearing Research,* 62**,** 1-21.
PARK, S., THEODOROS, D., FINCH, E. & CARDELL, E. 2016. Be clear: A new intensive speech treatment for adults with nonprogressive dysarthria. *American Journal of Speech-Language Pathology,* 25**,** 97-110.
PAUL, D., FRATTALI, C. & HOLLAND, A. 2004. *Functional assessment of communication skills for adults (ASHA FACS): Addendum,* Maryland, USA, American Speech-Language-Hearing Association.
PAWSON, R. 2002. Evidence-based policy: in search of a method. *Evaluation,* 8**,** 157-181.
PEARSON, B. Z. 2004. Theoretical and empirical bases for dialect-neutral language assessment: Contributions from theoretical and applied linguistics to communication disorders. *Seminars in Speech and Language,* 25**,** 13-25.
PERKINS, L., WHITWORTH, A. & LESSER, R. 1997. *Conversation analysis profile for people with cognitive impairment,* London, Whurr
PERKINS, L., WHITWORTH, A. & LESSER, R. 1998. Conversing in dementia: A conversation analytic approach. *Journal of Neurolinguistics,* 11**,** 33-53.
PETERSEN, R. C., CARACCIOLO, B., BRAYNE, C., GAUTHIER, S., JELIC, V. & FRATIGLIONI, L. 2014. Mild cognitive impairment: a concept in evolution. *Journal of Internal Medicine,* 275**,** 214-228.
PLANALP, S. & TROST, M. R. 2008. Communication issues at the end of life: Reports from hospice volunteers. *Health Communication,* 23**,** 222-233.
PRATCHETT, T. 2011. Living with early dementia. *Long-Term Conditions: Challenges in Health & Social Care***,** 5.
PRINCE, M. J. 2015. *World Alzheimer Report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends,* London, Alzheimer's Disease International.
RCSLT 2014. Speech and Language Therapy Provision for People with Dementia. London, UK: Royal College of Speech and Language Therapists.
REISBERG, B., FERRIS, S. H. & FRANSSEN, E. 1985. An ordinal functional assessment tool for Alzheimer's-type dementia. *Psychiatric Services,* 36**,** 593-595.
REVES, A., TIMMONS, S., FOX, S., MURPHY, A. & O'SHEA, E. 2018. Dementia Diagnostic Services for Ireland: a literature review.
REVEZ, A., TIMMONS, S., FOX, S., MURPHY, A. & O'SHEA, E. 2018. Systematic Review: Dementia Diagnostic Services for Ireland: a literature review 2018. Dublin, Ireland: National Dementia Office.
RIPICH, D. N., WYKLE, M. & NILES, S. 1995. Alzheimer's disease caregivers: The FOCUSED program: A communication skills training program helps nursing assistants to give better care to patients with Alzheimer's disease. *Geriatric Nursing,* 16**,** 15-19.
RYAN, K., CONNOLLY, M., CHARNLEY, K., AINSCOUGH, A., CRINION, J., HAYDEN, C., KEEGAN, O., LARKIN, P., LYNCH, M. & MCEVOY, D. 2014. Palliative care competence framework 2014. Dublin, Ireland: Health Service Executive.
SAMUELSSON, C. & HYDÉN, L.-C. 2017. Collaboration, trouble and repair in multiparty interactions involving couples with dementia or aphasia. *International Journal of Speech-Language Pathology,* 19**,** 454-464.
SANDELOWSKI, M. 2010. What's in a name? Qualitative description revisited. *Research in Nursing & Health,* 33**,** 77-84.
SATIZABAL, C. L., BEISER, A. S., CHOURAKI, V., CHÊNE, G., DUFOUIL, C. & SESHADRI, S. 2016. Incidence of dementia over three decades in the Framingham Heart Study. *New England Journal of Medicine,* 374**,** 523-532.
SAVUNDRANAYAGAM, M. Y., HUMMERT, M. L. & MONTGOMERY, R. J. 2005. Investigating the effects of communication problems on caregiver burden. *The*

Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 60**,** S48-S55.
SAVUNDRANAYAGAM, M. Y., SIBALIJA, J. & SCOTCHMER, E. 2016. Resident reactions to person-centered communication by long-term care staff. *American Journal of Alzheimer's Disease & Other Dementias®,* 31**,** 530-537.
SCHOENMAKERS, B., BUNTINX, F. & DELEPELEIRE, J. 2010. Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas,* 66**,** 191-200.
SHERRATT, C., SOTERIOU, T. & EVANS, S. 2007. Ethical issues in social research involving people with dementia. *Dementia,* 6**,** 463-479.
SHUB, D., BASS, D. M., MORGAN, R. O., JUDGE, K. S., SNOW, A. L., WILSON, N. L., WALDER, A., MURRY, B. & KUNIK, M. E. 2011. Irritability and social isolation in dementia patients with and without depression. *Journal of geriatric psychiatry and neurology,* 24**,** 229-234.
SIMMONS-MACKIE, N., SAVAGE, M. C. & WORRALL, L. 2014. Conversation therapy for aphasia: a qualitative review of the literature. *International Journal of Language & Communication Disorders,* 49**,** 511-526.
SMALL, J. A., GUTMAN, G., MAKELA, S. & HILLHOUSE, B. 2003. Effectiveness of communication strategies used by caregivers of persons with Alzheimer's disease during activities of daily living. *Journal of Speech, Language, and Hearing Research,* 4**,** 154-171.
SOHLBERG, M. M. & MATEER, C. A. 1989. *Introduction to cognitive rehabilitation: Theory and practice,* London, Guilford Press.
STRØM, B. S., ENGEDAL, K. & GROV, E.-K. 2016. A Psychometric Evaluation of the Threadgold Communication Tool for Persons with Dementia. *Dementia and Geriatric Cognitive Disorders Extra,* 6**,** 150-160.
SWAFFER, K. 2014. Dementia: stigma, language, and dementia-friendly. *Dementia,* 13(6)**,** 709-716.
SWINBURN, K., BYNG, S. & FIRENZA, C. 2006. *Communication Disability Profile*, Connect Press.
SWINBURN, K., PORTER, G. & HOWARD, D. 2004. *Comprehensive aphasia test,* London, Taylor & Francis.
TERI, L., MCCURRY, S. M., LOGSDON, R. & GIBBONS, L. E. 2005. Training community consultants to help family members improve dementia care: a randomized controlled trial. *The Gerontologist,* 45**,** 802-811.
THOMPSON, C. & BRIGGS, M. 2000. Support for carers of people with Alzheimer's type dementia. *The Cochrane Database of Systematic Reviews***,** CD000454-CD000454.
TOMOEDA, C. K. 2001. Comprehensive assessment for dementia: A necessity for differential diagnosis and management. *Seminars in Speech and Language,* 22**,** 275-290.
VOLKMER, A. 2013. *Assessment and therapy for language and cognitive communication difficulties in dementia and other progressive diseases,* Guilford, UK, J&R Press.
VOLKMER, A., SPECTOR, A., WARREN, J. D. & BEEKE, S. 2018a. Speech and language therapy for primary progressive aphasia: referral patterns and barriers to service provision across the UK. *Dementia,* 0(0)**,** 1-15.
VOLKMER, A., SPECTOR, A., WARREN, J. D. & BEEKE, S. 2018b. Speech and language therapy for primary progressive aphasia: referral patterns and barriers to service provision across the UK. *Dementia***,** 1471301218797240.
WADE, D. T. 1992. Measurement in neurological rehabilitation. *Current Opinion in Neurology and Neurosurgery,* 5**,** 682-686.
WALSHE, M. & MILLER, N. 2011. Living with acquired dysarthria: the speaker's perspective. *Disability and Rehabilitation,* 33**,** 195-203.
WATSON, C. 1995. Making Hanen Happen. *Toronto, Canada: The Hanen Center*.

WESCHSLER, D. 1981. *Adult Intelligence Scale, Revised (WAIS-R) Manual,* San Antonio, Psychological Corp.
WHITLATCH, C. J., JUDGE, K., ZARIT, S. H. & FEMIA, E. 2006. Dyadic intervention for family caregivers and care receivers in early-stage dementia. *The Gerontologist,* 46**,** 688-694.
WHITNEY, D. D. & TROSTEN-BLOOM, A. 2010. *The power of appreciative inquiry: A practical guide to positive change,* California, USA, Berrett-Koehler Publishers.
WHO 2001. International classification of functioning, disability and health: ICF. Geneva: WHO.
WHO 2017. Global action plan on the public health response to dementia 2017–2025. World Health Organisation.
WHOOLEY, M. A. 2016. Screening for depression—a tale of two questions. *JAMA Internal Medicine,* 176**,** 436-438.
WOODS, R. T., BRUCE, E., EDWARDS, R. T., HOUNSOME, B., KEADY, J., MONIZ-COOK, E. D., ORRELL, M. & RUSSELL, I. T. 2009. Reminiscence groups for people with dementia and their family carers: pragmatic eight-centre randomised trial of joint reminiscence and maintenance versus usual treatment protocols. *Trials,* 10**,** 64.
WORRALL, L., MCCOOEY, R., DAVIDSON, B., LARKINS, B. & HICKSON, L. 2002. The validity of functional assessments of communication and the Activity/Participation components of the ICIDH-2: do they reflect what really happens in real-life? *Journal of Communication Disorders,* 35**,** 107-137.
ZETTELER, J. 2008. Effectiveness of simulated presence therapy for individuals with dementia: a systematic review and meta-analysis. *Aging and Mental Health,* 12**,** 779-785.
ZIENTZ, J., RACKLEY, A., CHAPMAN, S. B., HOPPER, T., MAHENDRA, N., KIM, E. S. & CLEARY, S. 2007. Evidence-based practice recommendations for dementia: educating caregivers on Alzheimer's disease and training communication strategies. *Journal of Medical Speech-Language Pathology,* 15**,** liii-liii.

Appendices

Appendix 1.1 Copyright Permission

From: sudooley@tcd.ie <sudooley@tcd.ie>

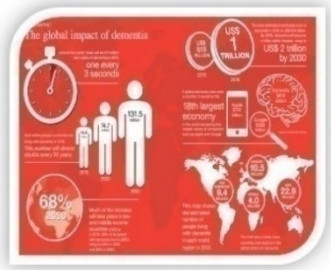
Sent: 23 June 2019 18:21

To: Alzheimer's Disease International <info@alz.co.uk>

Subject: Copyright question World Alzheimer's Report

Dear ADI team,

I am doing my Ph.D. in communication and dementia. I want to include this diagram below from the World Alzheimer's Report 2015. Is this possible is copyright free for these purposes?



Kind Regards,

Suzanna Dooley

PhD Student

Trinity College Dublin

ML

Mon 24/06/2019 11:14

Michael Lefevre <m.lefevre@alz.co.uk>

RE: Copyright question World Alzheimer's Report

To sudooley@tcd.ie

Hi Suzanna,

Thanks for your interest. Yes, you are welcome to use that infographic provided that you reference us as the source. https://www.alz.co.uk/permissions has more details.

Best regards,

Michael Lefevre
General Manager
Alzheimer's Disease International
64 Great Suffolk Street, London, SE1 0BL
t: +44 20 7981 0880

Website | Twitter | Facebook | Newsletter

Alzheimer's Disease International
The global voice on dementia

Appendix 4.1 Ethical Approval SLT Practice Survey

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

30/05/2018

Application	Academic Year 2017/18
Applicant:	HT18 Dooley, Suzanna
Title of Research:	Speech and Language Therapy Practice in Management of Cognitive Communication Difficulties in People with Dementia in Ireland.

Dear Suzanna,

Your application for ethics approval for the research project above was approved on Tuesday 30th January 2018, with just two minor requests for revisions. In section 5.5 there is no time interval between giving information about the study and asking participants to fill out the survey. The Committee requests that you make sure there at least three days in between.

In section 5.8 you indicate "not available" here, but there is a questionnaire that participants may want to have. The Committee suggests that you indicate that the questionnaire will be available upon request.

To be clear: your application is approved and you do not need to resubmit your application. We wish you the very best in your research activities. Please note that on completion of research projects, applicants should complete the End of Project Report Form.
Best wishes,

Professor John Saeed

Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences

School of Linguistic, Speech & Communication Sciences,
Trinity College,
Dublin 2, Ireland

T: [redacted]

Appendix 4.2 Gatekeeper E-mail

To whom it may concern,

My name is Suzanna Dooley, I am a registered PhD Student at the Department of Clinical Speech and Language Studies, Trinity College Dublin under the supervision of Dr. Margaret Walshe. I am contacting you as the chairperson of the (Name of Professional Body/ SIG). My research study aims to explore the current clinical practices of Speech and Language therapists (SLTs) in the management of communication difficulties associated with dementia. As part of this research study, I would like to gather further information on the practices of SLTs regarding the management of cognitive communication disorders associated with dementia in the Republic of Ireland. I have designed a short online survey seeing information on this.

I would be grateful if you would consider circulating the attached email that contains information on the project and the survey link to the members of (name of body /group inserted here). The survey should take no more than 10 minutes to complete. There are no anticipated risks for participants. No identifying information is sought, and any identifying information will be removed at the point off data analysis. The project has obtained ethical approval from the School of Linguistic, Speech and Communication Sciences, Trinity College, Dublin.

If you would be happy to act as gatekeeper and disseminate this email, or if you have any further questions or queries then I look forward to hearing from you. My contact details can be found below.

Many thanks,

Suzanna Dooley

Suzanna Dooley, PhD Candidate
Department of Clinical Speech and Language Studies
Tel:+353 86 6098109
Trinity College
7-9 South Leinster Street
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Email: sudooley@tcd.ie

Dr Margaret Walshe, Associate Professor
Department of Clinical Speech and Language Studies
Tel:+353 1 896 2382
Trinity College
7-9 South Leinster Street
Dublin 2
Email: walshema@tcd.ie

Appendix 4.3 Participant Email

Study Title

Speech and Language Therapy Management of Cognitive Communication Difficulties in People with Dementia in Ireland

Introduction

My name is Suzanna Dooley and I am currently registered as a PhD student in the Department of Clinical Speech and Language Studies, Trinity College, Dublin. My research study is focussed on examining the current practices of SLTs in the management of cognitive communication disorders associated with dementia. As part of this study, I would like to gather information on the experiences and practices of Speech and Language Therapists working with people with dementia. I am therefore inviting you to participate in a short online survey on this subject.

What's involved?

Participation in this study requires the completion of an online survey which can be found at this link [insert link here]. This survey contains 10 questions and should take approximately 15 minutes to complete. You can stop completing the survey at any time. Completion of the survey denotes your consent.

Confidentiality and Ethics

This survey is completely anonymised and you will not be required to provide any identifying information. Ethical approval has been granted by the School of Linguistics, Speech and Communication Sciences, Trinity College, Dublin. There are no risks associated with the completion of this survey.

Further Information

For further information regarding this survey please contact:

Suzanna Dooley, PhD Candidate
Clinical Speech and Language Studies
Tel:+353 86 6098109
Trinity College
7-9 South Leinster Street,
Dublin 2
Email: sudooley@tcd.ie

Dr Margaret Walshe, Associate Professor
Department of Clinical Speech and Language Studies
Trinity College
7-9 South Leinster Street
Dublin 2
Tel: +353 1 896 2382
Email: walshema@tcd.ie

Appendix 4.4 Web Page Posting

To whom it may concern,

My name is Suzanna Dooley, I am a registered PhD Student at the Department of Clinical Speech and Language Studies, Trinity College Dublin under the supervision of Dr. Margaret Walshe. I am contacting you as the chairperson of the (Name of Professional Body/ SIG). My research study aims to explore the current clinical practices of Speech and Language therapists (SLTs) in the management of communication difficulties associated with dementia. As part of this research study, I would like to gather further information on the practices of SLTs regarding the management of cognitive communication disorders associated with dementia in the Republic of Ireland. I have designed a short online survey seeing information on this.

I would be grateful if you would consider circulating the attached email that contains information on the project and the survey link to the members of (name of body /group inserted here). The survey should take no more than 10 minutes to complete. There are no anticipated risks for participants. No identifying information is sought, and any identifying information will be removed at the point off data analysis. The project has obtained ethical approval from the School of Linguistic, Speech and Communication Sciences, Trinity College, Dublin.

If you would be happy to act as gatekeeper and disseminate this email, or if you have any further questions or queries then I look forward to hearing from you. My contact details can be found below.

Many thanks,
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Dr Margaret Walshe, Associate Professor
Department of Clinical Speech and Language Studies
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7-9 South Leinster Street
Dublin 2
Tel:+353 1 896 2382 Email: walshema@tcd.ie

Appendix 4.5 Reminder E-mail

Dear colleague,

You may remember receiving an email 3 weeks ago about a survey we are conducting about *the Speech and language Therapy Management of Cognitive Communication Difficulties in People with Dementia in Ireland.* If you are still interested in completing this survey, please click on the following link (insert link here). An overview of the research purpose and scope are outlined below.

Introduction

My name is Suzanna Dooley and I am currently registered as a PhD student in the Department of Clinical Speech and Language Studies, Trinity College, Dublin. My research study is focussed on examining the current practices of SLTs in the management of cognitive communication disorders associated with dementia. As part of this study, I would like to gather information on the experiences and practices of Speech and Language Therapists working with people with dementia. I am therefore inviting you to participate in a short online survey on this subject.

What's involved?

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Confidentiality and Ethics

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For further information regarding this survey please contact:

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Appendix 4.6 Global Deterioration Scale

Some health-care professionals use the Global Deterioration Scale, also called the Reisberg Scale, to measure the progression of dementia. Within the GDS, each stage is numbered (1-7) and given a short title and a description of the clinical characteristics for that stage. Below is a summarised version.

Stage 1: No cognitive decline

- Experiences no problems in daily living.

Stage 2: Very mild cognitive decline

- Forgets names and locations of objects.
- May have trouble finding words.

Stage 3: Mild cognitive decline

- Has difficulty travelling to new locations.
- Has difficulty handling problems at work.

Stage 4: Moderate cognitive decline

- Has difficulty with complex tasks (finances, shopping, planning dinner for guests).

Stage 5: Moderately severe cognitive decline

- Needs help to choose clothing.
- Needs prompting to bathe.

Stage 6: Severe cognitive decline

- Loss of awareness of recent events and experiences.
- Requires assistance bathing; may have a fear of bathing.
- Has decreased ability to use the toilet or is incontinent.

Stage 7: Very severe cognitive decline

- Vocabulary becomes limited, eventually declining to single words.
- Loses ability to walk and sit.
- Requires help with eating.

Reisberg, B., Ferris, S. H., de Leon, M. J., and Crook, T. (1982). Modified from Global Deterioration Scale. American Journal of Psychiatry, 139:1136–1139.

Appendix 5.1 Assessing Cognitive Communication Skills in Dementia: A Scoping Review

Suzanna Dooley [12] and Margaret Walshe[1]

[1] Department of Clinical Speech and Language Studies, Trinity College Dublin, Dublin, Ireland

[2] St. Columcille's Hospital HSE, Loughlinstown, Co. Dublin, Ireland

Abstract

Background: Cognitive communication difficulties are a characteristic feature of dementia. These deficits have negative effects on all aspects of daily life. Yet, there are few options for standardized assessment of cognitive communication skills in people with dementia.

Aims: The purpose of this study was to review published cognitive-communication assessments to determine what psychometrically sound assessments exist that are applicable to all people with dementia.

Methods and Procedures: A scoping review of the literature was conducted using an established scoping review model. Cognitive-communication assessments validated in English with people with dementia were sought. A comprehensive search of eight relevant electronic databases was undertaken. Two reviewers independently analysed and assessed the psychometric quality of instruments that met inclusion criteria.

Outcomes and Results: Four cognitive-communication assessments were included in the review. Although psychometrically sound, none were suitable for administration at all stages of dementia. Only one was validated for different dementia types. None included subtests for evaluation of conversation ability, and none involved evaluation of communication partners' communication.

Conclusions and Implications: There are limited options for standardised communication assessment for individuals with dementia and their communication partners. Directions for the development of new measures are provided to facilitate research and improve clinical practice.

Key words: dementia, cognitive communication, functional communication assessment, communication partner.

Introduction

Dementia is a syndrome in which there is deterioration in cognitive function beyond what might be expected from normal ageing, affecting memory, thinking, behaviour and the ability to perform everyday activities World Health Organization (WHO 2017). Cognition and particularly memory, is affected early in Alzheimer's disease (AD) (Amieva *et al.*, 2005) and in other types of dementia also. Therefore, the focus for assessment and treatment has tended to be on cognition generally or on discrete cognitive domains such as memory. The effects of cognitive decline on the communication ability of individuals with dementia is well-documented yet communication is not often explicitly stated as part of the definition of dementia. As the prevalence of dementia grows and the demand for intervention increases with it, there is a growing need to focus on "communication" as part of the dementia syndrome (Jones *et al.*, 2016) and as a target for assessment and intervention by speech and language therapists (SLTs).

Problems with communication may be an initial presenting feature of dementia, although the nature of these impairments will vary depending on the underlying disease (Bourgeois and Hickey, 2011). Over time dementia causes increased disruption to the cognitive-linguistic system. This changes the way in which the person interacts, reducing communicative flexibility and effectiveness. This slows down and complicates even the most basic communication exchanges. A deterioration in functional communication, will impact on the individual's ability to communicate their needs, wants, feelings, and preferences verbally or non-verbally effectively so that others can understand. .This can lead to low self-esteem, reduced levels of independence and quality of life, with a significant impact on the personal relationships of the person with dementia (Jones, 2015). The communication partner frequently becomes the leading partner in conversation over time, as the person with dementia requires increasing support to communicate his/her needs and wishes. The collaborative nature of conversation means that communication partners have an integral role in scaffolding the conversation abilities of the person with dementia (Kindell *et al.*, 2017). A conversational partnership in the context of supported conversations in aphasia, emphasizes the skills and experience of the communication partner and focuses on creating communication opportunities to increase social participation (Kagan *et al.*, 2001). Adaptation by the communication partner to these changes in communication function is essential for the person with dementia to maintain autonomy, and to connect meaningfully with others for as long as possible. Revealing the communication competence of the person with dementia and developing support strategies to enhance retained communication skills is core to speech and language therapy practice. The goal of intervention is to improve and maintain communication competence despite the progressive decline in cognitive communication ability caused by dementia. Interventions should ideally be individualized to enhance the social communication competencies that are retained and to address specific barriers to communication. Communication interventions can reduce social isolation and help maintain relationships by improving communication competence.

Comprehensive assessment of cognitive communication skills forms the basis for intervention. Such assessments should evaluate a range of cognitive communication skills that underpin everyday communication. Cognitive communication assessments should guide clinicians in determining the best interventions to address communication difficulties and enable them to provide the best possible support to the person with dementia and their family. A broadened definition of communication competence (MacDonald 2017) (see Figure 1.) acknowledges the multiple cognitive processes that influence communication and are influenced by the person's unique communication environment.

<Note to Editor : Insert Figure 1 here>

The cognitive domain (i.e. executive function, attention, working memory, speed of processing, social cognition, reasoning and problem solving) impacts on the communication domain (i.e. auditory comprehension, verbal expression, pragmatics, reading and writing). A comprehensive focus on the individual's communication domain takes account of the physical (e.g., hearing and visual perception) and emotional (e.g., anxiety, confidence, depression) factors that can influence communication performance. This specifically refers to the person's functional communication ability to participate and fulfill his/her social, work and family roles. For every person with dementia it is argued that there will be a dynamic relationship between these contexts and domains (environment, cognitive, communication, physical and emotional), which will determine the communication competence of the individual. This is the context in which cognitive communication assessment should be undertaken which will then reflect each person with dementia's unique communication profile.

The assessment of cognitive communication skills to direct intervention can present a challenge to SLTs in practice (Volkmer, 2013). In an unpublished study involving 89 SLTs in Republic of Ireland in 2018 by Dooley and Walshe only 10% of respondents reported that they regularly carry out formal assessments with people with dementia. There are many contributing factors to this clinical practice, but limited access to appropriate assessments was cited as a significant reason. This perceived lack of assessment resources affects the clinician's ability to evaluate and manage communication services for individuals with dementia. Appropriate evaluation tools are necessary to facilitate description of communication deficits and to identify spared and impaired abilities around which to develop comprehensive plans of care (Tomoeda, 2001). Measuring change in communication function in dementia requires consideration of outcomes related to activities and participation in daily life.

Although several communication assessment tools exist, a comprehensive examination of the characteristics of these assessments for people with dementia has not been conducted.

Aims

The primary aim of this study was to comprehensively review the existing cognitive-communication assessments for people with dementia. The objective is to facilitate SLTs in their management of cognitive communication impairments, providing necessary information on assessment tools accessible to clinicians who work with people with dementia. For the purposes of this review, cognitive communication assessments were defined as objective tests available and appropriate for use by SLTs to evaluate a range of cognitive, linguistic and communication skills associated with dementia. The research questions were as follows:

What psychometrically sound cognitive communication assessments for dementia, are available to SLTs?

Further questions were posed for the assessments retrieved:

(a) Are available assessments validated on all types and stages of dementia?

(b) Do these assessments evaluate everyday (functional) communication skills?

(c) Do these assessments involve the communication partner?

(d) Do they inform intervention and care pathways?

Methods

A scoping review of the literature was conducted using the methodological framework set out by Arksey and O' Malley (2005). This review framework was considered most suited to meet the aims of the study, as it facilitates the synthesis of the main evidence available. It is considered a broad and detailed reviewing method that can facilitate the identification of gaps in the area under review. There are six stages to this framework (see Table 1).

