



Facilitating Speech Pathologists' Role in Working with People with Dementia

Elisa Choudery

Speech Therapy (State Examination Germany); Health Care Studies (BSc)

A thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy in Speech Language Pathology

School of Health Sciences

College of Health, Medicine & Wellbeing

University of Newcastle, NSW

August 2022

Statement of Originality

I hereby certify that the work embodied in the thesis is my own work, conducted under normal supervision. I confirm that the thesis contains no material which has been accepted, or is being examined, for the award of any other degree or diploma in any university or other tertiary institution, with the exception of the approved partner university associated with this Dual Award Doctoral Degree. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person, except where due reference has been made. I give consent to the final version of my thesis being made available worldwide when deposited in the University of Newcastle Digital Repository and its equivalent at the partner university, subject to the provisions of the *Copyright Act 1968* and any approved embargo.

Elisa Choudery, PhD Candidate

Acknowledgement of Authorship

I hereby certify that the work embodied in this thesis contains published paper/s/scholarly work of which I am a joint author. I have included as part of the thesis a written declaration endorsed in writing by my supervisor, attesting to my contribution to the joint publication/s/scholarly work.

By signing below, I confirm that Elisa Choudery contributed as primary author to the conceptualisation of data collection, analysis, and write up for the paper entitled “Guidelines for a Speech-Language Pathologist Role in Dementia Care: A Scoping Review”.

Dr Liz Spencer

Acknowledgements and Dedications

First and foremost, I am extremely grateful to my supervisors, Dr Liz Spencer and Associate Professor Sally Hewat, for their invaluable guidance, advice, continuous support, and patience during my PhD study. Thanks for not getting tired of giving me feedback on my chapters and working so flexibly to accommodate different time zones. Both of you have been endlessly patient with my work commitments and other responsibilities, for which I am very grateful.

A special thanks to the speech pathologists who took the time to participate in the different phases of my study. This research would not have been possible without the willingness of these people, who contributed to the research by sharing their knowledge, ideas and time.

I would like to express my heartfelt thanks to my family and friends for their unwavering support and patience throughout the duration of the research. Even though we were separated by distance, I always knew I could count on you. Thank you all for the support you gave me, I love you all!

Special thanks to Adriana Haro, who became a true friend of mine. Thanks for all the writing meet-ups and coffee dates. I am so grateful for your support throughout the most difficult times in my life and I am glad we met.

Thanks to my colleagues from the Swiss University of Speech and Language Science, who welcomed me with open arms and were so understanding of my current situation with academic and private responsibilities. I love working with you and I greatly value your support.

This thesis is dedicated to my husband, Nadim Choudery. I couldn't have done this without you. You were the one who encouraged me to take all these tiny steps and believed in me when I didn't. Thank you for leaving our lives in Germany behind and moving to Australia. I am so grateful for all the sacrifices you have made in order for me to pursue a PhD. But most of all, I am so proud of you for focusing on beating cancer. Seeing how you finished your cancer treatments and found your way back to normal is the most inspiring thing ever. You show me every day what really matters in life. I am so thankful for your support throughout the entire thesis process and I love you more than words can describe.

Danksagungen und Widmungen

Ich möchte meinen Betreuerinnen, Dr Liz Spencer und Associate Professor Sally Hewat, großen Dank aussprechen, für ihre kostbare Anleitung, ihren Rat, ihre ständige Unterstützung und ihre Geduld während meines Doktorats. Vielen Dank, für das unermüdliche Feedback zu einzelnen Kapiteln, sowie das große Maß an Flexibilität, sich an unterschiedliche Zeitzonen anzupassen. Beide hatten unendlich viel Geduld mit meinen beruflichen Verpflichtungen und privaten Herausforderungen, wofür ich sehr dankbar bin.