<Note to Editor Insert Table 1 here>

This review framework was expanded to incorporate other methodological enhancements suggested by Levac *et al*. (2010) and Peters *et al*. (2015). These enhancements included consultation with speech and language therapy experts in dementia and the making of recommendations for future research.

Scoping Review Framework

The research question was already formulated (see above). The second stage of the process was to find relevant assessment and studies through a comprehensive search of evidence from different sources; electronic databases, reference lists, websites, conference proceedings, hand searches etc. Inclusion criteria were published cognitive communication assessments validated in English for people with dementia. A comprehensive search strategy was formulated in conjunction with a university librarian. A search string was devised for PubMed, which consisted of a combination of medical subject headings (MeSH) and Title/Abstract keywords. This search

was then applied across selected databases and adapted accordingly. Other literature outside of standard academic publications and reference lists of relevant studies were also searched. No language filters were applied. Date filters were applied.

The search terms were as follows: (communication, communications, communication AND Alzheimer OR alzheimer's OR alzheimers OR dementia OR dementias OR Dementia). The eight relevant electronic databases searched from inception of the database to March 2018 were PubMed, EMBASE, Science direct, Web of Science, LLBA, PsycINFo, Scopus and SpeechBite. Other forms of searching undertaken were reviewing relevant article reference lists, hand searching of relevant textbooks and consulting with expert clinicians in dementia.

Reference manager software (EndNote X8) was used to manage the search findings. Inclusion criteria were as follows: published cognitive communication assessments validated in English for people with dementia. The inclusion criteria were then applied to the identified literature, to determine their relevance. Eligibility for inclusion was determined by screening titles and abstracts to retrieve full research articles. Electronic database searching yielded 7,584 articles, which were then screened for inclusion (PubMed 4,276, EMBASE 1,103, Science Direct 1,692, Web of Science 378, LLBA 61, PscyINFO 12, Scopus 25, SpeechBite 37). (Figure 2. PRISMA Flow Diagram).

<Note to Editor, Insert Figure 2 here>

Study Selection

The third step was study selection. After duplicates were removed, 7,527 studies were available for screening. Several irrelevant studies were identified from the abstracts, likely resulting from the broad application of some of the search terminology in the literature. To identify the studies that best addressed the research question, both authors applied the inclusion criteria to all the studies. A third reviewer was identified to arbitrate where there was disagreement, but this did not occur. When relevance of a study was unclear from the abstract, the full article was retrieved. The reviewers then read the full articles/assessment manual to determine suitability for inclusion. Other non-electronic searches yielded four assessments that were initially identified by the electronic database search. As suggested by Levac *et al*. (2010) and Peters *et al*. (2015) consultation was sought and received from SLTs who had clinical experience working with people with dementia. These SLTs comprised of Irish and international therapists (n=5) who worked in a range of clinical settings with at least five years experience in the dementia field. They confirmed that they were not aware of any cognitive communication assessment for people with dementia additional to those identified by this search. Following preliminary analysis, nine cognitive communication assessments met the inclusion criteria for the review.

Charting the Data

The next stage of the review involved organizing and recording key information obtained from the nine assessments included in the review. The researchers developed data chart forms to facilitate data extraction. Charting is described as an iterative process (Levac et al., 2010) where

the data charting form is updated on an ongoing basis, as required. As the researchers became more familiar with the data, the form was refined, so that key data could be charted. The charting approach takes a broader view (Pawson, 2002) that can include more specific information about the study and, in this case, assessment of psychometric characteristics of validity and reliability.

Data was extracted and collated and at this stage five of the nine assessments were excluded (See Table 2). Reasons for exclusion were the populations involved in validating the test and the lack of availability of the test for use by SLTs. For example, the CADL-2 (Holland *et al.*, 1999) was validated with people following stroke and traumatic brain injury and the ECAT (Bruce *et al.*, 2013) with older persons without neurological disease/disorder. The Barnes Language Assessment (Bryan *et al.*, 2001) was published in a journal and not as an assessment and therefore is not available for clinical use. Both authors individually analysed and assessed the methodological quality of these assessments. When available test manuals of these assessments were retrieved to analyse validation data.

<Note to Editor Insert Table 2 here >

The next stage of the scoping review framework involved collating, summarising and reporting the results.

Results

Four cognitive communication assessments were eligible for inclusion in the final review (Table 3). All four are available for SLTs working with people with dementia. These assessments are as follows:

- Severe Impairment Battery (SIB) (Saxton *et al.*, 1993),
- Arizona Battery for Communication Disorders (ABCD) (Bayles and Tomoeda, 1993),
- Functional Linguistic Communication Inventory (FLCI) (Bayles and Tomoeda, 1994),
- Cognitive Linguistic Quick Test (CLQT) (Helm-Estabrooks, 2001).

<Note to Editor, Insert Table 3 here>

Publication details and validation cohorts.

Publication dates of assessment included in the review ranged from 1993-2001. The most recently published was the CLQT, 17 years ago. They are all commercially available to SLTs through publishers in the UK and USA. SIB validation study (Saxton *et al.*, 1993) was carried out using the second of three versions of this assessment, as described in their test manual. The ABCD and FLCI were both developed using a combination of data from retrospective and prospective studies. Approximately half of the test items in the FLCI originated from a five-year longitudinal study (n=91) and remaining items were developed for the standardization study. The FLCI standardisation cohort had 40 subjects (Bayles and Tomoeda 1994). Longitudinal study data matched test suitability to the stage of dementia. CLQT was developed following a pilot

study and three subsequent research studies described in the test manual (Helm-Estabrooks, 2001).

Participants in these validation studies had conditions other than dementia and in two of the four assessments the dementia populations were proportionately small, ranging from 11 to 86 participants. The CLQT was validated on 11 people with dementia out of 299 participants, representing just 3.7% of the overall participant population. The total FLCI standardisation sample comprised 40 people with dementia. ABCD had 86 people with dementia (32%) out of 272 participants. In the case of SIB, 70 participants were selected for the validation study 50 of these (71%) were identified as having 'probable AD" and 19 (27%) as having 'possible AD'.

The validity and reliability of included assessments

None of the included assessments were specifically designed to address the full range of cognitive-linguistic domains that are typically impaired in dementia (i.e., attention, visual processing, memory, executive functioning, and auditory comprehension, verbal expression, reading and writing).

<Note to Editor – insert Table 4 here >

The concurrent validity of the SIB, ABCD and FLCI was measured against the Mini Mental State Exam (MMSE) (Folstein *et al.*, 1975). SIB was validated using the MMSE as well as the Dementia Rating Scale (Mattis, 1988). ABCD was validated using three measures including the MMSE, the Global Deterioration Scale (GDS) (Reisberg *et al.*, 1985) and the Block Design subtest of the WAIS-R (Wechsler, 1981). FLCI also used MMSE and the modified FAST (Sclan and Reisberg, 1992). (See Table 4). The validation of CLQT comprised of one pilot test and three research studies, one of these studies involved the CLQT being used by 30 SLTs. It was then refined without the use of concurrent assessment measures.

<Note to Editor – insert Table 5 here >

Internal consistency, test-retest reliability and interrater reliability

No reference to the internal consistency values was made for SIB, FLCI and CLQT. Internal consistency was tested on the ABCD subtests for 50 AD participants. Cronbach's alpha scores were highest (> 0.9) for storytelling and figure copying and lowest for comparative questions (0.5).

Test-retest reliability is used as a measure of the stability of a test, but the stability of the condition tested must also be considered. All tests included in the review were administered by the same tester on two separate occasions (see Table 5). SIB was retested within a time interval of 30 days and the correlation co-efficient between tests was high ($r=.99$, $P\leq.001$). In the case of ABCD, 20 of the 50 participants with AD in the standardization study were retested after one-week, moderate positive correlation ($r^2= 0.5$) was found between both tests of scores. Half of the FLCI participants (20/40) involved in the standardization study were retested one week after the initial assessment. There was high-test retest reliability between both results using Pearson's product-

moment and Kendell's Tau (>0.8 for 7/10 subtests) with this test. FLCI and ABCD tests were administered again after a week, one might consider familiarization with test materials within this timeframe. The CLQT was retested after 80 and 140 days with a non-clinical sample of 46 participants. According to the test manual "test-retest stability coefficients ranged between 0.61 and 0.90 for the cognitive domains". There was minimal difference in performances between test and retest with most participants receiving a perfect score on most tasks.

Inter rater reliability for the SIB was reported as high ($r = 0.99$, $p \leq 0.001$). For the ABCD, inter rater agreement was between 93.3%-98.3% on the 4 subtests evaluated. Inter rater reliability was not reported for the FLCI. Inter rater agreement for CLQT with 170 healthy participants was reported on two subtests that require clinical judgment. It was not clear how the correlation coefficient between both scorers was calculated, but it was reported as strong (Clock Drawing $r= 0.86$ and on the Generative Naming Task $r=0.99$).

Acceptability and feasibility

Factors considered in judging acceptability and feasibility were the currency of assessments (i.e. the length of time since validation), time taken to complete the test and stages and types of dementia subtypes covered by the test.

Currency of assessment: some tests were published as early as 1993, therefore some of the stimulus test materials are considered outdated. For example, the use of a telephone from the early 1900s as part of the reminiscence subtest of the FLCI might seem out of date in 2018.

Time taken to complete tests: administration times: of 30 mins or less (SIB, FLCI, CLQT) are suitable for administration with people with dementia, as there is reduced participant burden associated with a shorter assessment process. The estimated time taken to administer these assessments ranges from 15 mins (CLQT) to 90 mins (ABCD). The ABCD is time intensive (45-90 mins) to administer (Bayles and Tomoeda, 1991) and may need to be completed over several short assessment sessions, it is unclear from the test manual if this was a consideration in the validation process. However, certain subtests can be administered in isolation, which can reduce the assessment time and refine the assessment process. The other assessments (SIB, FLCI and CLQT) can be completed within a 30-minute clinical session. These administration times were stated in the assessment test manuals, but also fit with the direct clinical experience of the authors.

The inclusion of people with different dementia subtypes such as vascular dementia (VAD), frontotemporal dementia (FTD) and dementia with Lewy bodies (LBD) in these validation studies was limited. The SIB included one participant with vascular dementia and 69 participants with AD. ABCD validation was carried out with 86 people with AD (32%). 70 participants had Parkinson's Disease (PD) (26%), of whom 8 had dementia (2.9% of the total sample): differences between the performances of those with and without dementia were evident. A control group consisted of 86 age-matched healthy participants and 30 young healthy participants. The ABCD was the only assessment that attempted to address the difference in cognitive-linguistic profiles

that occur within dementia subtypes, albeit with just 2 subtypes; AD and non-demented Parkinson's disease.

The ABCD and the CLQT are suitable for use with people in the early stages of dementia, while the FLCI and the SIB were designed for use in the mid to late stages of dementia. None of the assessments in this scoping review are suitable for use with people with dementia across all the stages of cognitive decline.

Comprehensiveness of Available Assessments

The ultimate goal of assessment is to inform intervention. For people with dementia the key areas of assessment are the evaluation of functional communication skills and ideally the involvement of a communication partner in assessment to address the collaborative nature of conversation. The comprehensiveness of the assessments was evaluated according to the following parameters.

(a) *Evaluation of functional communication skills within assessments*

All 4 assessments give a total score/percentile rating and profile of cognitive linguistic impairment, but the assessment of functional communication skills is either restricted (SIB, FLCI) or absent (ABCD, CLQT).

SIB screens for deficits in attention, language, memory, visuospatial and construction skills. It has a short subtest evaluating social interaction, where the person is engaged in conversation. ABCD is an assessment of higher level language and cognitive skills. It includes subtests for screening hearing and visual impairments, which made it unique among this group of assessments. However, it does not evaluate writing, pragmatics or conversation skills (see Table 6).

<Note to Editor, insert Table 6 here >

FLCI assesses core linguistic parameters (comprehension, verbal expression, reading and writing) as well as non-verbal communication. As it's title suggests, it evaluates aspects of functional communication skills, such as greeting and leave taking, conversational contributions, appropriateness and the use of gesture. The CLQT assesses cognitive skills such as attention, visuospatial and executive functions rather than linguistic skills. Language subtests provide an overview of naming, story retelling and comprehension.

Functional communication is only briefly addressed by all four included assessments and there is limited evaluation of the non-verbal aspects of communication (SIB, FLCI).

(b) *Involvement of the communication partner in assessment*

Contextual analysis of communication skills is absent across all four assessments with no involvement of the communication partners (CPs) in the assessment process. The CPs are not interviewed regarding everyday communication and/or functional communication ability. The emphasis is on the person with dementia rather than on their conversation partner and/or the

dyad. There is also no focus either on the skills of the CP in supporting the person with dementia in conversation in any of the reviewed assessments.

All four assessments evaluated a range of cognitive, linguistic and in some cases functional communication skills, but none of these assessments involved the CP in the assessment process.

Discussion

This scoping review of cognitive communication assessments for people with dementia adds to the current body of evidence on assessment in people with dementia. The authors have critically appraised specific cognitive communication assessments in people with dementia. Several important findings from this review include; the limited availability of cognitive communication assessments that can be used with a range of subtypes and across the stages of dementia, the available assessments reviewed do not comprehensively evaluate functional communication and/or include communication partners.

Limited availability of cognitive communication assessments

It is evident that SLTs have a limited number of psychometrically sound cognitive communication assessments available for use with people with dementia that include parameters that are directly relevant to the management of cognitive communication disorders associated with dementia.

Available assessments not validated with a range of dementia subtypes and stages

Perceptible changes in language and communication are key in facilitating timely diagnosis and highlight the need for early involvement of SLTs in the diagnostic process. Subtle changes in communicative function may be an early sign of underlying neurological condition (Harris *et al.*, 2008). Objectively measuring and comparing changes in communication across the spectrum of dementia severity is impacted by the limited access to suitable assessments.

Currently available assessments are restricted by the type of clients they can be used with and their appropriateness for the stage of dementia. This impacts on the clinician's ability to determine the communication profile of the person with dementia, reducing the efficiency of the assessment process, and the ability to measure objective change in functional communication. Only the authors of the ABCD attempted to validate the test with people with dementia subtypes other than AD (Tomoeda, 2001). There is a lack of cognitive communication assessments that are suitable for use with other sub types of dementia such as VAD and FTD.

These reviewed assessments were developed for people in the early to mid stages or mid to late stages of dementia, so they cannot be used as repeatable assessment measures across all the stages. It is widely acknowledged that people with dementia have retained communication abilities even in the advanced stages of dementia (Hopper, 2003). This lack of assessment tools provides a challenge for SLTs and may restrict interventions offered to people who require maximum communication support in the late stages of dementia.

Restricted emphasis on functional communication

The results of this review support the hypothesis that clinicians must rely on informal assessments or those that are not developed with people with dementia. The identification of individualised functional goals and effective compensatory strategies for communication is more challenging without access to a range of cognitive communication assessments. The lack of functional communication assessment tools restricts the evaluation process and reduces the likelihood that meaningful interventions may be offered to people who require maximum communication support particularly in the mid to late stages of dementia.

Comprehensive assessment involves the consideration of a range of aspects of communication as reflected in the MacDonald's model (2017). When the evaluation of functional communication skills is limited, as was found in the reviewed assessments, this impedes the identification of specific support strategies to maximise retained functional skills. The identification of individualised functional goals and effective compensatory strategies for communication is more challenging without access to a range of cognitive communication assessments. There is a growing body of evidence (Eggenberger *et al.*, 2013, Liddle *et al.*, 2012) as to the multiple benefits of SLT intervention in the promotion of effective communication for people with dementia and their communication partners. In addition, cognitive communication assessments should evaluate beyond the level of impairment to consider the range of medical, personal, and contextual influences that impact on the person with dementia's communication competence (MacDonald, 2017). There is a clear benefit to the person with dementia especially in terms of enhancing positive behavior and meaningful interactions.

Communication skills of the communication partner not evaluated

Communication partners play an essential role by enabling the person with dementia to communicate to their best ability (Kindell *et al.*, 2017). This review found no involvement of the communication partner in these assessments of cognitive communication ability. Interventions that focus on a collaborative approach to dealing with communication breakdown have been widely researched and shown to be a highly effective way of improving communication for both the people with dementia and their family and/or professional carers (Broughton *et al.*, 2011, Conway and Chenery, 2016). Conversation coaching (Dooley and Conway, April 2016) is a communication intervention that focuses on the dyad (the person with dementia and their communication partner) to profile abilities and to target any behaviors that are impacting on communication confidence and conversational effectiveness. There is increasing research to support the positive impacts of carer training for those with even the most severe communication impairments. There is a growing body of evidence (Eggenberger *et al.*, 2013, Liddle *et al.*, 2012) as to the multiple benefits of SLT intervention in the promotion of effective communication for people with dementia and their communication partners.

Adaptation by the CP to reduced communication ability can help maintain the person with dementia's autonomy and independence (Orange *et al.*, 1996). None of the four assessments

reviewed assessed conversational skills, impacting on the clinician's ability to recommend appropriate interventions to enhance everyday conversation ability.

Implications for future research

This review suggests that there are many aspects of cognitive communication assessment with people with dementia that need further development. There are an increasing number of evidenced based interventions that can be used with people with dementia such as cognitive stimulation therapy (Hopper *et al.*, 2013), conversation based therapy (Kindell *et al.*, 2017), simulated presence therapy (Bayles *et al.*, 2006) and Montessori based approaches (Boyle *et al.*, 2006). SLTs are in a unique position to develop, implement and evaluate cognitive communication interventions for people with dementia (Cleary *et al.*, 2003). But without high quality cognitive communication assessment tools clinicians will be challenged to establish the effectiveness of individual interventions.

Conclusions

This review identified the lack of validated communication assessment tools that are available for use with people with dementia. A comprehensive examination of the characteristics of these assessments was conducted considering the key areas for the assessment of communication skills in dementia. It is unrealistic to expect that one cognitive communication assessment will meet all the requirements discussed here to evoke a comprehensive evaluation of functional communication. At a minimum, clinicians require assessment tools that are up to date, standardised with people with dementia and evaluate functional communication skills.

These available assessments are restricted by what type of clients they can be used with and the stage of dementia they are appropriate for. SLTs are best placed to determine the cognitive, linguistic and communication abilities of people with dementia and the development of new assessment tools, will facilitate them in their management. Lack of access to appropriate assessments is a barrier to SLT management and this was identified.

There is scope for future research in this area and the development of psychometrically robust tools to assess people with dementia and to ultimately ensure that they receive better quality care. Initial results of the validation of such a tool, Profiling Communication Ability in Dementia (P-CAD) (Dooley *et al.*, 2018) demonstrates high concurrent validity. The P-CAD will facilitate functional communication assessment, inform communication interventions and improve the quality of care people with dementia have available.

Acknowledgements

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References

AMIEVA, H., JACQMIN-GADDA, H., ORGOGOZO, J.-M., LE CARRET, N., HELMER, C., LETENNEUR, L., BARBERGER-GATEAU, P., FABRIGOULE, C. and DARTIGUES, J.-F. 2005. The 9 year cognitive decline before dementia of the Alzheimer type: a prospective population-based study. *Brain,* 128**,** 1093-1101.

ARKSEY, H. and O'MALLEY, L. 2005. Scoping studies: towards a methodological framework. *International journal of social research methodology,* 8**,** 19-32.

BAYLES, K. and TOMOEDA, C. 1991. ABCD: Arizona Battery for Communication Disorders of Dementia. *Tucson, AZ: Canyonlands Publishing*.

BAYLES, K. A., KIM, E., CHAPMAN, S. B., ZIENTZ, J., RACKLEY, A., MAHENDRA, N., HOPPER, T. and CLEARY, S. J. 2006. Evidence-based practice recommendations for working with individuals with dementia: Simulated presence therapy. *Journal of Medical Speech Language Pathology,* 14**,** xiii.

BAYLES, K. A. and TOMOEDA, C. K. 1993. *Arizona battery for communication disorders of dementia*, Canyonlands Publishing Tucson, AZ.

BAYLES, K. A. and TOMOEDA, C. K. 1994. *The functional linguistic communication inventory,* Texas, USA, Pro-Ed.

BOURGEOIS, M. S. and HICKEY, E. 2011. *Dementia: From diagnosis to management-A functional approach,* New York, Taylor & Francis.

BOYLE, M., MAHENDRA, N., HOPPER, T., BAYLES, K. A., AZUMA, T., CLEARY, S. and KIM, E. 2006. Evidence-based practice recommendations for working with individuals with dementia: Montessori-based interventions. *Journal of Medical Speech-Language Pathology,* 14**,** xv-xv.

BROUGHTON, M., SMITH, E. R., BAKER, R., ANGWIN, A. J., PACHANA, N. A., COPLAND, D. A., HUMPHREYS, M. S., GALLOIS, C., BYRNE, G. J. and CHENERY, H. J. 2011. Evaluation of a caregiver education program to support memory and communication in dementia: A controlled pretest–posttest study with nursing home staff. *International Journal of Nursing Studies,* 48**,** 1436-1444.

BRUCE, C., BRUSH, J. A., SANFORD, J. A. and CALKINS, M. P. Development and evaluation of the environment and communication assessment toolkit with speech-language pathologists. Seminars in speech and language, 2013. Thieme Medical Publishers, 042-052.

BRYAN, K., BINDER, J., DANN, C., FUNNELL, E., RAMSEY, V. and STEVENS, S. 2001. Development of a screening instrument for language in older people (Barnes Language Assessment). *Aging & mental health,* 5**,** 371-378.

CLEARY, S., DONNELLY, M. J., ELGAR, S. and HOPPER, T. Service delivery for Canadians with dementia: A survey of speech-language pathologists. Clinical Aphasiology Conference, Orcas Island, WA, 2003.

CONWAY, E. and CHENERY, H. 2016. Supporting quality care for people with dementia in the community: Training in home care staff to use person-centred communication. *Alzheimer's Australia*.

DOOLEY, S. and CONWAY, A. April 2016. Conversation Coaching Group for People with Dementia. *31st International Conference of Alzheimer's Disease International.* Budapest, Hungary: Alzheimer's Disease International.

DOOLEY, S., DOYLE, R., HOPPER, T., O'NEILL, D. and WALSHE, M. 2018. Profiling Communication Ability in Dementia (P-CAD):Validation of a Functional Cognitive-Communication Assessment. *Age and Aging.* 66th Annual and Scientific Meeting of the Irish Gerontological Society: Oxford University Press.

DOOLEY, S. and WALSHE, M. 2018. Speech and Language Therapy Practice in the Management of Cognitive Communication Difficulties in People with Dementia in Ireland. *Un published.* Dublin: Trinity College Dublin.

EGGENBERGER, E., HEIMERL, K. and BENNETT, M. I. 2013. Communication skills training in dementia care: a systematic review of effectiveness, training

content, and didactic methods in different care settings. *International Psychogeriatrics,* 25**,** 345-358.
FOLSTEIN, M. F., FOLSTEIN, S. E. and MCHUGH, P. R. 1975. “Mini-mental state”: a practical method for grading the cognitive state of patients for the clinician. *Journal of psychiatric research,* 12**,** 189-198.
HARRIS, J. L., KIRAN, S., MARQUARDT, T. P. and FLEMING, V. B. 2008. Communication Wellness Check-Up©: Age-related changes in communicative abilities. *Aphasiology,* 22**,** 813-825.
HELM-ESTABROOKS, N. 2001. *Cognitive Linguistic Quick Test: Examiner's Manual*, Psychological Corporation.
HOLLAND, A. L., FRATTALI, C. and FROMM, D. 1999. *Communication activities of daily living: CADL-2*.
HOPPER, T. 2003. “They’re just going to get worse anyway”: perspectives on rehabilitation for nursing home residents with dementia. *Journal of communication disorders,* 36**,** 345-359.
HOPPER, T., BOURGEOIS, M., PIMENTEL, J., QUALLS, C. D., HICKEY, E., FRYMARK, T. and SCHOOLING, T. 2013. An evidence-based systematic review on cognitive interventions for individuals with dementia. *American Journal of Speech-Language Pathology,* 22**,** 126-145.
JONES, D. 2015. A family living with Alzheimer’s disease: The communicative challenges. *Dementia,* 14**,** 555-573.
JONES, D., DREW, P., ELSEY, C., BLACKBURN, D., WAKEFIELD, S., HARKNESS, K. and REUBER, M. 2016. Conversational assessment in memory clinic encounters: interactional profiling for differentiating dementia from functional memory disorders. *Aging & mental health,* 20**,** 500-509.
KAGAN, A., BLACK, S. E., DUCHAN, J. F., SIMMONS-MACKIE, N. and SQUARE, P. 2001. Training volunteers as conversation partners using Supported Conversation for Adults with Aphasia (SCA): A controlled trial. *Journal of Speech, Language, and Hearing Research,* 44**,** 624-638.
KINDELL, J., KEADY, J., SAGE, K. and WILKINSON, R. 2017. Everyday conversation in dementia: a review of the literature to inform research and practice. *International journal of language & communication disorders,* 52**,** 392-406.
LEVAC, D., COLQUHOUN, H. and O'BRIEN, K. K. 2010. Scoping studies: advancing the methodology. *Implementation Science,* 5**,** 69.
LIDDLE, J., SMITH-CONWAY, E. R., BAKER, R., ANGWIN, A. J., GALLOIS, C., COPLAND, D. A., PACHANA, N. A., HUMPHREYS, M. S., BYRNE, G. J. and CHENERY, H. J. 2012. Memory and communication support strategies in dementia: Effect of a training program for informal caregivers. *International Psychogeriatrics,* 24**,** 1927-1942.
MACDONALD, S. 2017. Introducing the model of cognitive-communication competence: A model to guide evidence-based communication interventions after brain injury. *Brain injury,* 31**,** 1760-1780.
MATTIS, S. 1988. Dementia rating scale (DRS). *Psychological Assessment Resources :Odessa, FL.*
ORANGE, J., LUBINSKI, R. and HIGGINBOTHAM, D. 1996. Conversational repair by individuals with dementia of the Alzheimer's type. *Journal of Speech, Language, and Hearing Research,* 39**,** 881-895.
PAWSON, R. 2002. Evidence-based policy: in search of a method. *Evaluation,* 8**,** 157-181.
PETERS, M., GODFREY, C., MCINERNEY, P., SOARES, C., KHALIL, H. and PARKER, D. 2015. The joanna briggs institute reviewers' manual 2015: methodology for JBI scoping reviews.
REISBERG, B., FERRIS, S. H. and FRANSSEN, E. 1985. An ordinal functional assessment tool for Alzheimer's-type dementia. *Psychiatric Services,* 36**,** 593-595.

SAXTON, J., MCGONIGLE, K., SWIHART, A. and BOLLER, F. 1993. The severe impairment battery. *Thames Valley Test Company:London*.
SCLAN, S. G. and REISBERG, B. 1992. Functional assessment staging (FAST) in Alzheimer's disease: reliability, validity, and ordinality. *International psychogeriatrics,* 4**,** 55-69.
TOMOEDA, C. K. Comprehensive assessment for dementia: A necessity for differential diagnosis and management. Seminars in speech and language, 2001. Copyright© 2001 by Thieme Medical Publishers, Inc., 333 Seventh Avenue, New York, NY 10001, USA. Tel.:+ 1 (212) 584-4662, 275-290.
VOLKMER, A. 2013. *Assessment and Therapy for Language and Cognitive Communication Difficulties in Dementia and Other Progressive Diseases*, JR Press: North Guilford.
WECHSLER, D. 1981. *Wechsler adult intelligence scale: WAIS-R manual*, Harcourt Brace Jovanovich [for] The Psychological Corporation.

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DOI: 10.1080/02699052.2017.1379613

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Appendix 5.3 Poster Presentation at the AAIC Toronto 2016

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Assessing Functional Retained Communication Skills in Dementia: A Scoping Review

HRB Health Research Board

Suzanna Dooley[1] and Margaret Walshe[1]
[1]Department of Clinical Speech and Language Studies, Trinity College, Dublin.

Introduction

Cognitive communication difficulties are a characteristic feature of dementia. There are few instruments available to evaluate both functional and retained communication skills in people with dementia. These assessments are needed to facilitate speech language therapist (SLTs) in the management of cognitive communication impairments and evaluate the outcome of interventions.

Aims

The purpose of this scoping review was to identify readily available cognitive communication assessments specifically for use by SLTs with people with dementia and inform the development of a new assessment measure to direct evidence based practice.

Research Questions

1. What psychometrically sound cognitive communication assessments are available for use by SLTs who work with people with dementia?

2. For available instruments, the following sub-questions were posed:
   a) Are available assessments validated on all types and stages of dementia?
   b) What are the key linguistic and cognitive assessment domains in these assessments?
   c) Do these assessments evaluate functional communication skills?
   d) Do these assessments involve the primary communication partner?
   e) Do they inform intervention and care pathways?

Method

A scoping review of the literature was conducted using the methodological framework set out by Arksey & O' Malley[1]. Cognitive-communication assessments validated in English with people with dementia were sought.

8 electronic databases were searched yielding 7,584 articles.

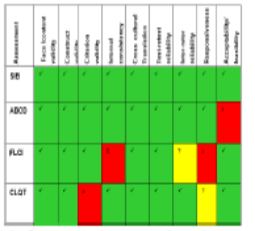
Articles were screened and duplicates removed leaving 9 articles that were assessed for eligibility. A further 5 were excluded by the two independent reviewers.
Four cognitive communication assessments were eligible for inclusion:
1. Functional Linguistic Communication Inventory (FLCI)[2]
2. Arizona Battery for Communication Disorders (ABCD)[3]
3. Cognitive Linguistic Quick Test (CLQT)[4]
4. Severe Impairment Battery (SIB)[5]

These assessments were critically reviewed with respect to their psychometric properties.

Results

- **None** of these cognitive-communication assessments were suitable for administration at **all stages of dementia.**
- Only **one** was validated for a range of dementia **sub types.**
- All 4 assessments evaluate a range of cognitive and linguistics skills appropriate for the stage of dementia within their scope
- **Contextual analysis** of communication skills is absent across all 4 assessments with **no involvement** of the primary communication partners **(PCPs)** in the assessment process.
- The **validity and reliability** of these assessments were psychometrically robust with the exception of responsiveness and feasibility. With 2 out of 4 assessments it was unclear whether there was **sensitivity to change** overtime. The ABCD is very comprehensive, but takes up to 90mins to administer **impacting on feasibility** for use with this population (see table).

Table 2.4 Overview of validity and reliability of cognitive communication assessments



* Key: Green= present, red= not present, yellow= unclear

Conclusions

- **No high quality** psychometrically sound cognitive-communication assessments currently exist that meet the standards set out by the reviewers.
- Available cognitive communication assessments **do not focus on functional communication** or the psychosocial impact of communication impairment.
- The **development of new assessments would improve the clinical practice** of Speech and language therapists and direct interventions for people with dementia.
- Work on this has commenced and the **Profiling Communication Ability in Dementia (P-CAD)** tool is currently undergoing validation.

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PCAD Facebook URL: https://www.facebook.com/P-CAD-1534606130176652/

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Health Research Board Ireland.
Health Services Staff Credit Union.

Selected References

1 Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International journal of social research methodology, 8*(1), 19-32.
2 Bayles, K. A., & Tomoeda, C. K. (1994). *The functional linguistic communication inventory*: Pro-Ed.
3 Bayles, K. A., Tomoeda, C. K., & Dharmaperwira-Prins, R. I. (1993). *ABCD: Arizona Battery for Communication Disorders of Dementia*: Canyonlands Pub.
4 Helm-Estabrooks, N. (2001). *Cognitive Linguistic Quick Test: Examiner's Manual*: Psychological Corporation.
5 Saxton, J., McGonigle, K., Swihart, A., & Boller, F. (1993). *Severe Impairment Battery Manual*: Thames Valley Test Company: Pearson

Appendix 7.0 Initial P-CAD

P-CAD

Profiling Communication Ability in Dementia

Administration and Scoring

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Client Name:_____ DOB: _____	SLT: _____ DOA: _____
Medical Diagnosis: MMSE:_____	Wears glasses Yes No Wears hearing aids Yes No Upper limb weakness Yes No

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Introducing the Profiling Communication Ability in Dementia Evaluation

The P-CAD tool evaluates the individual's functional communication ability and the use of communication support strategies to enhance function.

These individual areas are:

- attention ability
- auditory comprehension ability
- verbal expression ability
- conversational ability
- reading ability
- writing ability
- functional communication ability
- communication support strategies

It is designed so that the clinician evaluates the individual's functional communication abilities and communication support strategies in tandem as the assessment progresses. Communication between the client and their primary communication partner (PCP) is also evaluated and used to inform the overall communication profile.

The assessment materials are provided so that the clinician can evaluate retained communication abilities and the use and potential benefits of compensatory strategies. In the assessment pack there are two books; an administration & scoring book and the stimulus book.

Administration Steps:

1. The clinician completes Sections 1-7, highlighting the scores attained as the evaluation progresses.
2. These initial scores are put on the P-CAD Scoring Form and then subtotalled.
3. The clinician then completes the P-CAD Profile Form based on the clinical impression formed.
4. The level of communication Support (minimum, moderate or maximum) required across the range of cognitive communication skills can then be determined.
5. The clinician will finally complete the section on communication abilities and communication support strategies.

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1 P-CAD Administration and Scoring of Attention Ability

This section of the evaluation should be completed towards the end of the session. The attention skills score is determined by the clinician's subjective assessment of how attention is impacting on the person with dementia communication ability.

Attention is the ability to focus on certain aspects of the environment that one finds interesting and to flexibly manipulate this information. It is important to note that alertness and arousal are prerequisites for attention.

You can use this model of attention to guide you in this section.

Five Levels of Attention (Sohlberg & Mateer 1989)

- Focused Attention is the ability to perceive individual pieces of information.
- Sustained Attention is commonly called concentration, which predominantly involves vigilance.
- Selective Attention is the ability to avoid distractions from both external (e.g. noise) and internal (e.g. own thoughts) stimuli.
- Alternating Attention is the ability to shift the focus of attention and to alter it between tasks.
- Divided Attention is the ability to respond to multiple tasks at the same time or to give two or more responses simultaneously.

Instructions: The clinician will be evaluating the person with dementia overall ability to attend and concentrate on tasks during the assessment and will observe the attention skills demonstrated by them in the conversation task.

Normal range of function (Score=0)	Reduced attention impacts occasionally on communication ability (Score=1)	Reduced attention impacts frequently on communication ability (Score=2)	Reduced attention consistently impacts on communication ability (Score=3)
Normal Function	• Stable, focused and sustained attention throughout the evaluation session • Lapses of selective and/or alternating attention observed during evaluation session	• Sustained attention of periods up to 10-15 minutes observed during the evaluation session • External cuing needed to support the person's attention beyond this level	• Can focus attention on tasks and conversation with stimulation • Fluctuating levels of alertness observed during the evaluation • May be drowsy

Score (circle score given)	Comments
0 Normal function 1 Reduced ability to sustain attention that impacts occasionally on communication ability 2 Reduced ability to sustain attention that impacts frequently on communication ability 3 Reduced ability to focus and sustain attention consistently impacts on communication ability	

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2 P-CAD Administration and Scoring of Auditory Comprehension Ability

There are four parts to this section. The maximum possible score is 20 points.

1. Word Picture Matching (6 points)
2. Following verbal Instructions (6 points)
3. Answering Questions (3 points)
4. Paragraph Comprehension (5 points)

1. Spoken Word to Picture Matching (6 points)

Stimulus: Cards AC1- AC3

Instruction to clinician: Say "I am going to say a word and I want you to point to the corresponding picture. Show me the:

AC1: "Child" turn the page for the next item.

AC2: "Comb" turn the page for the next item.

AC3: "Money"

Score (circle score given)	Note
3 Client correctly identifies 3 pictures 2 Client correctly identifies 2 pictures 1 Client correctly identifies 1 picture 0 Client points to incorrect pictures or no response (NR) after 1 minute	Observe for and document strategies used by the client to facilitate understanding (e.g requests for repetitions or clarifications). The item is not re-scored but the response with repetition is noted
	Comments

2. Following Verbal Instructions (6 points)

Instruction to clinician: Place a pencil on the table in front of the person.

Say "I am going to ask you to follow some instructions. Are you ready?"

A. 'Look at the ceiling' (max score 1)

Score (circle score given)	Note
1 Correct response, person looks up to the ceiling 0 Incorrect response, person looks somewhere else in the room or NR response after 1 minute	Observe for and document strategies used by the client to facilitate understanding
	Comments

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B. 'Smile and then raise your arm' (max score 2)

Score (circle score given)	Note
2 Correct response, client attempts a smile and raises their hand. (Credit given for immobility, 2 points if they are immobile and could not raise their hand) 1 Partially correct response (just one information element correct) 0 Incorrect response, or response is unrelated to the instruction asked. Client reacts with different actions than the ones requested or NR after 1 minute	Observe for and document strategies used by the client to facilitate understanding Smile and then raise your arm 1 1 Comments

C. 'Look at the door and then give me the pencil' (max score 3)

Score (circle score given)	Note
3 Correct response, client attempts to look at the door and then hands the pencil to the clinician (Credit given for immobility, 3 points given if the client is immobile and unable to reach for the pencil 2 Correctly completes 2 elements of the instruction, person looks at the door and does something with the pencil or gives the clinician something else. 1 Completes one element of the instruction correctly. (client looks at the door or does something with the pencil. 0 Response is unrelated to the instruction or NR after 1 minute	Observe for and document strategies used by to facilitate understanding. The item is not re-scored but the response with repetition is noted 'Look at the door and then give me the pencil' 1 1 1 Comments

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2. Answering Questions *(3 points)*

Instruction to clinician: Say "I want you to answer 'Yes' or 'No' to the following questions".

A. Does milk go sour?
B. Is a wheel round?
A. Is Christmas in July?

Score (circle score given)	Note
A. Does milk go sour? 1 Answers Yes 0 Answers No or NR **B. Is a wheel round?** 1 Answers Yes 0 Answers No or NR **C. Is Christmas in July?** 1 Answers No 0 Answers Yes or NR	Observe for and document strategies used by the person with dementia to facilitate understanding. The item is not re-scored but the client's response with repetition is noted Comments

3. Paragraph Auditory Comprehension (5 points)

Instruction: Say "I want you to listen carefully to a short story. Afterwards, I am going to ask you some questions about the story"

A Night Out!

On Thursday evening Kate and Andrew went to the cinema. They were going to see "Gone with the Wind", an old time favourite of theirs.

Kate had booked the tickets online, so when they arrived at the Cineplex, Kate went to collect the tickets. Andrew bought two coffees and they joined the queue.

When they got to the top of the line the usher pointed out that their tickets were for Friday night. The movie was booked out for that evening. What a disappointment! They sat for half an hour and drank their coffee in the foyer and then went home.

Questions (correct answer highlighted)

1. Did they want to see the 'Sound of Music'? Yes/ No
2. Was the movie showing on Thursday evening? (Yes/No)
3. Were the people in this story called Kay and Tom? (Yes/No)
4. Did Kate buy the tickets in advance? (Yes/No)
5. Did they go straight home? (Yes/No)

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Score (circle score given)	Note
5 Answered all five questions correctly 4 Answered four questions correctly 3 Answered three questions correctly 2 Answered two questions correctly 1 Answered one question correctly 0 No questions answered correctly	Observe for and document strategies used by the person to facilitate understanding. The item is not re-scored but the client's response with repetition is noted
	Comments

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3 P-CAD Administration and Scoring of Verbal Expression Ability

There are four different sections to evaluate verbal expression. The maximum score for this section is 20 points

1. Greetings and Goodbyes (3 points)
2. Naming (6 points)
3. Picture description (5 points)
4. Talk about a topic (6 points)

Communication Support Strategies: The clinician observes the range and frequency of compensatory strategies that are being used to support verbal expression as the assessment progresses. The item is not scored but strategy use is noted. Strategies may include:

- The client uses circumlocution
- The client is allowed extra time to express ideas/opinions
- Primary communication partner / clinician is required to give a cue or prompt to facilitate understanding gives a cue or a prompt

1. Greetings and Goodbyes (Max score 3)

A) Response to a greeting

Instruction to clinician: Say "Hello_____, how are you today?"

Score (circle score given)	Note
1 Appropriate verbal response such as "I'm fine thank you" ,"I'm alright". 0 No verbal response	Observe for and document strategies being used
	Comments

B) Response to a compliment

Instruction to clinician: Say "I like your scarf/bag/glasses"
Record response below

Score (circle score given)	Note
1 Appropriate verbal response such as "Yes it's nice isn't it", "Thank You", "this old scarf!" 0 No verbal response	Document any non-verbal response
	Comments

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C) Goodbyes -Leave taking

Instruction to clinician: At the end of the evaluation, note how the client says goodbye.

Say "We have finished now, thanks for talking with me"

Score (circle score given)	Note
1 Appropriate verbal or non-verbal response such as saying "Thank you" "Goodbye" or a wave of the hand or appropriate natural gesture 0 No response	Document any non-verbal response
	Comments

2. Naming (max score 6)

These tasks will evaluate confrontation naming and generative naming

The maximum possible score for this section is 6 points

A) Confrontation Naming (3 points)

Picture Stimulus: Cards VE1-6

Instruction to clinician: Show pages VE1 -3 from the Picture Stimulus Book.

Say "I want you to name the items you see in the following pictures".

- VE1 'Tree'
- VE2 'Pencil'
- VE3 'Key'

Instruction to clinician: Show pages VE4 -6 from the Picture Stimulus Book .

Ask " What is this person doing?"

- VE4'Reading'
- VE5'Walking'
- VE6'Driving'

Score (circle score given)	Note
3 6 items named correctly 2 3-5 items named correctly 1 1-2 items named correctly	Record semantic errors and support strategies used by the person with dementia.
	Comments

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B) Generative naming (3 points)

Instruction: Say "I want you to name as many fruit as you can, you have one minute. Let me know when you are ready to start".

Score (circle score given)	Note
3 10 fruits named 2 6-9 fruits named 1 3-5 fruits named 0 2 or less fruits named	Record semantic errors and support strategies used by the client. Comments

3. Picture Description (max score 5 points)

The clinician should gain consent for recording this section.

Picture Stimulus: Show the picture card *The Classroom* VE7 to the client.

Instruction to clinician: Say "Have a look at this picture. When you are ready I want you to describe it to me in your own words. Try and use sentences if you can".

Picture description:

Score (circle score given)
5 A comprehensive description given, no evidence of word finding difficulty.
4 Less comprehensive picture description with some word finding difficulty.
3 Basic picture description. Word finding difficulty with circumlocution.
2 Attempts picture description. Severe word-finding difficulty, ungrammatical at times, mainly single words with some sentences that may be complete, but lacking content.
1 No serious attempt at picture description. Only single words used. Verbal expression is effortful and occasionally unintelligible.
0 Unable to attempt picture description. Limited or no meaningful verbal response

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4. Talk about a topic (5 points)

Having requested and **gained consent** from the client and PCP for video recording. The clinician video records a conversation sample (max 5 mins) between the client and their PCP. To stimulate conversation, the clinician asks them to talk about holidays, pets or music.

This same recorded conversation will be used in scoring the Conversation Skills and Functional Communication sections of the P-CAD.

People with advanced dementia may not be able to participate in this evaluation task, without the support of their primary communication partner and /or visual props.

It may not be possible to video record the communication partners. In this instance, the clinician should record the client in conversation with the clinician. The instructions for both scenarios are given below.

Select either of the following:	
Instruction for clinician to elicit conversation between the client and the PCP: Say "I would like to see how you are communicating together, so with your permission I am going to record you having a conversation. I'd like you to talk for a few minutes about something that interests you. For example, holidays, pets or music"	**Instruction for clinician-client conversation:** Say "I am going to record us talking about a topic you are interested in. We could talk about holidays, pets or music?"

Topic chosen:
Comments and observations:

Score (circle score given)	Conversation Ability
6	A well balanced conversation with, no evidence of word finding difficulty.
5	Occasional hesitations but compensates well and it does not impact significantly on the conversational balance.
4	Circumlocutory causing some disorganisation in the narrative. Mild word finding difficulty.
3	Moderate word-finding difficulty, ungrammatical at times, mainly single words with some sentences that may be complete, but lacking content.
2	Only single words used, engaged in the conversation but, effortful and difficult to follow.
1	Some non-verbal responses and passing turns. No verbal expression.
0	Poor levels of alertness not communicative.

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4. Administration and Scoring of Reading Ability

There are four different reading comprehension sections in this task.

The maximum score possible is 12 points.

1. Word level reading (3 points)
2. Sentence level reading (3 points)
3. Functional level reading (3 points)
4. Paragraph level reading (3 points)

Note and record strategies in the comment section that were observed to facilitate reading comprehension

- Pictures facilitated reading comprehension
- The client is allowed extra time to read
- The client benefits from rereading the text

Stimulus: The clinician shows the client the Reading Stimulus Book.

1. Word Level Reading Comprehension (3 points) allow 2 minutes

Instruction to clinician: Using the Reading Stimulus Book., show page RC1 - RC6 and say "Point to the word goes with the picture".

(Targets: Tree, Pencil, Key, Money, Comb, Ball)

Score (circle score given)	Comments	Targets	Correct or incorrect
3 6 correct answers given 2 3-5 correct answers given 1 1-2 correct answers given 0 No correct answers		Tree Pencil Key Money Comb Ball	

2. Sentence Level Reading Comprehension (3 points) allow 1 minute

Instruction to clinician: Show page RC7 & RC8 to the client and ask him/her to "Read the sentence and follow the instruction"

Score (circle score given)	Correct or incorrect
3 Completed both written instructions correctly 2 Completed the first instruction and one part of the second instruction accurately 1 Completed one instruction accurately 0 No correct responses or NR	Wave your hand 1 Point to the ceiling and the floor 1 1 Allow one point for the first instruction and two point for the second two-part instruction. (score 1 point if one one-part of the instruction is correct.

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3. Functional Level Reading Comprehension (3 points)

There are two parts to this section 3a and 3b.

3a. Reading stimulus: Page RC9 The Headlines (1 point) allow 2 minutes

Instruction to clinician: Show page RC8 and ask "Read this section and then show me the answer to the question

Score (circle score given)	Comments
1 Answered correctly "Low Pressure bringing rain to the North-West" 0 Answered incorrectly. Error of comprehension demonstrated	

3b. Stimulus: Page RC10 The Prescription (2 points) allow 2 minutes

Instruction to clinician: Show page RC3b. Ask "Read this section and then show me the answer to the question"

Score (circle score given)	Comments
2 Correctly answered *2. Once a day* 0 Incorrectly answered 1. 3. 4.	

4. Paragraph level Reading Comprehension (3 points) allow 5 minutes

Picture & Reading Stimulus Book: Page RC11 & RC12

Instruction to clinician: Say " Read this paragraph in your own time and then I will ask you to answer some questions based on what you have read". Allow 3 minutes. After the passage has been read, show the client the RC 10 the question page

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Stray Horses cause accident

(Correct answers are highlighted)

1. What is the name of this newspaper?
   a) The Daily News
   b) The Evening News
   c) The Evening News Daily

2. What was the name of the family involved in the accident?
   a) Kealy
   b) Hudson
   c) Kelly

3. Who were the passengers in the car?
   a) Mr. Kelly's daughters
   b) Mr. Kelly's sisters
   c) Mr. Kelly's sons

4. What were the weather conditions like at the time of the accident?
   a) It was raining
   b) It was frosty
   c) It was sunny

5. Was there loss of life in the accident?
   a) Yes
   b) No
   c) It didn't state either way

6. How could the accident have been avoided?
   a) Farmers should regularly check that fencing is secure
   b) Mr. Kelly could have driven more slowly
   c) This accident could not have been avoided

Score (circle score given)	Note
3 4-6 questions correctly answered 2 3-5 questions correctly answered 1 1-2 questions correctly answered 0 No correct answers or NR	Record error pattern, semantic, auditory, visual distractors

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5 P-CAD Administration and Scoring of Writing Ability

There are five different writing tasks in this section. The maximum score for this section is 12 points.

1. Writing name (1 point)
2. Writing personal address (2 points)
3. Writing a shopping list (3 points)
4. Writing a sentence about themselves (3 points)
5. Completing greetings on a birthday card (3 points)

Stimulus: Give the client the Writing Ability Form found at the back of the administration & scoring book.

1. Writing name (1 point)

Instruction to clinician: Ask the client to write their name.

Score (circle score given)	Note
1 Score one point if completed correctly i.e. writes their full name legibly. 0 Multiple errors of spelling or task not attempted	The mechanics of writing to be noted but not scored Comments

2. Writing personal address (2 points)

Instruction to clinician: Ask the client to write their personal address.

Score (circle score given)	Note
2 The address is completely correctly, full address including house number written legibly. 1 The address is partially correct with no more than two significant errors, minor spelling errors and/or one element omitted. 0 Multiple errors of spelling or task not attempted	The mechanics of writing to be noted but not scored Comments

3. Writing a shopping list to dictation (3 points)

Allow 5 minute per item.

Instruction to clinician: Ask the client to write down the 5 shopping list items listed below

Score (circle score given)	Comments	Targets	Correct or incorrect
3 Spells 4-5 words correctly 2 Spells 2-3 words correctly 1 Spells 1 word correctly 0 Multiple errors of spelling or task not attempted	The mechanics of writing to be noted but not scored	milk bread coffee cornflakes newspaper	

DO NOT COPY

4. Write a sentence about themselves (3 points)

Instruction to clinician: Ask the client to write a sentence about themselves

Score (circle score given)	Note
3 A well-constructed sentence without spelling errors with legible and clear writing 2 Adequate sentence structure, may have minor spelling errors or poorly formed letters 1 The sentence poorly constructed, is not legible, has significant spelling errors 0 Multiple errors of spelling or task not attempted	The mechanics of writing to be noted but not scored Comments

5. Complete greetings on a birthday card (3 points)

Instruction to clinician Ask the client to complete the birthday card template WR2.

Say "Here is a birthday card, can you fill it in with a message for your friend".

Score (circle score given)	Note
3 A well-constructed card with an appropriate message and legible writing 2 Card largely completed. May have a few spelling errors or poorly formed letters 1 Contains a name and/or one or two recognisable words 0 Multiple errors of spelling or task not attempted	The mechanics of writing to be noted but not scored Comments

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6 P-CAD Administration and Scoring of Conversation Ability

This section of the evaluation examines how the client communicates with his/her primary communication partner (PCP).

Review the video recording from Section 3. Then evaluate the following aspects of conversation ability; turn-taking, topic initiation & maintenance and trouble & repair in the conversation. This section will also help the clinician to evaluate the client's awareness of their communication impairment and the couple's ability to compensate in conversation.