Ein besonderer Dank geht an die Therapeutinnen, die sich die Zeit genommen haben, an den verschiedenen Phasen meiner Studie teilzunehmen. Das gesamte Projekt wäre ohne die Bereitschaft dieser Personen, die ihr Wissen, ihre Ideen und ihre Zeit zur Verfügung gestellt haben, nicht möglich gewesen.

Ich möchte meiner Familie und meinen Freunden für ihre unermüdliche Unterstützung und Geduld während der gesamten Dauer meines Doktorats von ganzem Herzen danken. Auch wenn wir durch die Entfernung getrennt waren, wusste ich immer, dass ich auf euch zählen konnte. Ich danke euch allen für die Unterstützung, die ihr mir gegeben habt. Ich liebe euch alle!

Besonderer Dank gilt Adriana Haro, die eine echte Freundin geworden ist. Danke für all die Treffen und Kaffeekränzchen. Ich bin so dankbar für deine Unterstützung während dieser schwierigen Phase in meinem Leben und ich bin froh, dass wir uns getroffen und gefunden haben.

Danke an meine Kolleginnen der Schweizer Hochschule für Logopädie Rorschach, die mich mit offenen Armen empfangen haben und so viel Verständnis für meine derzeitige Situation, inklusive akademischer und privater Verpflichtungen, hatten. Ich arbeite unendlich gerne mit euch zusammen und schätze eure Unterstützung sehr.

Diese Arbeit ist meinem Mann, Nadim Choudery, gewidmet. Ohne dich hätte ich das niemals geschafft. Du warst derjenige, der mich ermutigt hat, all diese kleinen Schritte zu machen und der an mich geglaubt hat, als ich es nicht tat. Danke, dass du unser Leben in Deutschland aufgegeben hast und mit mir nach Australien gezogen bist. Ich bin dir so dankbar für all die Opfer, die du gebracht hast, nur damit ich promovieren konnte. Aber vor allem bin ich so stolz auf dich, wie du unermüdlich gegen den Krebs gekämpft hast. Zu sehen, wie du deine Behandlungen abgeschlossen und wieder zur Normalität zurückgefunden hast, ist sehr inspirierend. Du zeigst mir jeden Tag, worauf es im Leben wirklich ankommt. Ich bin so dankbar für deine Unterstützung während des gesamten Prozesses der Dissertation und ich liebe dich mehr, als Worte je beschreiben könnten.

Related Publications and Presentations

Posters

Choudery, E., Spencer, L., & Hewat, S. (2019, June). *Working with people with dementia and their carers: Speech and language pathologists' experiences and perceptions* [Poster presentation]. Australian Dementia Forum, Tasmania.

Choudery, E., Spencer, L., & Hewat, S. (2020, May). *Speech–language pathologists in the management of dementia: A scoping review of professional guidelines, policies and recommendations* [Poster presentation]. Speech Pathology Australia National Conference [Conference cancelled].

Publication

Choudery, E., Spencer, L., & Hewat, S. (2022). *Guidelines for a speech–language pathologist role in dementia care: A scoping review* [Manuscript submitted for publication]. School of Health Sciences, University of Newcastle.