Clinician's notes Turn-taking: Topic initiation: Topic maintenance: Trouble: Repair:

Score	Discourse Skills
0	Evidence of good turn-taking by the couple and some initiation by the client. Effective topic management.
1	Minor imbalances in turn-talking and topic management. Miscommunications are dealt with efficiently and effectively and do not interrupt the conversational flow.
2	Some imbalance in turn-taking, one partner may dominate. Difficulty transiting between topics and/or reduced topic maintenance. Miscommunications are not always resolved efficiently or effectively. Some disruption to the conversational flow.
3	Significant disruptions to turn-taking and topic management. The client does not initiate in the main causing imbalance in the conversation. Miscommunications often cause complete conversation breakdown.

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7. P-CAD Administration and Scoring of Functional Communication

This section should be completed at the end of the evaluation. The client's functional communication ability and the required level of support will have been assessed on an ongoing basis as the evaluation progressed through the different sections. The score given is based on your subjective opinion of both the client's functional communication ability and the level of communication support required.

Clinical decisions will be informed by:

- how the client and their communication partner interacted with each other and the clinician during the evaluation including the videoed conversation. Including the use of compensatory strategies.
- a discussion with the client and their communication partner as to how dementia is impacting on the person's ability to function independently in a range of communication situations. You can use the questions provided or you own specific questions to determine how they are managing functionally.

Instruction to clinician: Ask the client and their communication partner some of the following questions to determine how they are communicating functionally.

	Direct questions towards the client initially. Record answer below question
1.	Do you /Does _____answer the phone and make phone calls independently?
2.	Do you /Does_____read and reply to text messages as usual?
3.	Do you /Does _____ participate confidently in group conversations?
4.	Do you /Does _____engage verbally in everyday social conversations about for example the weather?
5.	Are you/ Is_____ able to express their/your needs verbally?
6.	Are you/ Is_____ able to ask for help if you run into difficulty?
	Questions for the Primary Communication Partner
7.	Does_____ communicate mainly non-verbally?
8.	Is it difficult at times to understand what _____ is trying to communicate?
9.	Is communication often non-verbal through gestures and pointing?
10.	To what degree to you think your communication is balanced in terms of responsibility for the conversation/interaction

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Scoring

Instruction to clinician: The clinician evaluates functional communication using the information attained from the question section above and the scoring chart below.

Score	Functional Communication Ability
0	Communication within the normal range
1	**Communicates independently** in a range of communication situations with familiar and unfamiliar communication partners Converses **freely** in most situations May be challenged by group conversations
2	**Engages competently** in social exchanges with familiar communication partners. Consistently able to make needs known and conveys more information than this. Copes with one: one conversations most of the time with support
3	**Dependant Communicator** Unable to consistently express/ demonstrate basic care needs like thirst, pain or express choice Communication is difficult to interpret Mainly non-verbal communication

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8 P-CAD Administration and Scoring of Communication Support Strategies

This section of the evaluation examines how the client with his/her primary communication partner (PCP) use compensatory strategies to support communication. The video recording gives the clinician an opportunity to evaluate communication breakdown and repair.

This section will also help the clinician to evaluate the client's awareness of their communication impairment and the couple's ability to compensate in conversation. If the PCP was not available to make the recording the clinician can use the same guidelines to evaluate their own interactions with the client.

Instruction: Review the video recording with the following guidelines in mind.

1. Client's awareness of his/her own communication errors
2. Frequency with which communication support strategies are used and by whom. These are the term use to describe frequency:
   - Occasional use of strategies: strategies used from time to time to enhance a communication function
   - Frequent use of strategies: strategies used regularly to enhance a communication function
   - Consistent use of strategies: strategies used all the time to enhance a communication function
3. How effective are the use of communication support strategies in resolving communication breakdown?

Communication Support Strategies

Score	Communication Support Strategies
0	Compensatory Strategies not required to enhance conversation.
1	The client is aware of and will cover up communication errors. Occasional use of support strategies required to facilitate communication Both partners use communication support strategies effectively to facilitate communication
2	The client is not always aware of communication breakdown. Frequent use of support strategies required to facilitate communication Both partners use communication support strategies inconsistently to facilitate communication
3	No evidence of awareness of communication errors. Consistent use of support strategies required to facilitate communication. Client has limited or no use of effective compensatory strategies.

The P-CAD Communication Support Strategies are provided on pages 24 &25 as a resource for you. There are specific communication strategies for each section of the P-CAD which you can recommend to the client and their communication partner.

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P-CAD Overall Scoring Form

Instruction to clinician: Transfer the subtest ability scores into the overall scoring form. The clinician will then be able to determine the level of communication support that the client requires for the different cognitive communication abilities.

P-CAD Summary Profile Form

Instruction to clinician: Having completed the scoring form. Transfer this information on cognitive communication skills, based on your overall clinical impression to the identified levels of communication support on the P-CAD Summary Form. This will show the client's individual communication ability profile.

P-CAD Assessment Outcomes and Recommendations

Instruction to clinician: Use the section at the bottom of the P-CAD Summary Profile Form to outline your recommendations.

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Writing Ability Form

Write your full name

_____

Write your address

_____

_____

_____

_____

_____

Write down the 5 shopping list items

1. _____
2. _____
3. _____
4. _____
5. _____

Write a sentence about yourself

_____

_____

_____

DO NOT COPY

Write this Birthday Card to a friend

To _____

From _____

P-CAD Scoring Form

Cognitive Communication Skills	Scoring	Normal Function 0	Mild Impairment 1	Moderate Impairment 2	Severe Impairment 3
1.Attention Ability					
Impact of impaired Attention on Communication Ability		No impact on communication	Occasionally impacts on communication	Frequently impacts on communication	Consistently impacts on communication
Total		0	1	2	3
2.Auditory Comprehension Ability					
Word picture matching	6				
Following verbal instructions	6				
Answering questions	3				
Paragraph comprehension	5				
Total	/20	17-20	11-16	4-10	0-3
3. Verbal Expression Ability					
Greetings & Goodbyes	3				
Naming: Confrontation	3				
Generative	3				
Picture description	5				
Talk about a topic	6				
Total	/20	17-20	11-16	4-10	0-3
4. Reading Comprehension Ability					
Word level reading	3				
Sentence level reading	3				
Functional level reading	3				
Paragraph level reading	3				
Total	/12	10-12	7-9	4-6	0-3
5. Writing Ability					
Writing name	1				
Writing personal address	2				
Writing a shopping list	3				
Writing a sentence about themselves	3				
Completing birthday card	3				
Total	/12	10-12	7-9	4-6	0-3
6.Conversation Ability		0 Normal function	1 Mild imbalance	2 Moderate imbalance	3 Severe imbalance
7. Functional Communication Ability		0 Normal function	1 Mild impairment	2 Moderate impairment	3 Severe impairment
8. Communication Support Strategies		0 Normal function	1 Minimum Communication Support	2 Moderate Communication Support	3 Maximum Communication Support

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Appendix 7.1 Ethics Approval TT56 P-CAD Refinement

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Academic Year 2015/16

Applicant: TT56 Suzanna Dooley

Project title: Refinement of the Profiling Communication in Dementia tool (P-CAD).

Dear Ms Dooley,

Your submission for ethics approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin, on 6 May 2016, and has been approved in full. We wish you the very best in your research activities.

Dr Lorna Carson
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences
Trinity College Dublin

Scoil na nEolaíochtaí Teangeolaíochta, Urlabhra agus Cumarsáide
Coláiste na Tríonóide
Baile Átha Cliath 2, Éire

School of Linguistic, Speech & Communication Sciences,
Trinity College Dublin
Dublin 2, Ireland

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www.tcd.ie/slscs

Appendix 7.2 Focus Group 1: Letter of Invitation

Suzanna Dooley
School of Clinical Speech and Language Studies
Trinity College Dublin
Dublin2

To whom it concerns,

I am **Suzanna Dooley** and I work as a Speech and Language Therapist.

I am working with **Prof Margaret Walshe** from Trinity College Dublin.

I am researching ways of **improving communication** for people with dementia and their families.

I have developed a communication assessment called **Profiling Communication Ability in Dementia (P-CAD).**

I want the **opinions of people with dementia** about the P-CAD.

You would need to take part in a **small group discussion** with 2 or 3 other people with dementia.

There will be a researcher there to talk with you **about your opinions** of communication profile, the P-CAD.

Next step

Contact me if you want to get involved dooleysu@tcd.ie

086-6098109 or 01-89623822

You can get a **family member to call** me on your behalf.

Thank you for taking the time to read this information.

Yours Sincerely,

Suzanna Dooley

Associate Researcher in Speech & Language Therapy

Trinity College Dublin

Appendix 7.3 Focus Group 2: Letter of invitation

Suzanna Dooley
Associate Researcher
School of Clinical Speech and Language Studies
Trinity College Dublin

To whom it concerns,

I am conducting a research project in the area of dementia with Dr. Margaret Walshe in Trinity College Dublin which is being funded by a grant from the Health Research Board.

We are developing an assessment for Speech and language Therapists that can be used to evaluate the cognitive-communication abilities of people with dementia. It is called *Profiling Communication Ability in Dementia* (P-CAD).

I am looking for family carers of people with dementia to participate in this study.

I want to invite you to take part in this research by participating in a focus group. You will be reviewing and discussing the P-CAD in terms of how useful it might be in supporting everyday communication and planning health care for your family member with dementia.

I have attached a Participant Information Leaflet to this e-mail that will provide you with information about this study.

If you would like to participate in this study, please express your interest by sending an email to me at this email address dooleysu@tcd.ie. or by phone 086-6098109. Please do so within 1 week of receiving this email.

If you have any questions or would like to discuss this study further please do not hesitate to contact me or you can contact my research supervisor, Dr. Margaret Walshe, walshema@tcd.ie.

Thank you for taking the time to read this information.

Your Sincerely

Suzanna Dooley
Associate Researcher SLT
Trinity College Dublin

Appendix 7.4 Focus Group 1: Participant Information Leaflet: Accessible Version

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Dear Participant,

Information about me

- I am **Suzanna Dooley** and I work as a Speech and Language Therapist
- I am working with **Prof Margaret Walshe** from Trinity College Dublin
- I am researching ways of **improving communication** for people with dementia and their families

The research

- I have developed a communication profile called **the P-CAD** (Profiling Communication Abilities in Dementia)
- I will be using it with people with dementia over the next year to see if it **highlights communication abilities**

- I want the **opinions of people with dementia** about the P-CAD

- I want the **opinions of families** living with dementia too
- I want the **opinions of other professionals** find out if the communication profile provided is useful in:
    - **Supporting communicating** with people with dementia
    - **Planning treatment** and community services.

Permission

This research has Research Ethics Committee approval from **Trinity College Dublin**

How can you get involved?

- Take part in a **small group discussion** with 2 or 3 other people with dementia
- There will be a researcher there to talk with you **about your opinions** of communication profile, the P-CAD

Other Information

- This group will be held at **St Columcille's Hospital Loughlinstown**
- It will last for **about 45 minutes**
- The session will be **audio-recorded**

- You will be **anonymous** (your identity will be protected)

- You can **change your mind at any time** if you don't want to be involved

Next step

- Contact me if you want to get involved dooleysu@tcd.ie

086-6098109 or 01-89623822

- You can get a **family member to call** me on your behalf

Thank you for reading this information leaflet.

Appendix 7.5 Focus Group 1: Consent Form

Accessible Version

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Consent Form

Project title: Validation of the Profiling Communication Abilities in Dementia(P-CAD) Tool

The Research

- I understand that the P-CAD is a **communication assessment** for people with dementia

(Mark as appropriate)

- I know that this research is being done by Suzanna Dooley and Dr. Margaret Walshe from **Trinity College Dublin**

(Mark as appropriate)

The Focus Group

- I understand that I am being asked **to take part in a group discussion** about the P-CAD

(Mark as appropriate)

- I know that taking part in the focus group means **giving my opinions** on the P-CAD

(Mark as appropriate)

I understand the following

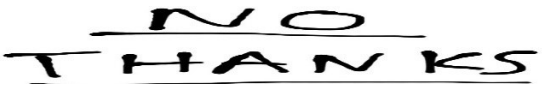
- This group will be held at **St Columcille's Hospital Loughlinstown**

- It will last for **30-45 minutes**

- The session will be **audio-recorded**

I will be **anonymous** (my identity will be protected)

- I can **change my mind at any time** if I don't want to be involved



Next Steps

- If I have any questions about this research, I can contact Suzanna Dooley

  e-mail: dooleysu@tcd.ie

  Phone: **086-6098109 or 01-89623822**

  I can get a family member **to call for me**

Signature of research participant

- I understand what is involved in this research
- I agree to participate in the study.
- I have been given a copy of the Participant Information Leaflet and a copy of this consent form to keep.

(Mark as appropriate)

---------- ----------

Signature of participant Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study

---------- ----------

Signature of researcher Date

Appendix 7.6 Focus Group 2 Participant Information Leaflet

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Participant Information Leaflet

Project title: Validation of the Profiling Communication Abilities in Dementia(P-CAD) Tool

Dear Participant/Family Carer,

I am conducting a research project with Dr. Margaret Walshe in Trinity College Dublin which is being funded by a Dementia grant from the Health Research Board. We are developing an assessment for Speech and language Therapists that can be used to evaluate the cognitive-communication abilities of people with dementia. It is called *Profiling Communication Ability in Dementia* (P-CAD).

What is the purpose of our research?

We want to develop and make available this assessment tool to facilitate Speech and Language Therapists (SLTs). It will enable them to engage in a timely way with people with dementia and their families and help promote and support communication. This is important research as people with dementia in Ireland have limited access to communication interventions.

What will your involvement entail?

I want to invite you and your family member to take part in this research by participating in separate focus groups. We are also providing a letter of invitation to your family member with dementia.

There will be one group of about four family carers and one group of four people with dementia. The family carer focus group will be reviewing and discussing the P-CAD in terms of how useful it might be in supporting everyday communication.

How will the focus group be set up?

It will be run in a location convenient to you. You family member with dementia will also be invited to participate in a separate focus group, but we do not require both

of you to participate in this research. The focus group will last for about one hour. You will be in a small group of about four family carers and the discussion with be led by the researchers.

These group will be audio-taped and transcribed for analysis. You and your family member's identity with be strictly confidential. Your identities will be anonymised and not disclosed to anyone outside of the research. Information will be collected, stored and analysed in accordance with the Data Protection Act (1998).

The benefits and risks of participating?

Benefits of participating in this research include; you will meet other family carers who are living with dementia. Your feedback will be used to refine and improve the P-CAD which will then be used with people with dementia and their families. The P-CAD when finally published will be available to Speech and Language Therapists for use in their work with people with dementia.

In the unlikely event of discussion topics causing upset to you or your family member you will be offered follow-up support on site. Please be assured if you or your family member do not wish to participate in the study, current or future service provision will not be affected. You may withdraw from this research at any time.

This study has been approved by the Faculty Research Ethics Committee of TCD. Nothing in this document restricts or curtails your rights.

Please contact me or Dr. Margaret Walshe if you would like to participate in this research. You can contact us by phone 086-6098109 or 01-89623822 or E-mail dooleysu@tcd.ie or walshema@tcd.ie.

I hope that you will consider participating in this study. It has the potential to improve the extent and nature of communication therapy available to people with dementia as well as ultimately improve their quality of life and that of their families.

Yours sincerely

_____

Suzanna Dooley

Associate Researcher

Appendix 7.7 Focus Group 2; Consent form

TRINITY COLLEGE DUBLIN
SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Consent Form

Project title: Validation of the Profiling Communication Abilities in Dementia(P-CAD) Tool

Suzanna Dooley, Associate Researcher, Department of Clinical Speech and Language Studies, Trinity College Dublin.

Research and Ethics overview

I am invited to **participate in this research project** which is being carried out by Suzanna Dooley and Dr. Margaret Walshe, Associate Professor in Speech and Language Pathology.

This study has been **approved by the Faculty Research Ethics Committee of TCD.** Nothing in this document restricts or curtails my rights.

An overview of my participation

My participation is **voluntary**. Even if I agree to participate now, I can withdraw at any time without any consequences of any kind.

By participating in this study, I understand I am being asked to take part in a **focus group**. This will involve reviewing and discussing the P-CAD in terms of how useful it might be in supporting everyday communication with my family member with dementia.

My feedback will provide a family member's **perspective** on the P-CAD. It will provide insights into how Speech and Language Therapists might best evaluate the everyday communications of people with dementia. My input will be used to amend the P-CAD.

Focus Group Format

I understand that I will participate in a **group discussion** in a **small focus group** with about four other family carers. The discussion with be led by the researchers.

These group conversations will be **audio-taped and transcribed for analysis**. My identity and that of my family members' **identity with be kept strictly confidential**. The group will be held in **a location convenient to me.** I understand that participating in this focus group has a **time commitment of one hour.**

In the unlikely event of discussion topics causing me upset I will be offered follow-up support on site.

Confidentiality

It has been explained to me that my identity and that of my family members will be **anonymised** and not disclosed to anyone outside of the research. Information will be collected, stored and analysed in accordance with the Data Protection Act (1998).

The research data will be kept in the locked filing cabinet for 5 years following completion of the study. After 5 years the **research materials will be destroyed** by the research supervisor, Dr Margaret Walshe.

Please be assured if you or your family member do not wish to participate in the study, current or future service provision will not be affected. **You may withdraw from this research at any time.**

Signature of research participant

I understand what is involved in this research and I agree to participate in the study. I have been given a copy of the Participant Information Leaflet and a copy of this consent form to keep.

---------- ----------

Signature of participant Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study

---------- ----------

Signature of researcher Date

Appendix 7.8 Focus Group 3 and 4: Letter of Invitation

Email to Speech and Language Therapists, HSCPs, Nurses and Medical Doctors.

Dear Colleague,

I am conducting a research project with Dr. Margaret Walshe, Associate Professor in Speech and Language Pathology, in Trinity College Dublin following a grant award from Health Research Board Grant in 2015. This research aims to validate a cognitive-communication evaluation called the Profiling Communication Ability in Dementia (P-CAD). The aim is to refine the P-CAD further.

I am looking for Speech and Language therapists (SLTs), Health and Social Care Professionals (HSCPS), Nurses and Medical Doctors to participate in this study. The participants I am seeking are those with clinical experience in the field of dementia.

I want to invite you to take part in this research by participating in a focus group. You will be reviewing and discussing the P-CAD in terms of how useful it might be in supporting everyday communication, health care management and planning. I have attached a Participant Information Leaflet to this e-mail that will provide you with information about this study.

If you would like to participate in this study, please express your interest by sending an email to me at this email address dooleysu@tcd.ie. or by phone 086-6098109. Please do so within 1 week of receiving this email.

If you have any questions or would like to discuss this study further please do not hesitate to contact me or you can contact my research supervisor, Dr. Margaret Walshe, walshema@tcd.ie.

Thank you for taking the time to read this information.

Your Sincerely

Suzanna Dooley
Associate Researcher SLT
TCD

Appendix 7.9 Focus Group 3 SLTs: Participant Information Leaflet

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Participant Information Leaflet

Project title: Validation of the Profiling Communication Abilities in Dementia(P-CAD) Tool

Suzanna Dooley, Associate Researcher, Department of Clinical Speech and Language Studies, Trinity College Dublin.

You are invited to participate in this research project which is being carried out by Suzanna Dooley and Dr. Margaret Walshe, Associate Professor in Speech and Language Pathology. This project is funded by Health Research Board, Ireland.

We are developing an assessment for Speech and language Therapists that can be used to evaluate the cognitive-communication strengths of the person with dementia and their CP. It is called *Profiling Communication Ability in Dementia* (P-CAD). The aim of this study is to test the face, content, construct and ecological validity of the P-CAD by requesting that Speech and Language Therapists review the tool and provide their opinions on it. Your involvement and feedback will be used to amend the P-CAD by improving its validity.

Your participation is voluntary. Even if you agree to participate now, you can withdraw at any time without any consequences of any kind.

What is the purpose of our research?

We want to develop and make available this assessment tool to facilitate Speech and Language Therapists (SLTs). It will enable them to engage in a timely way with people with dementia and their families and help promote and support communication. This is important research as people with dementia in Ireland have limited access to communication assessment and interventions.

This study has been approved by the Faculty Research Ethics Committee of TCD. Nothing in this document restricts or curtails your rights.

What will your involvement entail?

I want to invite you to take part in this research by participating in a focus group. You will be reviewing and discussing the P-CAD in terms of;

- How useful it might be in supporting everyday communication
- Relevance of the P-CAD profile domains to people with dementia and their carers
- It's ability to detect change in impairment and communication function over time
- Its usefulness across care settings.

How will the focus group be set up?

It will be run in a location convenient to you. The focus group will last for about one hour. You will take part in a facilitated group discussion with a group of six to eight Speech and Language Therapists.

This group discussion will be audio-taped and transcribed for analysis. Your identity with be strictly confidential. Your identity will be anonymised and not disclosed to anyone outside of the research. Information will be collected, stored and analysed in accordance with the Data Protection Act (1998).

The benefits and risks of participating?

Your feedback will be used to refine and improve the P-CAD which will then be used with people with dementia and their families. The P-CAD when finally published will be available to Speech and Language Therapists for use in their work with people with dementia. Please be assured that you may withdraw from this research at any time.

This focus group will take place on Tuesday 7th June in the Department of CSLS in TCD at 10.30- 12.00am.

Please contact me or Dr. Margaret Walshe at your earliest convenience, if you would like to participate in this research. You can contact us by phone 086-6098109 or 01-89623822 or E-mail dooleysu@tcd.ie or walshema@tcd.ie. I hope that you will consider participating in this study.

Thank you for reading this information leaflet

Appendix 7.10 Focus Group 3 SLTs: Consent Form

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Consent Form

Project title: Validation of the Profiling Communication Abilities in Dementia (P-CAD) Tool

Suzanna Dooley, Associate Researcher, Department of Clinical Speech and Language Studies, Trinity College Dublin.

Research and Ethics overview

I am invited to participate in this research project which is being carried out by Suzanna Dooley and Dr. Margaret Walshe, Associate Professor in Speech and Language Pathology. I have read the information leaflet and understand the scope of the research. This study has been approved by the **Faculty Research Ethics Committee of TCD.** Nothing in this document restricts or curtails my rights.

An overview of my participation

My participation is **voluntary**. Even if I agree to participate now, I can withdraw at any time without any consequences of any kind.

By participating in this study, I understand I am being asked to take part in this research by participating in a **focus group with a time commitment of 90 mins**.

I understand I will be reviewing and discussing the P-CAD in terms of;

- How useful it might be in supporting everyday communication
- Relevance of the P-CAD profile domains to people with dementia and their carers
- It's ability to detect change in impairment and communication function over time
- Its usefulness across care settings.

My background, involvement and commitment

I am a **Speech and Language Therapist (SLT)** who is working with people with dementia and have at least three years post graduate experience. I understand that

the aim of this study is to test the face, content, construct and ecological validity of the P-CAD by requesting that I review the tool and **provide my opinions** on it.

I understand that the focus group will last for about one hour and that I will be in a **small group of about six to eight participants**. The group discussion with be led by the researchers. The group discussion will be **audio-taped and transcribed** for analysis.

When the group discussion has finished I will **return the P-CAD forms** provided. As the finding from this study may be published in the future.

Focus Group Outcome

My feedback will be used to **refine and improve** the P-CAD which may in the future be published and used by SLTs with people with dementia and their families.

Confidentiality

My identity with be strictly confidential. My identity will be **anonymised** and not disclosed to anyone outside of the research study. Any information obtained from me during the research will be treated **confidentially** by the primary investigator Suzanna Dooley (SD) and Dr. Margaret Walshe, Assistant Professor in Speech and Language Pathology.

I understand that the audio recordings be kept in a **locked filing cabinet** in the Department of Clinical Speech and Language Studies in Trinity College Dublin. The primary investigator SD and Dr. Margaret Walshe will be the only individuals who will have access to this cabinet. Any electronic information will be kept on a **password protected computer** to which only the primary investigator will have access to. The research data will be kept in the locked filing cabinet for 5 years following completion of the study. After 5 years the research materials will be destroyed by the research supervisor, Dr Margaret Walshe.

If I have any questions about this research, I can contact the primary investigator Suzanna Dooley, dooleysu@tcd.ie and Dr. Margaret Walshe, walshema@tcd.ie

Signature of research participant

I understand what is involved in this research and I agree to participate in the study. I have been given a copy of the Participant Information Leaflet and a copy of this consent form to keep.

---------- ----------

Signature of participant Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study

---------- ----------

Signature of researcher Date

Appendix 7.11 Focus Group 4 HSCPS, Nurses and Medical Doctors: Participant Information leaflet

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Participant Information Leaflet

Project title: Validation of the Profiling Communication Abilities in Dementia (P-CAD) Tool

Suzanna Dooley, Associate Researcher, Department of Clinical Speech and Language Studies, Trinity College Dublin.

You are invited to participate in this research project which is being carried out by Suzanna Dooley and Dr. Margaret Walshe, Associate Professor in Speech and Language Pathology. This project is funded by Health Research Board, Ireland.

We are developing an assessment for Speech and language Therapists that can be used to evaluate the cognitive-communication strengths of the person with dementia and their CP. It is called *Profiling Communication Ability in Dementia* (P-CAD). The aim of this study is to test the face, content, construct and ecological validity of the P-CAD by requesting that health and social care professionals (HSCPs), nurses and medical doctors review the tool and provide their opinions on it.

Your participation is voluntary. Even if you agree to participate now, you can withdraw at any time without any consequences of any kind.

What is the purpose of our research?

We want to develop and make available this assessment tool to facilitate Speech and Language Therapists (SLTs). It will enable them to engage in a timely way with people with dementia and their families and help promote and support communication. This is important research as people with dementia in Ireland have limited access to communication interventions.

What will your involvement entail?

I want to invite you to take part in this research by participating in a focus group.

You will be reviewing and discussing the P-CAD in terms of how useful it might be in supporting everyday communication.

Your involvement and feedback will be used to amend

the P-CAD by improving its validity. It is important that we have feedback from HSCPs, nurses and doctors, as the P-CAD profile form and recommendations will be a useful resource for the multi-disciplinary team (MDT) in facilitating communication with the person with dementia and in planning an individualised care pathway. We see specific application of the P-CAD Profile in assisting decision making.

How will the focus group be set up?

It will be run in a location convenient to you. The focus group will last for about one hour. You will be in a small group of about six to eight participants and the discussion with be led by the researchers.

These group will be audio-taped and transcribed for analysis. Your identity with be strictly confidential. Your identity will be anonymised and not disclosed to anyone outside of the research. Information will be collected, stored and analysed in accordance with the Data Protection Act (1998).

The benefits and risks of participating?

Your feedback will be used to refine and improve the P-CAD which will then be used with people with dementia and their families. The P-CAD when finally published will be available to Speech and Language Therapists for use in their work with people with dementia. The P-CAD profile and recommendations will then be available to the MDT in the medical record.

Please be assured that your involvement is voluntary, and you may withdraw from this research at any time. This study has been approved by the Faculty Research Ethics Committee of TCD. Nothing in this document restricts or curtails your rights.

Please contact me or Dr. Margaret Walshe if you would like to participate in this research. You can contact us by phone 086-6098109 or 01-89623822 or E-mail dooleysu@tcd.ie or walshema@tcd.ie.

I hope that you will consider participating in this study. It has the potential to improve the extent and nature of communication therapy available to people with dementia as well as ultimately improve their quality of life and that of their families.

Thank you for reading this information leaflet

Appendix 7.12 Focus Group 4: HSCPS, Nurses and Medical Doctors: Consent Form

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Consent Form

Project title: Validation of the Profiling Communication Abilities in Dementia(P-CAD) Tool

Suzanna Dooley, Associate Researcher, Department of Clinical Speech and Language Studies, Trinity College Dublin.

Research and Ethics overview

I am invited to participate in this research project which is being carried out by Suzanna Dooley and Dr. Margaret Walshe, Associate Professor in Speech and Language Pathology.

This study has been approved by **the Faculty Research Ethics Committee of TCD**. Nothing in this document restricts or curtails my rights.

An overview of my participation

My participation is **voluntary**. Even if I agree to participate now, I can withdraw at any time without any consequences of any kind.

By participating in this study, I understand I am being asked to take part in this research by participating in a **focus group**. I will be reviewing and discussing the P-CAD in terms of how useful it might be in supporting everyday communication and care planning. I understand that participating in this focus group has a **time commitment of one hour.**

My feedback will provide a wider perspective on the P-CAD and this will be used to amend this latest version of the P-CAD.

My background, involvement and commitment

I am a **Health Professional** working with people with dementia and their families. I understand that the aim of this study is to test the face, content, construct and ecological validity of the P-CAD by requesting that I review the tool and **provide my opinions** on it.

I understand that the focus group will last for about one hour and that I will be in a **small group of about six participants**. The group discussion with be led by the researchers. The group discussion will be **audio-taped and transcribed** for analysis. When the group discussion has finished, I will **return the P-CAD forms** provided. As the finding from this study may be published in the future.

Focus Group Outcome

My feedback will be used to **refine and improve** the P-CAD which may in the future be published and used with people with dementia and their families. At this stage, the P-CAD profile and recommendations will then be **available to the MDT** in the medical record.

Confidentiality

My identity with be strictly confidential. My identity will be **anonymised** and not disclosed to anyone outside of the research study. Any information obtained from me during the research will be treated **confidentially** by the primary investigator Suzanna Dooley (SD) and Dr. Margaret Walshe, Assistant Professor in Speech and Language Pathology.

I understand that the audio recordings be kept in a **locked filing cabinet** in the Department of Clinical Speech and Language Studies in Trinity College Dublin. The primary investigator SD and Dr. Margaret Walshe will be the only individuals who will have access to this cabinet. Any electronic information will be kept on a **password protected computer** to which only the primary investigator will have access to. The research data will be kept in the locked filing cabinet for 5 years following completion of the study. After 5 years the research materials will be destroyed by the research supervisor, Dr Margaret Walshe.

If I have any questions about this research, I can contact the primary investigator Suzanna Dooley, dooleysu@tcd.ie and Dr. Margaret Walshe, walshema@tcd.ie

Signature of research participant

I understand what is involved in this research and I agree to participate in the study. I have been given a copy of the Participant Information Leaflet and a copy of this consent form to keep.

---------- ----------

Signature of participant Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study

---------- ----------

Signature of researcher Date

Appendix 7.13 Focus Groups (1,2,3,4) Topic Guides

PARTICIPANTS WITH DEMENTIA

FOCUS GROUP

Topic Guide

1. Refreshments & Housekeeping
2. Outline the P-CAD research project.
3. Purpose of the group and group ground rules.
4. What is the group's opinion on this type of ability-based assessment?
5. What is the group's opinion on this information being shared by the MDT?
6. What is the group opinion on the length of this evaluation?
7. What is the group opinion on being video recorded in conversation?
8. What is the group opinion on the usefulness of communication support strategies?
9. Any other feedback
10. Close meeting

CARERS FOCUS GROUP

Topic Guide

1. House keeping

2. Outline the P-CAD research project.

3. Purpose of the group and group ground rules

4. Facilitator to review the P-CAD Summary sheet with group members and outline the sub sections and potential recommendations and context in which the P-CAD might be used.

5. Discuss the groups opinions on the administration of the P-CAD
   - Assessment time
   - Video-recording
   - Gaining consent and proxy consent

6. Discuss P-CAD content and its relevance to everyday communication for families living with dementia (particularly section 7).

7. Elicit the group's opinion on the PS form, the overall scoring, communication support levels and recommendations.

8. Ask the group if knowing the PWD's communication abilities and being given communication support strategies would be useful for families.

9. Any other feedback

10. Close meeting

SLTs FOCUS GROUP

Topic Guide

1. Refreshments & Housekeeping. (3.15)

2. Outline the P-CAD research project. (3.20)

3. Purpose of the group and group ground rules (3.25)

4. Group facilitator to give an overview of the P-CAD evaluation, the administration and scoring system including the profile summary form.
   Specific questions on sections

   (30 mins to discuss)

   Cover page: Is there anything missing or surplus on this page?

   Section 1: Is the attention section appropriately positioned in the evaluation? Will including attention ability in the P-CAD yield useful clinical information?

   Section 2: Are the levels of auditory comprehension being assessed appropriate?

   Section 3: Does this section need a generative naming task? Is the confrontation naming task detailed enough? Should the Conversation Ability section come here after section 3?

   Section 4: Is this section too long? Is the paragraph reading section too long and is the reading level high enough?

   Section 5: Is this section too long? Should we omit write a sentence about yourself?

   Section 6: What are the SLTs opinions on video recording clients? Will this section impact on SLT recommendations and therapy planning? Might the P-CAD evaluate trouble source, repair initiation and resolution in more detail? Is it necessary to include word finding ability at conversational level as well as picture description?)

   Section 7: Are these questions appropriate? Omitted/surplus questions?

   Section 8: Will the terms frequency and effectiveness objective enough to measure change over time? (4.00)

5. Group to review the PS form and the scoring system. Seek opinions on the direction of the scoring the terms/language used. (4.10)

6. Group to review the P-CAD Picture Stimulus Book. Seek opinions on style, clarity and appropriateness of drawings (4.15)

7. Discuss if there are barriers to using the P-CAD in the acute setting? (4.20)

8. Discuss how the P-CAD might impact on SLT management and patient outcomes? (4.25)

9. Any other feedback

HSCPs, Nurses and Doctors FOCUS GROUP

Topic Guide

1. Refreshments & House keeping
2. Outline the P-CAD research project.
3. Purpose of the group and group ground rules
4. Facilitator to review the P-CAD Summary sheet with group members and outline the sub sections and potential recommendations and context in which the P-CAD might be used.
5. Discuss the overall appearance of the PS form. Is it user friendly?
6. Discuss the P-CAD overall levels (communication support) and scoring.
7. Would the P-CAD evaluation be useful to the MDT in managing PWD and in planning care pathways?
8. Could this information on communication abilities impact on the evaluation of capacity and assisted decision making?
9. Show the group some PS form alternatives (Limited text, detailed level descriptions, graph) to determine if they prefer one over the other.
10. Any other feedback
11. Close meeting

Appendix 7.14 Coded Transcript: HSCP, Nursing and Medical Physicians Focus Group

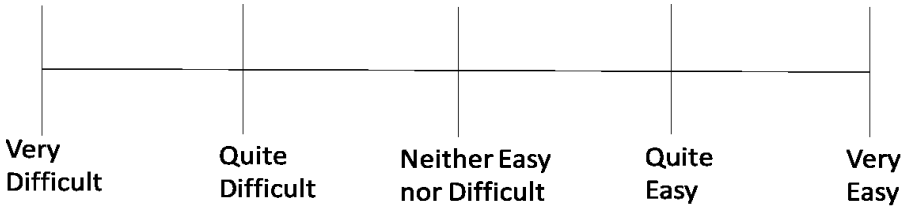
Transcript	Codes
P01: the core support strategies are quite nice are they different from the functional communication section?	Communication
SD: they are subsumed into functional communication. Some of these strategies you are looking at here will be used to support functional communication…….do you know what I mean	
P01: (yeah….) are the strategies for the patients and the staff	
SD: yes, for use by the family, the staff and person with dementia too, do you think we need separate strategies for family and staff	
P01: the language will need to be easy for the family to pick up, a very easily worded document, I think the person trying to get consent for something will look at the profile and say what are they strong at and use that. Like I do in my physio session, I think it will guide conversations the family, just reading through the strategies through quickly I think they are very useful	P-CAD amendment Care Communication
P02: I suppose in terms of capacity and how best you can go about looking for consent, it is useful. But you are not going to be able to look at this and say they are/are not going to be able to give consent, but you'll have the strategies to go and see and do the best you can do on that day (P03: you can use in conjunction with an Addenbrookes or some other cognitive assessment)	Care Communication Communication
P01: say if… their reading comprehension is really good you could write it down and look at their strengths really and try and target those to have the conversation	Care
P04: P-CAD will contribute towards our decisions on capacity, but I see it being used more globally on the ward, avoiding communication problems in the day to day life of that person, you know where little things can become catastrophic and trying to avoid major roadblocks because they have a communication problem when they come into hospital	Communication

Appendix 8.1 P-CAD: SLT Pilot Feedback Questionnaire

P-CAD Feedback Questionnaire

This questionnaire should be completed by you following the completion and scoring of the P-CAD with your clients and their communication partners.

1. How easy/difficult was this P-CAD to administer?
   (Please circle)



Comments	

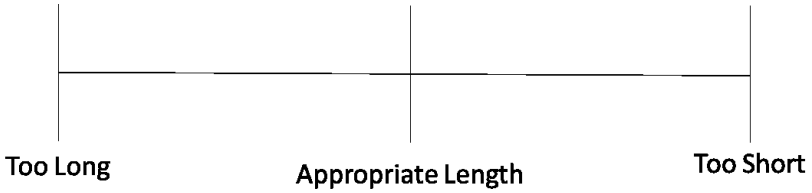
2. How long on average did it take you to complete and score each individual P-CAD?

Please tick:

<20 minutes	
20-30 minutes	
30-40 minutes	
>50 minutes	

If it took longer than 50 minutes, please specify the time: _____

3. Rate the P-CAD in terms of length of time to administer?
   (Please circle)



4. Do you think there are items on the P-CAD that are unnecessary and could be removed? (If yes please describe further below)

Please tick:

Yes	
No	

Comments	

5. Do you think the Summary Profile Form captures the person's individual communication profile to guide management? (If No please describe further below)
   Please tick:

Yes	
No	

Comments	

6. Do you think there any skills or support strategies that were missing from the P-CAD which you feel should be included? (If yes please describe further below)

Please tick:

Yes	
No	

Comments	

7. Were there any skills or support strategies which you found to be unclear?

(If yes please explain further below)

Please tick:

Yes	
No	

Comments	

8. Were there any parts of the P-CAD you felt were difficult to understand?

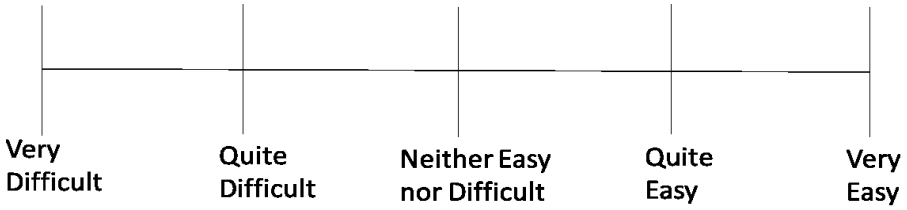
(If yes, please explain further below)

Please tick:

Yes	
No	

Comments	

9. Please rate how easy or difficult it was to score the P-CAD?
(Please circle)



Comments	

10. Do you agree with the weighting of the scores provided for each subsection on the P-CAD?

Please tick:

Yes	
No	

Comments	

11. Do you believe that the P-CAD has potential to detect change in communication ability as dementia progresses?

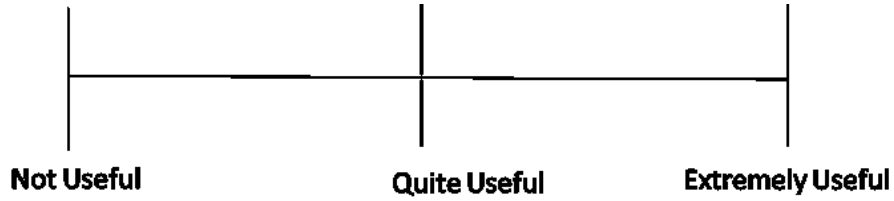
Please tick:

Yes	
No	

Comments	

12. Overall, please rate and comment on the usefulness of the P-CAD as an assessment tool for people with dementia?

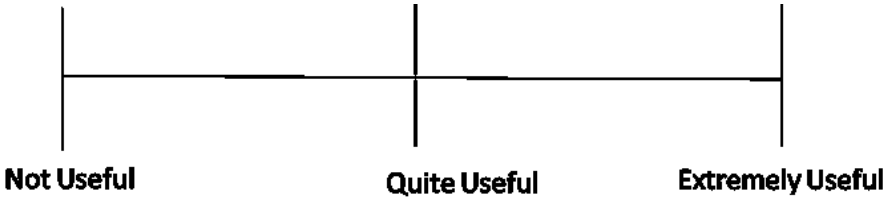
(Please circle)



Comments	

13. Overall, please rate and comment on the usefulness of the P-CAD as an assessment tool for primary communication partners?

(Please circle)



Comments	

14. Did the P-CAD impact on your clinical decision-making regarding case management.

(If yes please explain further below)

Please tick:

Yes	
No	

Comments	

15. Do you believe that the P-CAD is appropriate to use with people with dementia in a range of settings e.g care homes, acute hospital, memory clinics etc.)?

Please tick:

Yes	
No	

Comments	

16. If you could suggest one change to the P-CAD, what would it be?

_____

_____

_____

_____

Thank you.

Please return this completed questionnaire with the P-CAD including the administration and scoring information to the primary investigator, Suzanna Dooley, as per instructions in the Participant Information Leaflet

Appendix 8.2 Ethics Approval HT32

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Academic Year 2015/16

Applicant: HT32 Suzanna Dooley

Project title: Refinement of the Profiling Communication in Dementia tool (P-CAD)

Dear Suzanna,

Your submission for ethics approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin, on Friday 19 February 2016, and has been approved in full. We wish you the very best in your research activities.

Dr Lorna Carson
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences
Trinity College Dublin

Scoil na nEolaíochtaí Teanga-olaíochta, Urlabhra agus Cumarsáide
Coláiste na Tríonóide
Baile Átha Cliath 2, Éire

School of Linguistic, Speech & Communication Sciences,
Trinity College Dublin
Dublin 2, Ireland

T 353 (0)1 896 1560

slscs@tcd.ie
www.tcd.ie/slscs

Appendix 8.3 SLT Pilot Participant Information Leaflet

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Participant Information Leaflet

Project title: Validation of the Profiling Communication Abilities in Dementia(P-CAD) Tool

Suzanna Dooley, Associate Researcher, Department of Clinical Speech and Language Studies, Trinity College Dublin.

You are invited to participate in this research project which is being carried out by Suzanna Dooley and Dr.Margaret Walshe, Associate Professor in Speech and Language Pathology.

The P-CAD was developed to evaluate the communication strengths of the person with dementia and their CP. The aim of this study is to test the face, content, construct and ecological validity of the P-CAD by requesting that participating Speech and Language Therapists (SLTs) use the tool and provide their opinions on it. This project is funded by Health Research Board, Ireland.

Your involvement and feedback will be used to amend the earlier version of the P-CAD by improving its validity. Your participation is voluntary. Even if you agree to participate now, you can withdraw at any time without any consequences of any kind.

The materials provided to you for this study will include the P-CAD administration and scoring guidelines, some testing materials, copies of the P-CAD profile form and scoring form, and a feedback questionnaire. If convenient for you, these will be brought to your place of work by the primary investigator, Suzanna Dooley and the procedure for administration explained. Written consent for participation will be taken at this time. Your participation in this study should require a maximum of 5 hours of your time.

Participation in this study will require that you:

1. Read the P-CAD administration and scoring recommendations, including the profile summary form and the scoring form before use.

2. Use the P-CAD to evaluate the communication skills of a minimum of **3 people** with dementia and their primary CPs.
3. Complete a feedback questionnaire to provide your views and perspectives on the tool.

Any information or data which is obtained from you during this research will be treated confidentially. The research materials will not seek the provision of any identifying information relating to you or your clients and any information obtained from you during this research will be treated confidentially by the research team. You will be asked to generate a random study identity number for each P-CAD Summary form. This code, known only to you, will allow you to return the completed questionnaires and P-CAD forms anonymously. You can return the completed forms and P-CAD materials using a stamped addressed envelope that will be provided to you by the primary investigator.

We do not foresee any risks to you being a participant once confidentiality is adhered to. You will not benefit in monetary terms from your participation, but ultimately when the P-CAD is published you will be able to use it with your clients which will assist you in your assessment and management of this client group.

It is asked that the P-CAD evaluation forms and P-CAD feedback questionnaire are completed and returned within 4 weeks from the time they are given by you. If you have any questions about this research, you can contact the primary investigator Suzanna Dooley, dooleysu@tcd.ie or 086-6098109. You are also free to seek further clarification and information by contacting the research collaborator for this project, Dr. Margaret Walshe, walshema@tcd.ie

If you are willing to participate in this study, please express your interest by sending an email to the primary investigator Suzanna Dooley, dooleysu@tcd.ie. Expressions of interest will close on (date provided)

Data from this research project will be published in future so it is important that you do not use or share your draft version on the P-CAD with other SLTs or professionals until the final amended version is published.

Thank you for reading this information leaflet

Appendix 8.4 Reminder E-mail for SLT Participants

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Participant Information Leaflet

Project title: Validation of the Profiling Communication Abilities in Dementia(P-CAD) Tool

Dear Participants,

Thank you to those of you who have already completed the P-CAD questionnaire and returned to me. I really appreciate your help. Please disregard this email further.

For those who have yet to respond, I would be grateful if the questionnaire along with the P-CAD stimulus book and unused P-CAD scoring forms could be returned to me in the stamped addressed envelope provided.

Your feedback is important, and we do appreciate the time taken to assist us in this project.

If you have any queries or difficulties with return of questionnaire, please feel free to contact me directly at this email address.

With kind regards and best wishes,

Suzanna Dooley

Speech and Language Therapist Researcher

dooleysu@tcd.ie

Appendix 8.5 CAD Stimulus Book PDF

F-CAD

Picture and Feature Stimulus Book

© Dooley & Walshe 2016
dooleysu@tcd.ie

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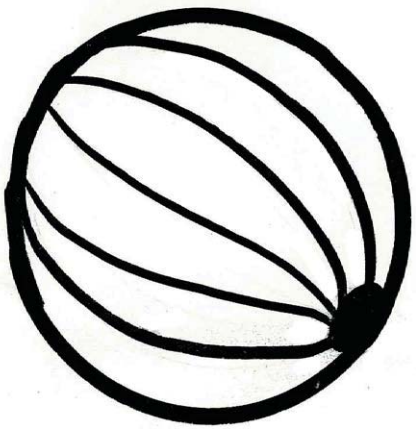

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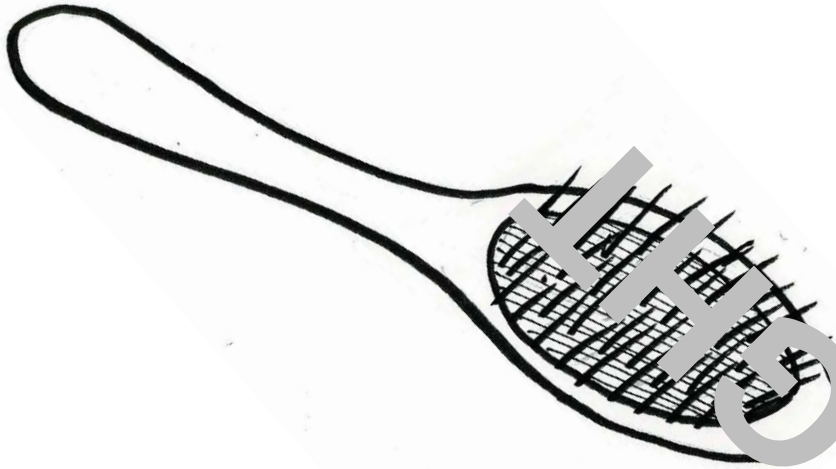

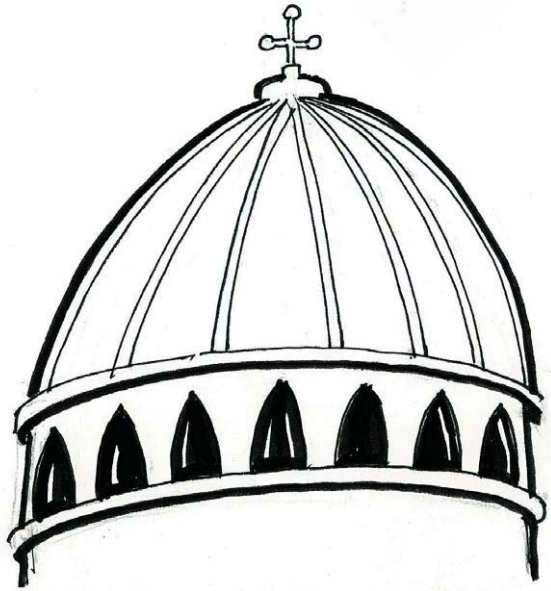

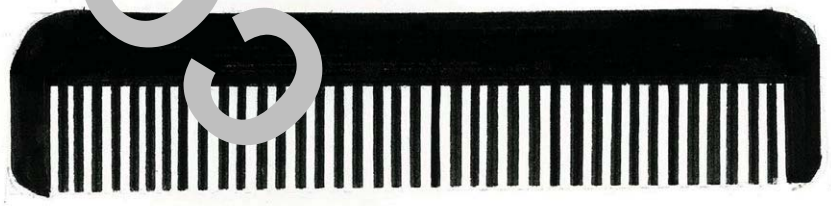

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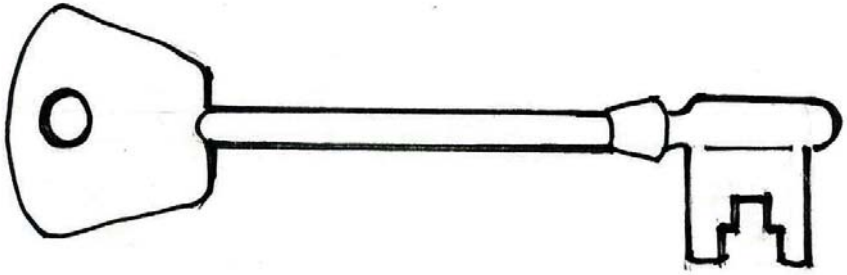