Table of Contents

Statement of Originality	ii
Acknowledgement of Authorship	iii
Acknowledgements and Dedications	iv
Related Publications and Presentations	vi
Table of Contents	vii
List of Figures	x
List of Tables.....	xi
List of Abbreviations.....	xii
Abstract	xiii
Chapter 1: Overview	17
1.1 Background	17
1.2 Dementia Types	18
1.3 Cognitive Changes, Risk Factors and Prevention of Dementia	21
1.4 Assessment and Diagnosis of Dementia	25
1.5 Pharmacological Intervention	26
1.6 Non-Pharmacological Intervention	27
1.7 Person-Centred Management of Dementia	28
1.8 International Classification of Functioning, Disability and Health, and Dementia	30
1.8.1 Functioning and Disability in Dementia	31
1.8.2 Contextual Factors in Dementia.....	31
1.8.3 ICF Components in Person-Centred Dementia Care	32
1.9 Summary and Conclusion	32
Chapter 2: Speech Pathologists' Role in Working With People With Dementia.....	34
2.1 Evidence-Based Practice	34
2.2 Application of ICF Principles in SP	35
2.3 Cognitive-Communication Disorders Associated With Dementia	37
2.3.1 Direct Cognitive-Communication Intervention Strategies	38
2.3.2 Indirect Cognitive-Communication Intervention Strategies	42
2.3.3 Summary of the Evidence for Cognitive-Communication Intervention	44
2.4 Feeding and Swallowing Difficulties Associated With Dementia.....	44
2.4.1 Intervention Strategies: Swallowing and Feeding	46
2.4.2 Conclusion: Swallowing and Feeding Difficulties	48
2.5 Summary and Conclusion	49
Chapter 3: Guidelines for a Speech-Language Pathologist Role in Dementia Care: A Scoping Review.....	50
3.1 Manuscript Submitted to the <i>International Journal of Speech-Language Pathology</i>	51

3.2	Summary and Conclusion	67
Chapter 4: Methodological Approach.....		68
4.1	Human-Centred Design.....	68
4.2	Application of HCD to Other Disciplines	71
4.3	Research Design.....	73
4.3.1	Phase 1: Identifying Patterns and Requirements of Users	74
4.3.2	Phase 2: Ideation.....	74
4.3.3	Phase 3: Prototyping	74
4.3.4	Phase 4: User Feedback	74
4.3.5	Phase 5: Iteration	75
4.3.6	Phase 6: Implementation.....	75
Chapter 5: Phase 1: Mixed-Method Study		76
5.1	Research Rationale and Design.....	76
5.2	Ethics Approval and Ethical Considerations.....	77
5.3	Stage 1: Survey	78
5.3.1	Survey Instrument.....	78
5.3.2	Survey Recruitment and Procedure	82
5.3.3	Survey Data Analysis.....	83
5.4	Stage 2: Interviews.....	83
5.4.1	Interview Recruitment and Procedure	84
5.4.2	Interview Data Analysis.....	84
5.4.3	Validity, Reliability, and Trustworthiness	85
5.5	Survey Results.....	86
5.5.1	Participants	86
5.5.2	Clinical Practice	89
5.5.3	Summary: Survey	97
5.6	Interview Results.....	98
5.6.1	Participants	98
5.6.2	Themes	99
5.6.3	Summary: Interviews.....	108
5.7	Discussion and Conclusion: Survey and Interviews	109
Chapter 6: Phase 2: Ideation.....		111
6.1	Research Method.....	111
6.2	Participants.....	112
6.3	Data Collection	113
6.4	Analysis.....	114
6.5	Results.....	118
6.5.1	Content	118
6.5.2	Purpose	121
6.5.3	Platform	123
6.5.4	Design	125
6.6	Summary	127

Chapter 7: Phases 3 and 4: Prototyping and User Feedback.....	128
7.1 Development of a Dementia Resource Guide for SPs	128
7.1.1 Rationale	128
7.2 Phase 3: Prototyping	131
7.2.1 Prototyping Procedure	132
7.2.2 Summary of Phase 3: Prototype Development	141
7.3 Phase 4: User Feedback	141
7.3.1 Recruitment.....	142
7.3.2 Method	142
7.3.3 Results	144
7.4 Summary and Conclusion: User Feedback and Prototype Implementation.....	149
7.4.1 Implementation of the Prototype	150
Chapter 8: Discussion and Conclusion.....	151
8.1 Overview and Summary.....	151
8.2 Implications.....	155
8.2.1 Methodological Implications of HCD Approach.....	155
8.2.2 Clinical Implications.....	156
8.3 Limitations of the Study.....	158
8.4 Future Directions.....	160
8.5 Conclusion	162
References	163
Appendices	211
Appendix A: Scoping Review Results and Tables.....	211
Appendix B: Phase 1 – Stage 1: Survey Material	218
Appendix C: Phase 1 – Stage 2: Interview Material	234
Appendix D: Phase 2 – Focus Group Material	244
Appendix E: Phase 4 – User Feedback	258
Appendix F: Webpage Prototype	269