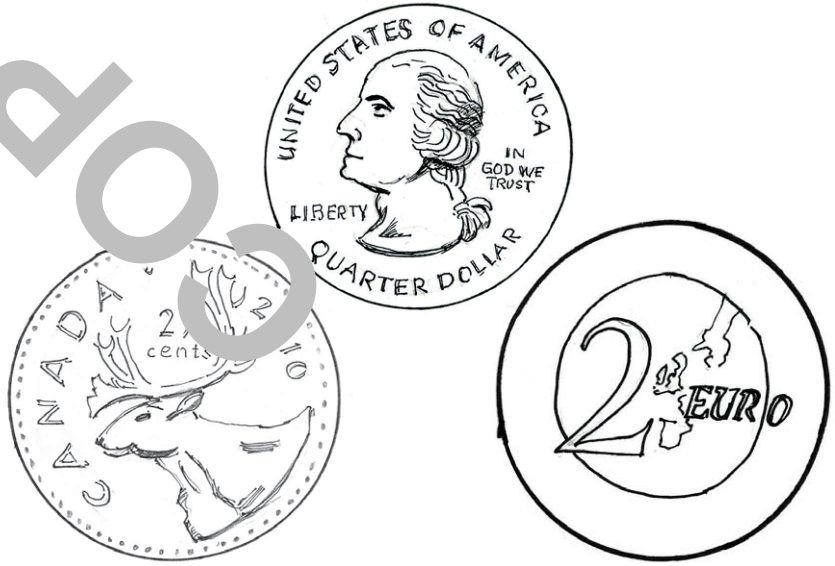

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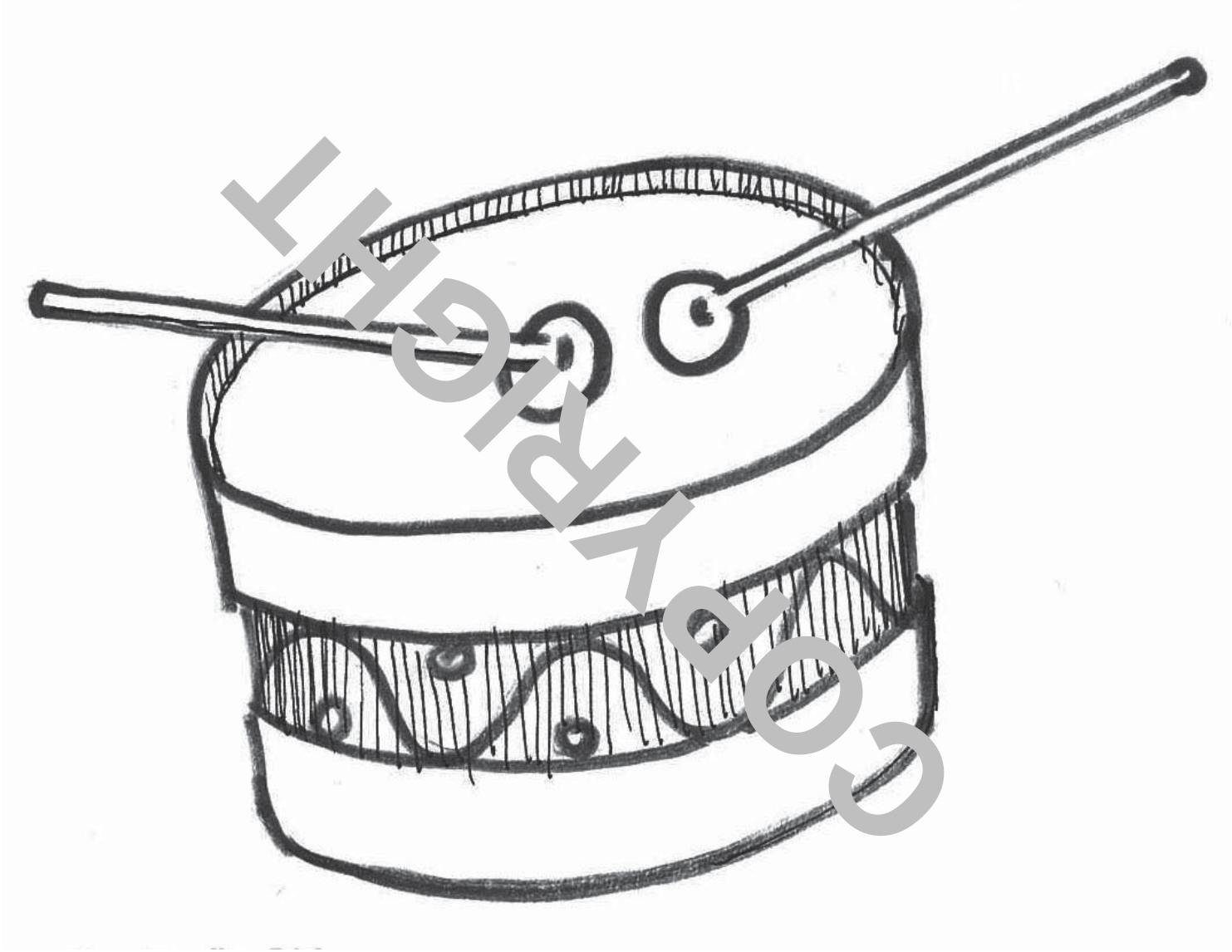

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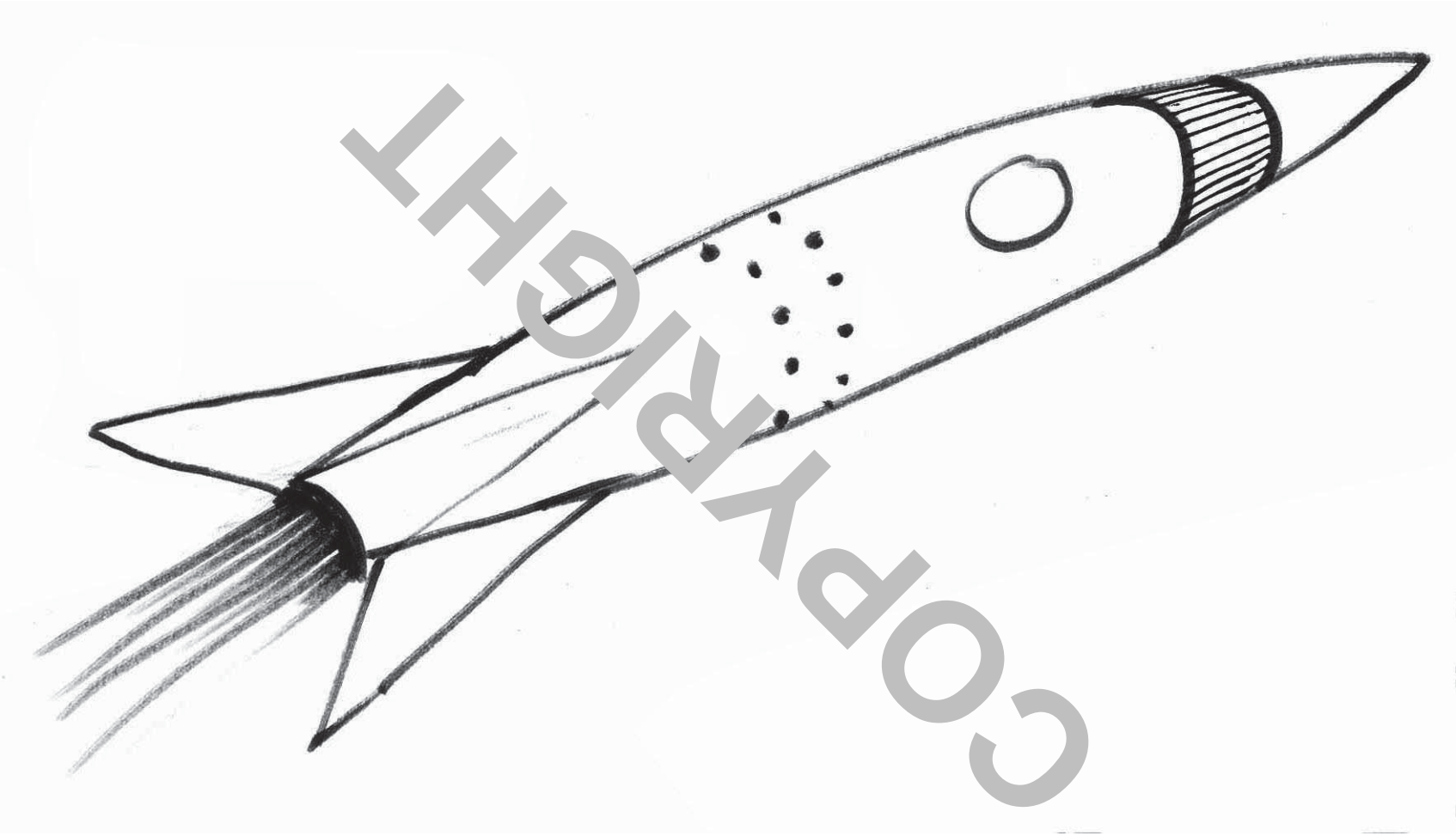

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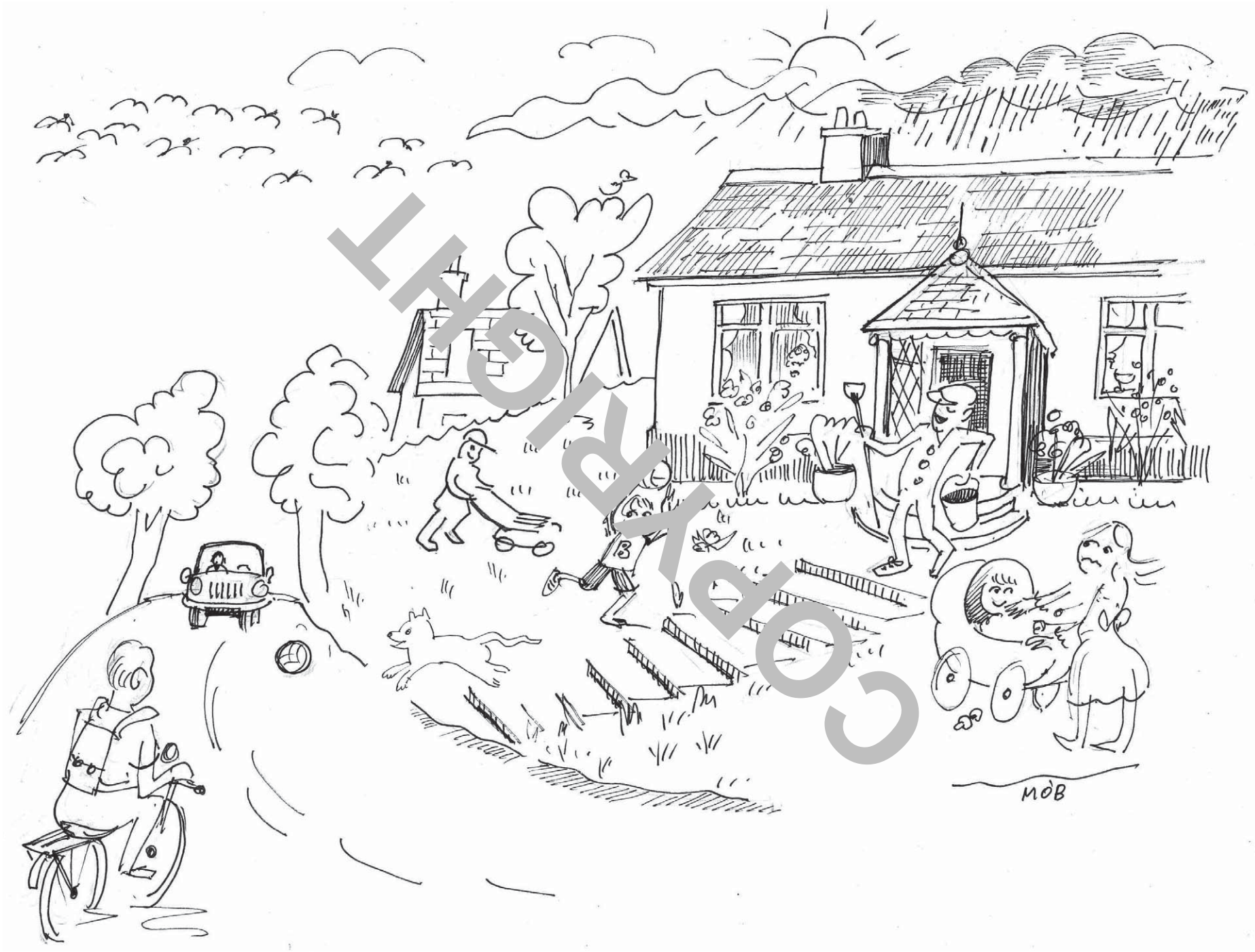

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road tree leaf glee

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match **pencil** **cup** **stencil**

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key **lock** **knee** **glass**

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purse **money** **honey** **home**

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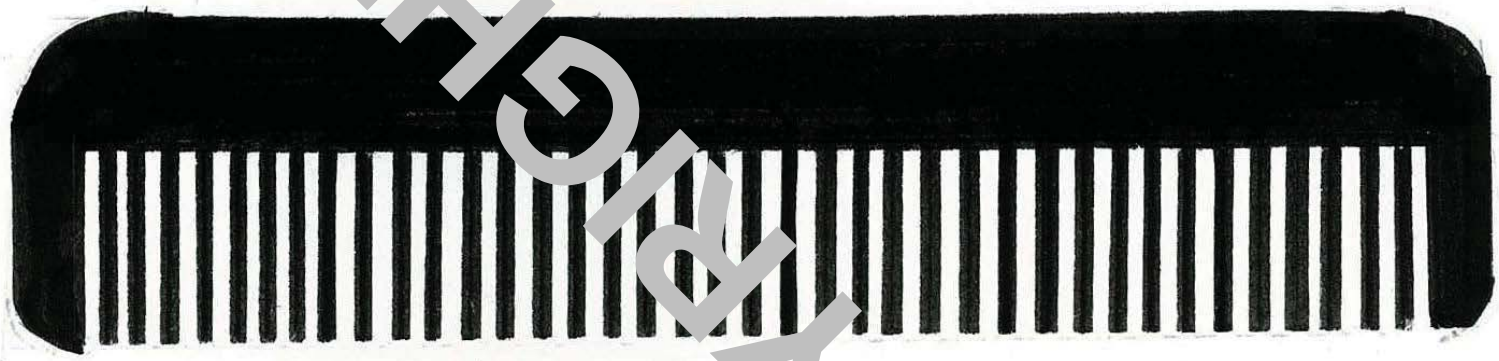

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rain hair comb tomb

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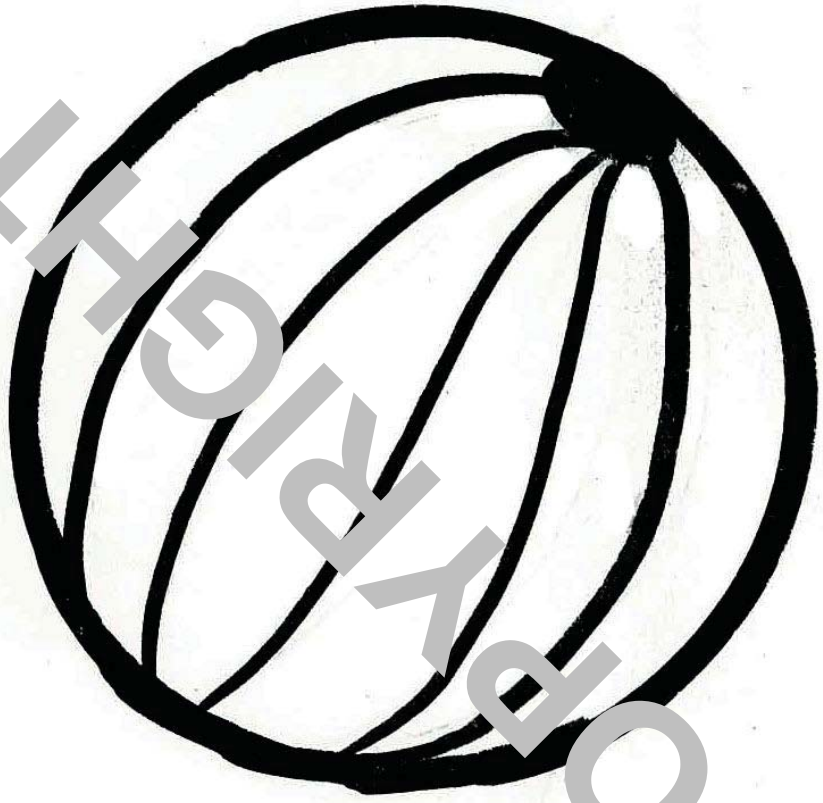

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doll ball hat goal

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Wave your hand

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Point to the ceiling and the floor

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Take one tablet daily before food. If you experience any side-effects discontinue taking these medications

How often do medicines have to be taken?

1. Three times a day
2. Once a day
3. Once a week
4. None of the above

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THE EVENING NEWS

22 January 2017

Stray Horses cause accident

Jim Quinn

A 57-year-old man and his daughters were injured in a road accident near Kilkenny yesterday evening. The Kelly family were travelling in their saloon car on the Kilkenny by-pass when the incident occurred. There were two loose horses on the road which caused Mr. Kelly to drive into the embankment to avoid a collision. Intense rain at the time of the accident affected visibility.

The Kelly family were attended at the scene of the accident by the ambulance and fire brigade. They were transferred by ambulance to the Regional Hospital. Mr. John Kelly is in a stable condition and his daughters Hannah and Lara have minor injuries.

It was reported that the horses escaped earlier in the day from a nearby farm and strayed down onto the road. The horses have been impounded under Section 3 of the Animals Act, 1985, their owner will be prosecuted in due course

Thankfully, the injuries sustained to the Kelly family were not life threatening and there were no other vehicles involved in the accident.

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Stray Horses Cause Accident

Point to the correct answer for each question

1. What is the name of this newspaper?
   a) The Daily News
   b) The Evening News
   c) The Evening News Daily

2. What was the name of the family involved in the accident?
   a) Kealy
   b) Hudson
   c) Kelly

3. Who were the the passengers in the car?
   a) Mr. Kelly's sisters
   b) Mr. Kelly's daughters
   c) Mr. Kelly's sons

4. What were the weather conditions like at the time of the accident?
   a) It was raining
   b) It was frosty
   c) It was sunny

4. Was there loss of life in the accident?
   a) Yes
   b) No
   c) It didn't state either way

5. How could the accident have been avoided?
   a) Mr. Kelly could have driven more slowly
   b) Farmers should regularly check that fencing is secure
   c) This accident could not have been avoided

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Shopping list
(Clinician's stimulus)

milk
bread
coffee
cornflakes
newspaper

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P-CAD

Profiling Communication Ability in Dementia

Administration and Scoring

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Client name: _____ DOB: _____ MRN:_____ Medical Diagnosis:_____ _____ _____	SLT: _____ DOA: _____ Retest:_____ Test location: Home ☐ Ward ☐ Office ☐ _____ P-CAD discontinued due to _____
English 1st language Yes No _____ Cognitive Assessment Results_____ _____ _____	**Circle as appropriate**: Wears glasses Yes No Wears hearing aids Yes No Upper limb weakness Yes No Consent for video recording given Yes No

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2 P-CAD Auditory Comprehension Ability

There are **four parts** to this section. The maximum possible score is 14 points.

1. Word picture matching (3 points)
2. Following verbal Instructions (3 points)
3. Answering questions (3 points)
4. Paragraph comprehension (5 points)
5. Note and record communication support strategies in the comment section. Strategy use is not scored. Note the effectiveness of repetitions but do not re-score the item.

1. Spoken Word to Picture Matching (3 points)

Stimulus: Cards AC1- AC3

Instruction Say "I am going to say a word. Please point to the matching picture._____"

"Child" (turn the page for the next item)

"Comb" (turn the page for the next item)

"Money"

Target	Score (circle score given)
Child Comb Money	3 Client correctly identifies 3 pictures 2 Client correctly identifies 2 pictures 1 Client correctly identifies 1 picture 0 Client points to incorrect pictures or no respon[illegible]/NR) [illegible] 10 secs.
	Su[illegible]Sect[illegible]n Sco[illegible] /3

2. Following Verbal Instructions (3 points)

Observe and document strategies used by the client to facilitate understanding. (e.g., asks for repetition, repeats instructions [illegible]self). Response with repetition is noted but not scored.

Instruction: Say "I am going to ask you to follow some instructions. Are you ready?"

A. 'Look at the ceiling' (max score 1)

Score (circle score given)	Notes
1 Correct response 0 Incorrect response, person looks somewhere else in the room or no response (NR) within 10 sec	

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B. 'Smile and then raise your arm' (max score 2)

Notes	Score (circle score given)
2 Correct response (Credit given for attempt to raise arm but incomplete because of limb apraxia, hemiplegia, etc.) 1 Partially correct response (just one information element correct) 0 Incorrect response. Client responds with different actions	Smile and then raise your arm 1 1 Sub section Score 2.A. and 2.B /3

3. Answering Questions *(3 points)*

Instruction to clinician: Say "I want you to answer 'Yes' or 'No' to the following questions".

A. Does milk go sour?
B. Do you eat an orange before you peel it?
C. Alice is taller than Mark is Mark smaller?

Score (circle score given)	Notes
A. Does milk go sour? 1 Answers Yes 0 Answers No or NR B. Do you eat an orange before you peel it? 1 Answers No 0 Answers Yes or NR C. Alice is taller than Mark is Mark small 1 Answers Yes 0 Answers No or NR	
	Sub Section Score /3

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4. Paragraph level Auditory Comprehension (5 points)

Instruction: Say "I am going to tell you a short story. Afterwards, I am going to ask you some questions about the story. Listen carefully because I can only tell it once".

A Night Out!

On Thursday evening Jane and Andrew went to the cinema. They were going to see "Gone with the Wind", an old-time favourite of theirs.

Jane had booked the tickets online, so when they arrived at the cinema, she went to collect the tickets. Andrew bought two coffees and they joined the queue (/stood in line).

When Jane and Andrew got to the top of the line the usher pointed out that their tickets were for Friday night.. What a disappointment! They sat for half an hour and drank their coffee in the foyer and then went home.

Questions (correct answer highlighted)

1. Did they want to see the 'Sound of Music'? Yes/ No
2. Did they go to the cinema on Thursday evening? (Yes/No)
3. Were the people in this story called Julie and Tom? (Yes/No)
4. Did Jane buy the tickets in advance? (Yes/No)
5. Did they go straight home? (Yes/No)

Score (circle score given)	Note
5 Answered all five questions correctly 4 Answered four questions correctly 3 Answered three questions correctly 2 Answered two questions correctly 1 Answered one question correctly 0 No questions answered correctly	You may repeat the story but the client's response after repetition is not scored.
	Sub Section Score /5

Total Auditory Comprehension Ability Score

Sub sections	Scores
Spoken Word to Picture Matching	/3
Following Verbal Instructions	/3
Answering Questions	/3
Paragraph level Auditory Comprehension	/5
Total Score	/14

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3 P-CAD Verbal Expression Ability

There are four different sections to evaluate verbal expression. The maximum score for this section is 11 points

1. Greetings and Goodbyes (3 points)
2. Naming (4 points)
3. Picture description (4 points)
4. Note and record communication support strategies and non-verbal communication in the comment section. Strategy use is not scored. Document the frequency and effectiveness of strategy use.

6 P-CAD Conversation Ability

This section of the evaluation examines how the client communicates with his/her communication partner (CP).

Having requested and **gained consent** from the client and CP for video recording. The clinician video records a conversation sample **(1 min - 5 mins max)** between the client and their CP. To stimulate conversation, the clinician asks them to talk about holidays, pets or music. Alternatively, the conversation partners can bring in a video recorded conversation that they recorded at home.

People with advanced dementia may not be able to participate in this evaluation task, without the support of their communication partner and /or visual props.

It may not be possible to video record the communication partners. In this situation, the clinician should record the client in conversation with the clinician. The instructions for both scenarios are given below.

Select either of the following:	
Instruction for clinician to elicit conversation between the client and the CP: Say "I would like to see how you are communicating together. Talk for a few minutes about something that interests you. For example, holidays, pets or music"	**Instruction for clinician-client conversation:** Say "I am going to record us talking about a topic you are interested in. We could talk about holidays, pets or music?

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Review the video recording and complete communication ability profiles 1 and 2.

Evaluate the conversation, using profile ratings and taking into account the context of the conversation. These profiling forms have a similar layout and rating system but evaluate conversation skills from two different perspectives.

Profile 1: Evaluates 5 aspects of conversation ability of the person with dementia. These are comprehension, engagement, expression, resolving breakdown and sharing responsibility for conversation management.

Profile 2: Evaluates 3 aspects of communication partner support. These are recognising communication potential, adjusting communication style and resolving communication breakdown.

Reviewing the video recorded conversation with the communication partners is recommended. This allows the partners to identify what is working well in the conversation and identifies areas for behaviour change. The clinician will give online feedback and identify with the conversation partners priorities for improving their conversation where appropriate.

Useful definitions

Communication breakdown: disturbance in the conversation due to problems in attending, speaking, hearing and/or understanding.

Communication repair: the client or CP signals a problem in the conversation and attempts are made to resolve the conversation breakdown through the use or reparative strategies such as a request for clarification, repetitions, or paraphrasing.

Profile 1: The Conversation Abilities of the Person with Dementia

Conversation Abilities	0	1	2	3	Score
Attends to and **comprehends** the conversation	Does not attend to and/or seem to comprehend the conversation	Attends to and comprehends less than half of the conversation	Attends to and comprehends more than half of the conversation	Attends to and comprehends all of the conversation	
Engages and **participates** in the conversation with non-verbal communication through use of facial expression, gesture, vocalisations and postural positioning	Does not engage in the conversation through either verbal or non-verbal modalities	Engages in the conversation up to half of the time through either verbal or non-verbal communication	Engages is the conversation over half of the time through either verbal or non-verbal communication	Engages in this conversation all of the time through either verbal or non-verbal communication	
Expresses his/her message verbally/non-verbal effectively (use of greeting, requesting, expresses feelings, commenting, & protesting).	Verbal or nonverbal communicative attempts are ineffective in this conversation	Expresses his/her message effectively less than half of the time during the conversation	Expresses his/her message effectively more than half of the time during the conversation	Expresses his /her message effectively all of the time during the conversation	
Resolving communication breakdown	No attempt to resolve communication breakdown	Tries to resolve miscommunications less than half of the instances of communication breakdown even if the conversational flow is not restored in the conversation	Tries to resolve miscommunications in more than half of the instances of communication breakdown even if the conversational flow is not restored in the conversation	Tries and successfully resolves communication breakdown nearly all of the time in the conversation	
Shares the responsibility for conversation management, with their communication partner by establishing, maintaining and progressing the conversation.	No attempts to share, establish, maintain or progress the conversation	Minimal attempts (1-2 within conversation observed) to share, establish, maintain or progress the conversation	Some attempts (more than 5 within the conversation observed) to share, establish, maintain or progress the conversation	Shares equally in the conversation by establishing, maintaining and progressing the conversation	

PCAD Profile 1 Score	Subtotal score	/15
0= 0-3 1= 4-7 2= 8-11 3=12-15	Total Conversation Ability Score	/3

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Profile 2: The Communication Abilities of their Communication Partner

Ability to acknowledge and support the person with dementia in conversation	0	1	2	3	Score
Recognises the communication **potential** of the person with dementia by trusting their inherent competence to participate in the conversation. This is evidenced by: • Verbal and nonverbal communication that is respectful, inclusive and expectant of engagement • Explicitly or implicitly acknowledging verbal & non-verbal communication attempts • Following their lead in conversation	Does not recognise the communication potential of the person with dementia in the conversation	Recognises the communication potential of the person with dementia less than half of the time	Recognises the communication potential of the person with dementia more than half of the time	Recognise the communication potential of the person with dementia nearly all the time	
Supports the person with dementia in conversation by **adjusting** their communication style: • slowing down their rate of speech • allowing extra time for the person to respond • avoiding test questions • using communication aids e.g. photos, pen & paper, picture symbols	Unhelpful adjustments to communication style observed	Adjusts communication style by using appropriate conversational support strategies/aids less than half of the time	Adjusts communication style by using appropriate conversational support strategies/aids more than half of the time	Adjusts communication style by using appropriate conversational support strategies/aids effectively nearly all the time	
Resolves communication breakdown by: • Clarifying • Repeating • Rephrasing • Simplifying • Using humour	Does not attempt to resolve communication breakdown	Tries to resolve communication breakdown, less than half of the time even if the conversational flow is not restored in the conversation	Tries to resolve miscommunication in more than half of the instances of communication breakdown even if the conversational flow is not restored in the conversation	Tries and successfully resolves communication breakdown nearly all the time in the conversation	
(This score not added to the total score) 0= 0-1 1= 2-4 2= 5-7 3= 8-9			CP Profile 2 Score		/9

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7 P-CAD Communication Support Strategies

This section of the evaluation examines how the client with his/her communication partner (CP) use compensatory strategies to support communication. The video recording gives the clinician an opportunity to evaluate communication breakdown and repair.

This section will also help the clinician to evaluate the client's awareness of their communication impairment and the couple's ability to compensate in conversation. If the CP was not available to make the recording the clinician can use the same guidelines to evaluate their own interactions with the client.

Instruction: Review the video recording with the following guidelines in mind.

1. Client's **awareness** of his/her own communication breakdown
2. **Frequency** with which communication support strategies are used and by whom. These are the term use to describe frequency:
   - **Occasional** use of strategies: strategies used from time to time to enhance a communication function
   - **Frequent** use of strategies: strategies used regularly to enhance a communication function
   - **Consistent** use of strategies: strategies used all the time to enhance a communication function
3. How **effective** are the use of communication support strategies in repairing communication breakdown?

Communication Support Strategies

Score	Communication Support Strategies
3	Compensatory strategies not required to enhance conversation.
2	The client is aware of and will address communication breakdown. **Occasional** use of support strategies required to facilitate communication Both partners use communication support strategies effectively to facilitate communication
1	The client is not always aware of communication breakdown. **Frequent** use of support strategies required to facilitate communication Both partners use communication support strategies inconsistently to facilitate communication
0	No evidence of awareness of communication errors. **Consistent** use of support strategies required to facilitate communication. Client has limited or no use of effective compensatory strategies.

The P-CAD Communication Support Strategies are provided on pages 25 &26 as a resource for the clinician. There are specific communication strategies for each section of the P-CAD which can be recommended to the client and their communication partner.

Total Communication Support Strategies score	

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8. P-CAD Functional Communication Ability

This section should be completed at the **end of the evaluation.** The client's functional communication ability and the required level of support will have been assessed on an ongoing basis as the evaluation progressed. The score given is based on the clinician's subjective opinion of the client's functional communication ability.

Clinical decisions will be informed by:

- a discussion with the client and their communication partner as to how dementia is impacting on the person's ability to function independently in a range of communication situations.
- how the client and their communication partner interacted with each other and the clinician during the evaluation and was this representative of their everyday communication ability

Instruction to clinician: Ask the client and their communication partner some of the following questions to determine how they are communicating in everyday situations.

Q.	Direct questions towards the client initially. Record answers below questions
1.	What are your biggest communication challenges? What hinders you?
2.	Do you /Does _____ engage verbally in everyday social conversations about for example the weather?
3.	Do you /Does _____ answer the phone and make phone calls independently?
4.	Do you /Does _____ read and reply to text messages and /or e-mails independently?
5.	Do you /Does _____ participate confidently in group conversations?
6.	Are you/ Is _____ able to ask for help if you run into difficulty? (Probe: at home or out in the community)
7.	Are you/ Is _____ able to express their/your needs verbally? If no does _____ communicate mainly non-verbally?
8.	What are your greatest communication strengths? What helps you?

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Scoring

Instruction to clinician: The clinician evaluates functional communication using the information attained from the question section above and the scoring chart below.

Score	Functional Communication Ability
3	No communication difficulties identified or reported.
2	**Communicates effectively** in a wide range of communication situations with occasional support May be challenged by group conversations
1	**Communicates effectively in a restricted range of communication situations with frequent support** Consistently able to make needs known and conveys more information than this. Copes with one to one conversations most of the time with support
0	**Only communicates effectively with maximum support** Unable to consistently express/ demonstrate basic care needs like thirst, pain or express choice Communication is difficult to interpret Mainly non-verbal communication

Total Functional Communication Score	

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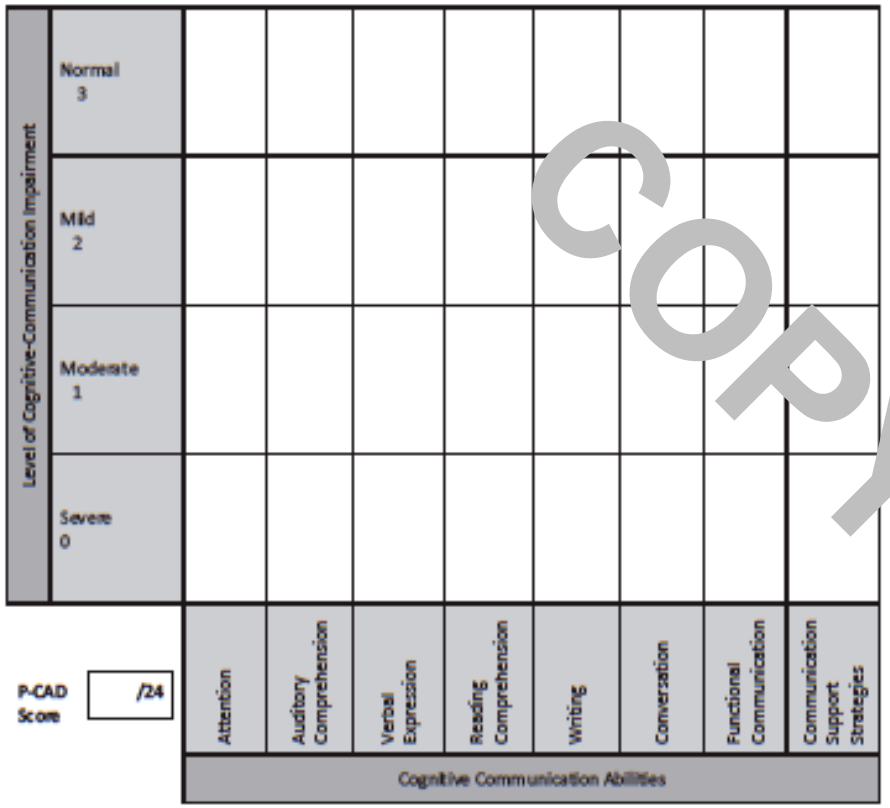
P-CAD Abilities Profile



Communication Abilities

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Profiling Communication Ability in Dementia P-CAD

Client_____

MRN_____

AFFIX HOSPITAL LABEL HERE

Summary Profile Form

P-CAD SCORE _____

Date of Assessment _____

Date of Re-assessment _____

Speech & language Therapist _____

Level of communication support required

Minimum **Moderate** **Maximum**

	COGNITIVE COMMUNICATION ABILITIES	NO COMMUNICATION SUPPORT REQUIRED	MINIMUM COMMUNICATION SUPPORT	MODERATE COMMUNICATION SUPPORT	MAXIMUM COMMUNICATION SUPPORT
1	Attention Ability	No observable or reported deficits in attention during the evaluation.	Reduced attention impacts occasionally on communication ability	Reduced attention impacts frequently on communication ability	Reduced attention consistently impacts on communication ability
2	Auditory Comprehension Ability	No auditory comprehension difficulties identified or reported	Understands all but the most complex conversations	Understands everyday conversations	Basic understanding is inconsistent
3	Verbal Expression Ability	No verbal language difficulties identified or reported	Mild reduction in verbal language	Moderate reduction in verbal language	Little or no verbal communication
4	Reading Comprehension Ability	No reading comprehension difficulties identified or reported	Reads all but the most complex material	Basic reading ability is intact	Little or no reading comprehension
5	[illegible]ting Ability	No writing difficulties identified or reported	Writes all but the most complex	Basic writing ability is intact	Little or no writing ability
6	[illegible]ability	Conversation is dynamic in relation to initiation, turn-[illegible]king and topic [illegible]aintenance.	Conversation is mostly dynamic	Conversation is sometimes dynamic	Conversation is rarely dynamic
7	Functional Commu[illegible]on Abilities	Comm[illegible]cation [illegible] within the [illegible] ra[illegible]	Communicates independently almost always	Communicates independently frequently	Communicates independently occasionally
8	Communication support strategies	[illegible]ommunicat[illegible] support st[illegible]es **alway**[illegible] effe[illegible]	**Frequent effective** use of communication support strategies used by both partners	**Occasional effective** use of communication support strategies by one partner	**No evidence of effective use** of communication support strategies

Communication Abilities	Communication Support Strategies

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Appendix 9.1 Ethical Approval TT76 P-CAD Validation

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

18th July, 2016

Application TT78 Academic Year 2015/16

Applicant: Suzanna Dooley

Title of Research: Validation of the Profiling Communication Abilities in Dementia Tool

Dear Ms Dooley,

Your submission for ethics approval for the research project above was considered by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin, on Monday, 18 July 2016, and has now been approved in full. We wish you the very best in your research activities.

Best wishes,

Dr Lorna Carson
Chair, Research Ethics Committee
School of Linguistic, Speech and Communication Sciences

Scoil na nEolaíochtaí Teanga-olaíochta,
Urlabhra agus Cumarsáide,
Coláiste na Tríonóide,
Baile Átha Cliath 2, Éire

School of Linguistic, Speech & Communication Sciences,
Trinity College,
Dublin 2, Ireland

T 353 (0)1 896 1580
slscs@tcd.ie
www.tcd.ie/slscs

Appendix 9.2 Letter Seeking Access

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Participant Information Leaflet

Project title: Validation of the Profiling Communication Abilities in Dementia (P-CAD) Tool

Dear

I am conducting a research project with Dr. Margaret Walshe, Associate Professor in Speech and Language Pathology, and Orla Gilheaney Assistant Speech and language Therapy Researcher, in Trinity College Dublin following a grant award from Health Research Board in 2015. This research aims to validate a cognitive-communication evaluation called the Profiling Communication Ability in Dementia (P-CAD). This study has been approved by the Research Ethics Committee School of Linguistic, Speech and Communication Sciences, Trinity College Dublin.

The assessment is for speech and language therapists, focused on communication abilities to inform use of strategies to support the person with dementia's communication. We need to validate the P-CAD on 100 people with dementia and their family carers/ s. We would very much like to validate the P-CAD in several different settings and with different communities of people with dementia.

I am writing to investigate the possibility of recruiting people from **********for this phase of the project. Participation involves either me or two other speech and language therapists completing the P-CAD with both the person with dementia and their family carer. We also need to complete the Global Deterioration Scale, the Mini Mental State Examination 2 and another communication test Functional Linguistic Communication Inventory.

Testing should take approximately 1½ hours. In return, we will offer information and feedback to the couple on the most effective communication strategies to use in communication and provide the team with a communication profile for the person.

Your role would be to act as a gate keeper disseminating the participant information leaflet and a copy of the consent form to clients on your data base who may potentially choose to participate in this research.

I am happy to answer any other questions on the project. I am available at this email address or on my mobile (086 6098109).

Yours sincerely,

Suzanna Dooley BSc. CSLS IASLT

Associate Researcher

Department of Clinical Speech and Language Studies

Trinity College Dublin

Appendix 9.3.1 Introductory Letter to Carer participants/ Communication partners

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Suzanna Dooley
Associate Researcher
School of Clinical Speech and Language Studies
Trinity College Dublin

To whom it concerns,

I am conducting a research project in the area of dementia with Dr. Margaret Walshe and Orla Gilheaney in TCD. This project is funded by the Health Research Board. We are developing an assessment for Speech and Language Therapists that can be used to evaluate the cognitive-communication abilities of people with dementia. It is called *Profiling Communication Ability in Dementia* (P-CAD).

I am looking for family carers of people with dementia and people with dementia to participate in this study. I want to invite you to take part in this research by participating in a communication assessment with a Speech and Language Therapist. I have attached a Participant Information Leaflet to this e-mail that will provide you with information about this study.

If you would like to participate in this study, please express your interest by sending an email to me at this email address dooleysu@tcd.ie. or by phone 086-6098109. Please do so within 2 weeks of receiving this email.

If you have any questions or would like to discuss this study further please do not hesitate to contact me or you can contact the Principal Investigator, Dr. Margaret Walshe, walshema@tcd.ie.

Thank you for taking the time to read this information.

Your Sincerely,
Suzanna Dooley
Associate Researcher SLT
Trinity College Dublin

Appendix 9.3.2 Letter of Introduction for people with dementia (accessible format)

TRINITY COLLEGE DUBLIN

PARTICIPANT INFORMATION LEAFLET

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

- We are Speech and Language Therapists working on research in dementia in Trinity College Dublin.
- Our names are **Suzanna Dooley**, **Prof Margaret Walshe and Orla Gilheaney**
- We are researching ways of **improving communication** for people with dementia and their families
- We are developing a communication assessment called **Profiling Communication Ability in Dementia(P-CAD)**

How can you get involved?

- We are **looking to use the P-CAD** with people with dementia
- Your **communication partner will also be present** in the session
- Call in the **next 2 weeks if** you want to get involved
- You can get a **family member to call** on your behalf

Next step

Contact us if you want to get involved:

Suzanna Dooley **086-6098109** dooleysu@tcd.ie
Margaret Walshe **01-8962382** walshema@tcd.ie

Appendix 9.4.1 PIL for Communication Partners

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Participant Information Leaflet

Project title: Validation of the Profiling Communication Abilities in Dementia (P-CAD) Tool

Dear Carer/Family member,

We are conducting a research project in **dementia**. This is funded by the **Health Research Board.** We are developing an assessment for **speech and language therapists** that can be used to evaluate the communication abilities of people with dementia. It is called ***Profiling Communication Ability in Dementia*** **(P-CAD).**

What is the purpose of our research?

We want to develop and make available this **assessment** to facilitate speech and language therapists to provide better care to people with dementia and their families and to promote and support communication. This is important research as people with dementia in Ireland have limited access to communication interventions.

We want to invite you and your family member to take part in this research by participating in a **communication assessment**. This will involve two or three different parts.

What will your involvement entail?

This will involve **approximately 1 ½ hours assessment**. You will be asked to give some background information on how you communicate with your communication partner with dementia in everyday situations.

You will also be asked to have a short conversation with your communication partner with dementia. **This will be video recorded.** A copy of this video

recording will be made available to you on request. This video will not be used for any other purpose other than this research.

You and your communication partner's identity will not be made available to anyone outside the research team. All records are coded, and data anonymised. Your identities will not be disclosed to anyone outside of the research. Information will be collected, stored and analysed in accordance with the Data Protection Act (1998).

The assessment will be run in a **location convenient to you**. Please bring along reading glasses if you use them.

The benefits and risks of participating?

Following the assessment session, if you wish, you and your family member **can be given some advice** on your communication and some strategies that will support communication further.

The final version of the P-CAD when finally published will be available to speech and language therapists for use in their work with people with dementia.

In the unlikely event of discussing topics that might cause upset to you will be offered follow-up support on site and directed to support services locally.

Please be assured if you do not wish to participate in the study, current or future service provision for you or your communication partner will not be affected. **You may withdraw from this research at any time.**

This study has been approved by the Research Ethics Committee School of Linguistic, Speech and Communication Sciences, Trinity College Dublin. Nothing in this document restricts or curtails your rights.

Please contact us if you would like to participate in this research.

Suzanna Dooley 086-6098109 dooleysu@tcd.ie

Dr. Margaret Walshe 01-8962382 walshema@tcd.ie.

Thank you for reading this information leaflet

Appendix 9.4.2 Consent form for Communication partners

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Consent Form

Project title: Validation of the Profiling Communication Abilities in Dementia (P-CAD) Tool

Suzanna Dooley, Associate Researcher, Department of Clinical Speech and Language Studies, Trinity College Dublin (TCD). Dr. Margaret Walshe, Associate Professor in Speech and Language Pathology TCD. Orla Gilheaney Assistant Researcher TCD.

Research and Ethics overview

I am invited to **participate in this research project** which is being carried out by those named above.

I understand that this study has been approved by the Research Ethics Committee, School of Linguistic, Speech and Communication Sciences, Trinity College Dublin**.** Nothing in this document restricts or curtails my rights.

An overview of my participation

My participation is **voluntary**. Even if I agree to participate now, I can withdraw at any time without any consequences of any kind.

By participating in this study, I understand I am being asked to take part in a **communication assessment with my family member with dementia.** This will involve **approximately 1 ½ hours assessment**. I will be participating in some sections of the assessment by giving background information on how we communicate in everyday situations. My input will be used to amend this latest version of the P-CAD.

I will also be required to have a short conversation with your family member with dementia, **this will be video recorded.** I understand that this video will not be used for any other purpose other than this research. If I am an appointed decision-making representative for a person with dementia I will be asked to support decision making around their participant in the research, including video recording.

Confidentiality

It has been explained to me that my identity and that of my family members will be **anonymised** and not disclosed to anyone outside of the research. Information will be collected, stored and analysed in accordance with the Data Protection Act (1998).

The research data will be kept in the locked filing cabinet for 5 years following completion of the study. After 5 years the **research materials will be destroyed** by the Principal Investigator, Dr Margaret Walshe.

I understand that my family member and I do not wish to participate in the study, current or future service provision will not be affected.

Signature of research participant

I understand what is involved in this research and I agree to participate in the study. I have been given a copy of the Participant Information Leaflet and a copy of this consent form to keep.

---------- ----------

Signature of participant Date

Supported Decision making

I understand what is involved in this research and I agree to_____ (name of other) participating in the study. _____ (name of client) is unable to give consent due to a severe cognitive-communication impairment. And I _____ as his/her decision-making representative consent on his/her behalf.

---------- ----------

Signature of participant Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study

---------- ----------

Signature of researcher Date

Appendix 9.5.1 Accessible PIL for People with Dementia

TRINITY COLLEGE DUBLIN

PARTICIPANT INFORMATION LEAFLET

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

- We are Speech and Language Therapists working on research in dementia in Trinity College Dublin.
- Our names are **Suzanna Dooley**, **Prof Margaret Walshe and Orla Gilheaney**
- We are researching ways of **improving communication** for people with dementia and their families

The research

- We have developed a communication assessment called **the P-CAD** (Profiling Communication Abilities in Dementia)
- We will be using it with people with dementia over the next year to see if it **helps us learn more about people's communication abilities**

- The P-CAD will be useful for;

Supporting people with dementia to **communicate better**

Planning treatment and community services.

Permission

This research has Research Ethics Committee approval from **Trinity College Dublin**

How can you get involved?

- We are **looking to use the P-CAD** with people with dementia
- Your **communication partner will also be present** in the session

What is required?

- You will take part in a **communication assessment**

- This will take **about 1 ½ hours** (90mins) to complete with you and your communication partner

- We can complete the assessment **over 1 or 2 sessions whatever** works for you
- Part of the session will be **video-recorded,** and you can have a copy of the recording if you want

- Your identity will always be protected during assessment.

- You can have a **copy of the assessment** summary if you want afterwards
- We may also use information from the **picture description task** in **future research**

Where will the assessment take place?

- This session will be held at ******* or somewhere convenient for you
- You can **change your mind at any time** if you don't want to be involved

Next step

- Contact us if you want to get involved:
  Suzanna Dooley **086-6098109** dooleysu@tcd.ie
  Margaret Walshe **01-8962382** walshema@tcd.ie

- You can get a **family member to call** on your behalf.

Thank you for reading this information leaflet.

Appendix 9.5.2 Accessible Consent Form for People with Dementia

TRINITY COLLEGE DUBLIN

SCHOOL OF LINGUISTIC SPEECH AND COMMUNICATION SCIENCES

Consent Form

Project title: Validation of the Profiling Communication Abilities in Dementia (P-CAD) Tool

The Research

- I understand that the P-CAD is a **communication assessment** for people with dementia

(Mark as appropriate)

- I know that this research is being done by Suzanna Dooley, Dr. Margaret Walshe and Orla Gilheaney from **Trinity College Dublin**

(Mark as appropriate)

The Communication Assessment

- I understand that I am being asked to take part in a **communication assessment using the P-CAD** and some other tests.