List of Figures

Figure 1.1 <i>Dementia in the ICF Framework</i>	31
Figure 4.1 <i>HCD Principles and Activities According to ISO 13047, 1999</i>	69
Figure 4.2 <i>The User-Centred Design Process According to ISO 9241-210 (2019)</i>	70
Figure 4.3 <i>HCD Project Phases</i>	73
Figure 5.1 <i>Phase 1 Mixed-Method Study Stages</i>	77
Figure 5.2 <i>Types of Dementia Covered in Participants' Further Training</i>	88
Figure 5.3 <i>Referral Patterns</i>	89
Figure 5.4 <i>Stage of Disease for Initial Referral to SP</i>	90
Figure 5.5 <i>Reasons for Referrals</i>	91
Figure 5.6 <i>Roles of SPs in Assessments of PWD</i>	92
Figure 5.7 <i>Therapy Focus</i>	93
Figure 5.8 <i>Approach to Goal Setting</i>	94
Figure 5.9 <i>Types of Intervention</i>	95
Figure 5.10 <i>Team Involvement</i>	96
Figure 5.11 <i>SP Involvement in Other Services for PWD</i>	97
Figure 7.1 <i>Blog: Eat, Speak, & Think</i>	130
Figure 7.2 <i>Digital Board: Outline of Website Content</i>	133
Figure 7.3 <i>Wireframe for Website Prototype</i>	135
Figure 7.4 <i>Order of Content Categories on Home Page on Website</i>	136
Figure 7.5 <i>Logo: Dementia Messages Website</i>	136
Figure 7.6 <i>Navigation Buttons</i>	137
Figure 7.7 <i>Drop-Down Navigation</i>	138
Figure 7.8 <i>Contact Button</i>	139
Figure 7.9 <i>Dementia Messages Group Forum</i>	140
Figure 7.10 <i>Rating of Aspects of the Website Design</i>	145
Figure 7.11 <i>Usefulness of Website Content Categories</i>	146
Figure 7.12 <i>Statements About Purpose of the Website</i>	148
Figure A1 <i>PRISMA Flow Diagram</i>	211

List of Tables

Table 3.1 <i>Manuscript Authors and Contributions</i>	50
Table 5.1 <i>Initial Coding Outcome Example – Excerpt From Participant Interview SP7</i>	85
Table 5.2 <i>Demographic Information of Survey Participants</i>	87
Table 5.3 <i>Demographic Information of Interview Participants</i>	98
Table 5.4 <i>Themes and Subthemes From Interview Data</i>	99
Table 6.1 <i>Guiding Questions</i>	113
Table 6.2 <i>Categorisation of Portions of Focus Group Discussion</i>	116
Table 6.3 <i>Organisation of Codes Into Categories and Subcategories</i>	117
Table 6.4 <i>Subcategories: Content</i>	118
Table 6.5 <i>Subcategories: Purpose</i>	122
Table 6.6 <i>Subcategories: Platform</i>	123
Table 6.7 <i>Platforms Used by Participants</i>	124
Table 6.8 <i>Subcategories: Design</i>	126
Table 7.1 <i>Further Website Content Ideas</i>	147
Table A1 <i>Overview of Reviewed Documents</i>	212
Table A2 <i>SLP Role Within Documents</i>	215