(Mark as appropriate)

I understand the following

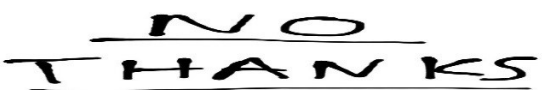
- This assessment will be held at **********

- It will last for **about 1 ½ hours**

- Parts of the sessions will be **video-recorded,** and I can get a copy if I want

- My identity will always be protected

- I can **change my mind at any time** if I don't want to be involved



Next Steps

- If I have any questions about this research, I can contact Suzanna Dooley

  e-mail: dooleysu@tcd.ie or walshema@tcd.ie

  Phone: **086-6098109 or 01-8962382**

- I can get a **family member to call** on my behalf

Signature of research participant

✓ I understand what is involved in this research
☑ I agree to participate in the study.
☑ I have been given a copy of the **Participant Information Leaflet** and a copy of this **consent form to keep.**

---------- ----------

Signature of participant Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study

---------- ----------

Signature of researcher Date

Appendix 9.6 P-CAD Proforma

ID No.	Participant Initials: D.O.B.:	Gender: __Male __Female	Date of Initial Assessment	Location of Initial Assessment	Date of Re-test	Location of Re-test:	Consent Provided	Assessor Initials	Access to SLT services:

Diagnosis *(please tick)*:			**Co-Morbid Conditions *(please complete):***			**Highest Level of Education Achieved *(please tick):***	
Alzheimer's Disease	Dementia with Lewy Bodies		Visual deficit			Attended primary school	
						Completed primary school	
Mild Cognitive Impairment	Parkinson's Disease Dementia		Hearing impairment, rated as per SWSR assessment			Attended secondary school	
Corticobasilar Degeneration	Frontotemporal Dementia		Upper limb weakness			Completed the Leaving Certificate/equivalent exams	
Mixed Dementia	Vascular Dementia		Depression, rated as per 2-question test			Attended college	
Creutzfeldt-Jakoff Disease	Huntington's Disease		Other *(please specify):*			Graduated from college	
Normal Pressure Hydrocephalus	Wernicke-Korsakoff Syndrome					Post-graduate degree	

Proforma- Assessment Results

Stage of Dementia as per Global Deterioration Scale *(please tick):*	**Score**
No cognitive decline	1
Very mild cognitive decline (age associated memory impairment)	2
Mild cognitive decline (mild cognitive impairment)	3
Moderate cognitive decline (mild dementia)	4
Moderately severe cognitive decline (moderate dementia)	5
Severe cognitive decline (moderately severe dementia)	6
Very severe cognitive decline (severe dementia)	7

MMSE-2 Assessment Scores *(please complete):*	**Score**
Overall MMSE-2 score	/30
Registration and recall	/6
Orientation and time	/5
Orientation to place	/5
Attention and calculation (Serial 7s)	/5
Naming	/2
Repetition	/1
Comprehension	/3
Reading	/1
Writing	/1
Drawing	/1

FLCI Assessment Scores *(please complete):*	**Score**
Overall FLCI score	/87
Greeting and naming	/15
Answering questions	/12
Writing	/11
Comprehension of signs and object-to-picture matching	/6
Word reading and comprehension	/18
Reminiscing	/6
Following commands	/2
Pantomime	/9
Gesture	/4
Conversation	/4

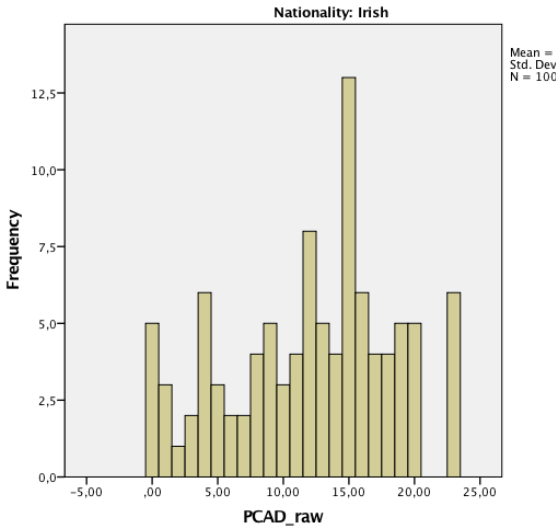
- P-CAD Assessment Scores

P-CAD	Score	Level of Impairment and Impact on Conversation			
Overall P-CAD score	/24	Normal	Mild	Moderate	Severe
Attention ability	/3	No impact	Occasional impact	Frequent impact	Consistent impact
Auditory comprehension ability	/3	No impact	Occasional impact	Frequent impact	Consistent impact
Verbal expression ability	/3	No impact	Occasional impact	Frequent impact	Consistent impact
Reading comprehension ability	/3	No impact	Occasional impact	Frequent impact	Consistent impact
Writing ability	/3	No impact	Occasional impact	Frequent impact	Consistent impact
Conversation ability	/3	No impact	Occasional impact	Frequent impact	Consistent impact
Functional communication ability	/3	No impact	Occasional impact	Frequent impact	Consistent impact
Communication support strategies ability	/3	No impact	Occasional impact	Frequent impact	Consistent impact

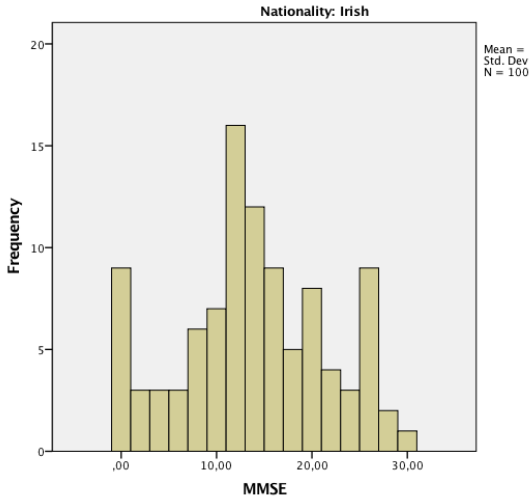
Appendix 9.7 Distribution of Test Scores

TESTS RESULTS DISTRIBUTION: HISTOGRAMS

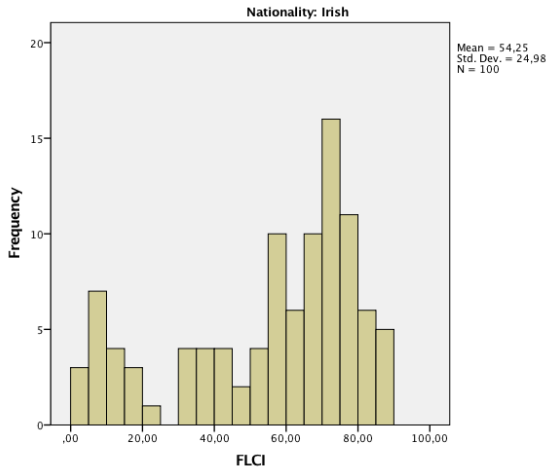
	N	Range	Minimum	Maximum	Mean	Std. Deviation	Skewness		Kurtosis	
	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic	Std. Error
MMSE	100	30,00	,00	30,00	13,36	7,721	-,016	,241	-,654	,478
FLCI	100	86,00	1,00	87,00	54,24	24,977	-,818	,241	-,583	,478
PCAD_	**100**	**23,00**	**,00**	**23,00**	**12,08**	**6,269**	**-,286**	**,241**	**-,728**	**,478**



P-CAD raw scores are <u>not</u> normally distributed.



MMSE-2 scores are normally distributed.



-> FCLI scores are not normally distributed.

Appendix 9.8 Outcome Measure Test Score Scaling and Comparisons.

GDS Levels	P-CAD Mean	P-CAD SD	MMSE-2 Mean	MMSE-2 SD	FLCI Mean	FLCI SD
4	16.08	4.01	18.23	5.90	68.63	13.56
5	11.58	4.43	12.35	4.03	55.00	18.40
6	4.33	3.05	4.80	4.09	24.31	19.76
7	1.00	1.15	0.50	1.12	6.50	4.57
Total	**12.02**	**6.28**	**13.33**	**7.55**	**54.03**	**24.97**

P-CAD		MMSE-2		FLCI	
67.01	16.71	60.76	19.68	68.63	13.56
48.25	18.45	41.18	13.43	55.00	18.40
18.06	12.70	16.00	13.62	24.31	19.76
4.17	4.81	1.67	3.73	6.50	4.57

MMSE-2 and P-CAD Support Levels

One-Way ANVOA P-CAD Communication Support Levels and MMSE-2 Scores

P-CAD Levels	N	Mean MMSE-2	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
0	1	25.00	.	.	.	.	25	25
1	51	17.18	6.477	.907	15.35	19.00	1	30
2	31	12.74	4.604	.827	11.05	14.43	4	21
3	17	2.35	3.707	.899	.45	4.26	0	12
Total	100	13.36	7.722	.772	11.83	14.89	0	30

Independent-Samples Kruskal-Wallis Test Summary

Total N	100
Test Statistic	44.513[a]
Degree Of Freedom	3
Asymptotic Sig.(2-sided test)	.000

a. The test statistic is adjusted for ties.

Descriptives: MMSE-2 & P-CAD Levels of Support

MMSE2

	N	Mean	Std. Deviation	Std. Error	95% Confidence Interval for Mean		Minimum	Maximum
					Lower Bound	Upper Bound		
0	17	2.35	3.707	.899	.45	4.26	0	12
1	31	12.74	4.604	.827	11.05	14.43	4	21
2	51	17.18	6.477	.907	15.35	19.00	1	30
3	1	25.00	.	.	.	.	25	25
Total	100	13.36	7.722	.772	11.83	14.89	0	30

Appendix 9.9 Reliability Testing Data

ANOVA

MMSE2

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	2949.810	3	983.270	31.963	.000
Within Groups	2953.230	96	30.763		
Total	5903.040	99			

Test and time	**MMSE2 Score** T1	**MMSE2** Score T2	**FLCI** Score T1	**FLCI** Score T2	**PCAD Score** T1	**PCAD Score** T2
Scores	23	22	80	74	20	19
	13	12	77	83	15	18
	26	29	84	84	23	23
	25	18	85	78	18	18
	21	18	76	73	19	15
	10	5	16	32	4	7
	7	7	66	46	11	10
	20	11	76	56	13	13
	4	8	62	55	12	12
	25	25	87	83	23	18
	30	25	78	81	20	16
	15	20	76	69	15	12
Mean scores	**18.25**	**16.66**	**71.91**	**67.83**	**16.08**	**15.08**

P-CAD Subsection Correlation Analysis (Inter Rater reliability)

P-CAD Section 1

			SECTION1S	SECTION1O
Spearman's rho	SECTION1S	Correlation Coefficient	1.000	.690**
		Sig. (2-tailed)	.	.001
		N	20	20
	SECTION1O	Correlation Coefficient	.690**	1.000
		Sig. (2-tailed)	.001	.
		N	20	20

**. Correlation is significant at the 0.01 level (2-tailed).

P-CAD Section 2

			SECTION2S	SECTION2O
Spearman's rho	SECTION2S	Correlation Coefficient	1.000	.990**
		Sig. (2-tailed)	.	.000
		N	20	20
	SECTION2O	Correlation Coefficient	.990**	1.000
		Sig. (2-tailed)	.000	.
		N	20	20

**. Correlation is significant at the 0.01 level (2-tailed).

P-CAD Section 3

			SECTION3S	SECTION3O
Spearman's rho	SECTION3S	Correlation Coefficient	1.000	.959**
		Sig. (2-tailed)	.	.000
		N	20	20
	SECTION3O	Correlation Coefficient	.959**	1.000
		Sig. (2-tailed)	.000	.
		N	20	20

**. Correlation is significant at the 0.01 level (2-tailed).

P-CAD Section 4

			SECTION4O	SECTION4S
Spearman's rho	SECTION4O	Correlation Coefficient	1.000	.969**
		Sig. (2-tailed)	.	.000
		N	20	20
	SECTION4S	Correlation Coefficient	.969**	1.000
		Sig. (2-tailed)	.000	.
		N	20	20

**. Correlation is significant at the 0.01 level (2-tailed).

P-CAD Section 5

			SECTION5S	SECTION5O
Spearman's rho	SECTION5S	Correlation Coefficient	1.000	.994**
		Sig. (2-tailed)	.	.000
		N	20	20
	SECTION5O	Correlation Coefficient	.994**	1.000
		Sig. (2-tailed)	.000	.
		N	20	20

**. Correlation is significant at the 0.01 level (2-tailed).

P-CAD Section 6

			SECTION6S	SECTION6O
Spearman's rho	SECTION6S	Correlation Coefficient	1.000	.816**
		Sig. (2-tailed)	.	.000
		N	20	20
	SECTION6O	Correlation Coefficient	.816**	1.000
		Sig. (2-tailed)	.000	.
		N	20	20

**. Correlation is significant at the 0.01 level (2-tailed).

P-CAD Section 7

			SECTION7S	SECTION7O
Spearman's rho	SECTION7S	Correlation Coefficient	1.000	.903**
		Sig. (2-tailed)	.	.000
		N	20	20
	SECTION7O	Correlation Coefficient	.903**	1.000
		Sig. (2-tailed)	.000	.
		N	20	20

**. Correlation is significant at the 0.01 level (2-tailed).

P-CAD Section 8

			SECTION8S	SECTION8O
Spearman's rho	SECTION8S	Correlation Coefficient	1.000	.938**
		Sig. (2-tailed)	.	.000
		N	20	20
	SECTION8O	Correlation Coefficient	.938**	1.000
		Sig. (2-tailed)	.000	.
		N	20	20

**. Correlation is significant at the 0.01 level (2-tailed).

Appendix 9.10 P-CAD Feedback for Participants

Name: _____

Date of Assessment: _____

- **Overall level of communication support required:**

  _____

- **Your three key communication strengths are:**
  1. _____
  2. _____
  3. _____
- **The following strategies will best support your communication:**
  1. _____
  2. _____
  3. _____

If you wish, you can contact your local speech and language therapy service using the details below:

Service name: _____

Address: _____

Phone Number: _____

_____

Speech & Language Therapy Researcher **Date**

[This form is not for research purposes. It gives feedback to participants only. We don't keep a copy of this form.

Appendix 10.1 Abstract Irish Gerontological Society 2018

Profiling Communication Ability in Dementia (P-CAD): Validation of a Functional Cognitive-Communication Assessment

Suzanna Dooley[1] and Margaret Walshe[1]

[1]Department of Clinical Speech and Language Studies, Trinity College Dublin

Background: Cognitive communication difficulties are characteristic of dementia with negative impact. Yet, clinicians have few options for standardized assessment of these cognitive communication skills**.** The newly devised P-CAD facilitates evaluation of the functional communication abilities of individuals with dementia, guiding intervention and providing a measure of change in communication abilities of people with dementia over time. The aim of this project was to validate the P-CAD with the objective of providing clinicians with a much needed psychometrically sound assessment for individuals with dementia.

Method: 100 people with dementia and their communication partners were recruited over a 12-month period. The P-CAD was validated against MMSE-2, Global Deterioration Scale (GDS) and Functional Linguistic Communication Inventory (FLCI). Inter-rater reliability and sensitivity to change over time (3 months) were also tested with a subgroup of individuals. Participants with dementia were at different stages of dementia and presented with a range of dementia subtypes.

Results: Statistically significant correlations were found between P-CAD scores, MMSE-2 scores ($r=0.830$, $p<0.001$) and FLCI scores ($r=0.863$, $p<0.001$). There were no significant changes over time in any of the 3 scales for the participants (N=11) who completed follow-up measures. Interrater reliability for the P-CAD (N=20) was strong between raters for all measures; GDS (ICC=0.969, $p<0.001$); MMSE-2 (ICC=0.997, $p<0.001$); FLCI (ICC=0.999, $p<0.001$). There were significant correlations between the level of communication support on the P-CAD and GDS (rho= -0.580, $p<0.001$) and the MMSE-2 (rho=0.633, $p<0.001$) scores.

Conclusions: The P-CAD is a valid reliable cognitive communication assessment for use with people with all subtypes and stages of dementia. It is now ready for use in clinical practice, informing interventions aimed at improving conversations between people with dementia and their communication partners.

Appendix 10.2 Poster Presentation IGS Killarney 2018

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Profiling Communication Ability in Dementia (P-CAD):Validation of a Functional Cognitive-Communication Assessment

HRB Health Research Board

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Introduction
Cognitive communication difficulties are characteristic of dementia with negative impact. Yet, clinicians have few options for standardised assessment of cognitive communication skills in people with dementia. The newly devised P-CAD facilitates evaluation of functional communication abilities of people with dementia, with a specific focus on conversational skills. It guides intervention, providing measurement of change over time.

Aims
To validate the P-CAD with the objective of providing clinicians with a much needed psychometrically sound assessment for people with dementia.

P-CAD
A functional cognitive communication assessment developed for use by Speech and Language Therapists with people with dementia.
The administration time is 30 mins.

Purpose of P-CAD
- ✓ Profiles communication abilities
- ✓Measures change in communication ability
- ✓Uses appreciative enquiry
- ✓Informs care pathways
- ✓Guides communication intervention

P-CAD is different
- ✓Current and validated for use with people with dementia
- ✓Focuses on retained skills
- ✓Communication partner involvement
- ✓Identifies specific communication support strategies

Research Objectives
Phase 1: To refine the content, construct, face and ecological validity of P-CAD. It was revised based on feedback from focus groups and an SLT pilot phase.
Phase 2: To validate it against other measures and establish its reliability and sensitivity to change over time.

Method
100 people with dementia and their communication partners were recruited over 12 months.

The P-CAD was validated against:
- Mini Mental State Examination-2 (MMSE-2)
- Functional Linguistic Communication Inventory (FLCI)[2]
- Global Deterioration Scale (GDS)[1]

Inter-rater reliability and sensitivity to change over time (3 months) were also tested.

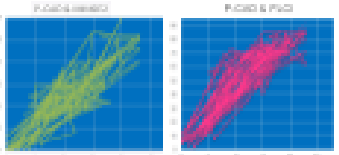
Participant Demographics

Gender			
Male	35	5	
Female	64	11	
Age (years)			80(8.65)
Education(years)			12.3(4.5)

Alzheimer's disease	51
Early Onset AD	2
Executive Dementia	23
Mixed Dementia	9
Dementia with Parkinson's disease	2
Lewy Body Dementia	4
Frontal Temporal Dementia	2
Huntington's Dementia	0
Vascular Dementia	0
Total	100

The majority of participants were female (64%), with an average age of 80years and there were a range of dementia subtypes. Over half the participants had Alzheimer's disease (51%) and 28% had vascular dementia.

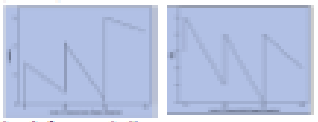
Results
Statistically significant and strong correlations were found between P-CAD scores, MMSE-2 scores (r_s=0.826, p<0.001) and FLCI scores (r_s=0.863, p<0.001).



Inter-rater Reliability (N=20)
There are highly significant correlations between the two raters for all four measures:
GDS (ICC=0.969, p<0.001)
MMSE-2 (ICC=0.997, p<0.001)
FLCI (ICC=0.999, p<0.001)
P-CAD (ICC=0.981, p<0.001)

Change over time
There were no significant changes over time in any of the 3 scales for the participants (N=11) who completed follow-up measures. The test was underpowered due to the low number of repeated measures at the second time point.

Level of Communication Support
There are significant correlations between the recommended levels of communication support on the P-CAD and the stage of dementia, GDS (r_{sb}= -0.586, p<0.001) and level of cognitive impairment on the MMSE-2 (r_{sb}=0.633, p<0.001).



Level of communication support needed increases with the progressing dementia as measured by the GDS and MMSE2.

Conclusions
The P-CAD is a valid and reliable cognitive communication assessment, appropriate for use with people across all subtypes and stages of dementia. It is now ready for use in clinical practice, informing interventions aimed at improving conversations between people with dementia and their communication partners.

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Acknowledgements
Health Research Board Ireland

Selected References:
[1] Reisberg B. et al. (1982). The Global Deterioration Scale for Assessment of Primary Degenerative Dementia. The American Journal of Psychiatry, 139, 1136-1139
[2] Bayles K. & Tomoeda C. (1993). The functional linguistic communication inventory. Texas: Pro-Ed.

Appendix 10.3 Poster Presentation ADI Conference 2016

31st International Conference
of Alzheimer's Disease International
21-24 April 2016
BUDAPEST 2016

Poster Abstracts

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Topic: Early intervention

CONVERSATION COACHING GROUP FOR PEOPLE WITH DEMENTIA AND THEIR COMMUNICATION PARTNERS

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Abstract:

Introduction: In Ireland, people with early stage dementia are typically not referred for cognitive communication assessment. Communication difficulties are inherent in a diagnosis of dementia. Speech and language therapists (SLTs) are well placed to work with individuals and family carers throughout the course of the illness to identify communication difficulties and needs. By providing support, enabling understanding and recommending strategies, SLTs are able to work with carers and people with dementia (PWD) to help maintain their interpersonal relationships. The aims of this intervention were (1) to provide psychosocial support to the PWD and their caregivers, (2) to provide education to PWD and their family caregivers about facilitating communication in dementia, and (3) to identify individual communication strategies to enhance communication.

Method: We selected five couples based on strict inclusion criteria, attending the day hospital service in St. Columcille's Hospital. We delivered a six-week intensive communication intervention. This entailed both group and individual based sessions, including a community outing. We used a range of outcome measures, both standardised and informal. This intervention was delivered by two SLTs. A core conversational analytic approach through video analysis was used, to identify individualised communication support strategies. Group sessions consisted of an educational focus, through didactic and experiential learning methods.

Results: All members of the group improved their functional communication ability and required a reduced level of communication support as measured by standardised communication tools. The incidence of communication breakdown was reduced significantly with couples using prescribed communication support strategies on average 83% of the time. Members of the group developed a leaflet titled "Supporting Communication in Dementia" which was circulated throughout the hospital and in local community centres. All members of the group reported positive outcomes. Some of their testimonials included comments such as "I've made a great change. Now I'm in the moment, more aware of how I sound. I'm not afraid, I know the parameters already."

Conclusion: This is an effective and transferable group intervention which targets the individualised needs of PWD and their family caregivers.

Keywords: Cognitive-communication, Early intervention, Speech and Language Therapy

Appendix 10.4 Conversation Coaching for People with Dementia (Feasibility Study)

SESSION	CONTENT	METHOD	GOAL
1. Introductions & Overview of the programme	• Identify group goals & ground rules • How dementia impacts on communication • How to make your own conversation video & confidentiality	• Group Session • Information giving and sharing experiences • Demonstration in using tablets and smart phones to make a good video	• Meet and become comfortable with group members • Orientate to the programme • Have increased understanding of the impact of dementia of communication • Teach how to record everyday conversations for analysis
2. Video Analysis and feedback with conversation couples	• Video feedback • What is working well • What is not • Discuss strategies to use	• Individual Session with SLT • Online video feedback • Analysis of turns, topic and conversational repair • Recommendation & discussion	• Help partners to become aware of their conversation patterns • Improve conversation flow through use of support strategies • "I have dementia" card
3. Communicating Well	• Good communication styles • Verbal/Non-verbal communication • Questions	Group Workshop • Role play • Exercises • Handouts	• Increase awareness about communicating well and support strategies
4. Community Outing	• Community based meet-up	• Organised by the Group	• Participants will have opportunities to practice communication support strategies in a functional setting. • They can share experiences and enjoy the surroundings
5. Individual follow-ups	• Review how things are going • Review videos • The effects of using strategies more • Address any new concerns	Individual Session with SLT • Open discussion with therapist and clients	• Identify what is working well and do more of it • Fine tune communication support strategies • Trouble shoot any problems
6. Final Session	• Revise goals of the programme • What has changed • Widening the communication circle • Breaking down social barriers • Maintaining new learning	Group Session • Feedback • Brainstorming • Peer-supported conversations	• Revision • Reflections • Improving communication networks helping others to help you • Produce a handout for the public about how to help people with dementia reveal their communicative competence • Consolidation

Group Overview

People with dementia experience **communication difficulties**. The exact nature of these difficulties can vary from person to person and across the stages of dementia.

The person may have difficulty with understanding, talking, reading or writing.

Communication is a **two-way process**. Both communication partners have a role to play.

This group aims to **facilitate communication** for people with dementia. It will provide **education** for both the person with dementia and their families. This will include how best to **support** communication and specific communication interventions to improve communication. There will also be opportunities for **social engagement** & support from others living with dementia.

FURTHER INFORMATION

Useful websites:

www.dementia.ie

www.alzheimer.ie

www.rcslt.org

If you have any questions or concerns surrounding communication in dementia, ask your speech and language therapist for advice.

Speech and Language Therapy Department
St Columcille's Hospital,
Loughlinstown
01-2115068

CONVERSATIONAL COACHING GROUP FOR PEOPLE WITH DEMENTIA AND THEIR COMMUNICATION PARTNERS

DAY HOSPITAL

6 WEEK PROGRAMME

Group Outline

This group will run for six weeks. Attendance from both the person with dementia and their communication partner is required at all stages.

Session 1: Introductions & Overview of the Programme
"How Dementia Impacts on Communication"
Location: Day Hospital

In this session, we will identify the group goals and ground rules. We will discuss how dementia impacts on communication, what types of conversations we like to have and instruction in making conversation videos.

Session 2: Video Analysis & Feedback with Individual Couples
"Developing Communication Support Strategies"
Location: arranged with SLT

In this individual session, each couple will meet with their SLT. We will discuss communication styles using the conversation videos. We will identify what is working well, what is not working and what strategies we can use to improve communication.

Session 3: Group Session
"Communicating Well with Dementia"
Location: Day Hospital

In this session, we will explore all forms of communication including non-verbal communication. We will learn about communication support strategies which can improve communication for people with dementia and their communication partners.

Session 4: Community Outing
"Living Well: Participation in your Community"
Location: organised by group

During this community-based outing, organised by the group, participants will have opportunities to practice communication support strategies in a functional setting.

Session 5: Individual Follow-ups
"Reviewing Progress towards Better Communication"
Location: arranged with SLT

In this second individual session with the SLT, each couple will review what is working well in their conversation, the effects of communication support strategies and address any new concerns around communication.

Session 6: Final Group Session
"What has changed? Maintaining new learning"
Location: Day Hospital

In this final group session, we will revise the goals of the programme, discuss what has changed, and explore widening the communication circle by breaking down social barriers. We will conclude by creating a handout for the public regarding communication in dementia.

Appendix 10.5 Research Outputs

Published Journal Articles

1. DOOLEY, S. & WALSHE, M. 2019. Assessing Cognitive Communication Skills in Dementia: A scoping review. *International Journal of Language & Communication disorders,* 0**,** 1-13

Published abstracts

1. Dooley, S. & Conway, A. April (2016). Conversation Coaching Group for People with Dementia. *31st International Conference of Alzheimer's Disease International.* Budapest, Hungary: Alzheimer's Disease International, 169.
2. Dooley, S., Doyle, R., Hopper, T., O'Neill, D. Walshe, M. (2018). Profiling Communication Ability in Dementia (P-CAD): Validation of a Functional Cognitive-Communication Assessment. Age and Ageing, 47,36.

Oral Presentations

1. Dooley, S & Walshe, M. (2017). "Assessing Functional retained Communication Skills in Dementia". RSCI Sphere Annual Network Conference, Dublin. Ireland, 12th January 2017.
2. Dooley, S. & Walshe, M. (2017). "Cognitive Communication Assessment in Dementia: The P-CAD Project". Trinity College Dublin, Dublin, Ireland, 9th November 2017
3. Dooley, S. & Walshe, M. (2019). "Management of Cognitive Communication Difficulties in Dementia: A Cross Sectional Survey of Speech and Language Therapists in Ireland". IASLT Biennial Conference 2019, Dublin, Ireland.

Poster Presentations

1. Dooley, S & Walshe, M. (2017). "Assessing Functional retained Communication Skills in Dementia". Alzheimer's Association International Conference, Toronto, Canada July 2016.

2. Dooley, S., Doyle, R., Hopper, T., O'Neill, D. Walshe, M. (2018). "Profiling Communication Ability in Dementia (P-CAD): Validation of a Functional Cognitive-Communication Assessment". Irish Gerontological Society, 66th Annual and Scientific Conference, Kerry, Ireland, September 2018
3. Dooley, S., Doyle, R., Hopper, T., O'Neill, D. Walshe, M. (2018). "Profiling Communication Ability in Dementia (P-CAD): Validation of a Functional Cognitive-Communication Assessment". Alzheimer's Association International Conference, London, England, July 2017.
4. Dooley, S., Doyle, R., Hopper, T., O'Neill, D. Walshe, M. (2018). "Profiling Communication Ability in Dementia (P-CAD): Validation of a Functional Cognitive-Communication Assessment". IASLT Biennial Conference 2019, Dublin, Ireland.