List of Abbreviations

APA	American Psychiatric Association
ASHA	American Speech-Language-Hearing Association
CT	Computed tomography
DEMQOL	Dementia Quality of Life measurement
DLB	Dementia with Lewy bodies
DQoL	Dementia Quality of Life instrument
FINGER	Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability
FTD	Frontotemporal dementia
GP	General practitioner
HCD	Human-centred design
ICF	International Classification of Functioning, Disability and Health
ISO	International Organization for Standardization
MAPT	Multidomain Alzheimer Preventive Trial
MCI	Mild cognitive impairment
MMSE	Mini-Mental State Examination
MOOC	Massive open online course
MRI	Magnetic resonance imaging
N/A	Not applicable
NDIS	National Disability Insurance Scheme
PDF	Portable document format
PPA	Primary progressive aphasia
PWD	Person/People with dementia
QUALID	Quality of Life in Dementia scale
RCSLT	Royal College of Speech and Language Therapists
SAC	Speech-Language & Audiology Canada
SLP	Speech-language pathologist
SMARRT	Systematic Multi-Domain Alzheimer's Risk Reduction Trial
SP	Speech pathology / Speech pathologist
SPA	Speech Pathology Australia
WHO	World Health Organization

Abstract

As a result of an aging population, dementia is recognised as a global health problem. The prevalence of dementia cases is expected to increase drastically in the coming years and will represent a burden to the economy and society. Consequently, dementia will affect allied health professionals' workloads as well. Dementia is an umbrella term for several diseases and symptoms, and leads to changes in responsive behaviours. Changes affect thinking, memory, reasoning, language, and daily behaviour such as eating and swallowing. This has an impact on a person's ability to participate in daily activities and socialise with family members and carers. Speech pathologists (SPs) have the expertise to provide support and intervention for people with dementia in areas of communication and swallowing. Despite growing literature addressing effectiveness of approaches and strategies for communication, swallowing, and feeding, there has been little previous data on current clinical practice of Australian SPs in the management of dementia. Furthermore, the role of SPs and collaboration with other allied health professionals when working with people with dementia is undefined. The current research aimed to increase understanding of SP practice in Australia on the practice continuum of dementia and to explore professional needs in order to facilitate clinical practice for people with dementia and their families and carers.

In Chapter 1, key facts about dementia are presented including diseases and symptoms, prevention, and interdisciplinary management. In light of this, the SP role and principles of practice are explained in Chapter 2.

Chapter 3 presents a scoping review that was conducted to identify the SP role on a professional and multidisciplinary level. Included were clinical guidelines, position statements and recommendations on the management of dementia. Full-text review resulted in 20 documents that met the inclusion criteria, including five documents specifically written for SPs. The professional documents had different levels of depth. Eight documents from other allied health areas included reference to SPs as part of non-pharmacological treatment in the management of dementia.

Based on findings from the scoping review, clinical practice of Australian SPs in the management of dementia remained unclear. This study used a mixed-methods human-centred design framework to explore SPs' current practice when working with people with dementia. Overall, the framework consisted of six phases and involved SPs as experts from the beginning

of the research process. The methodological approach with the phases are outlined in Chapter 4.

In Chapter 5 (Phase 1) the current SP practice in Australia was investigated through a mixed-method study. Initially, an online survey was distributed, followed by in-depth interviews with SPs. Results indicated that SPs who worked with people with dementia received mainly referrals for swallowing and feeding rather than cognitive-communication disorders. The majority performed assessments and provided therapy for people with a dementia diagnosis mostly in the later stages of the disease. Further, SPs provided details of their current practice and communicated that graduate entry curricula did not cover dementia in an extensive way. As a consequence, their current practice included wide-ranging researching and accessing further professional development in order to extend their knowledge in the area of dementia. One of the main findings of this part of the research was that SPs wanted clearer guidelines to guide their practice and specific information that could be provided to other professionals about the roles of SPs and the timing of involvement in care for people with dementia from early to late stages.

Following the investigation of current practice and services, the idea for a resource guide for SPs emerged as a result of experiences and insights shared. Accordingly, two focus groups were conducted with SPs who worked with people with dementia, the procedure and results are outlined in Chapter 6 (Phase 2). By including them in the ideation phase, ideas and needs for a resource guide came directly from an end-user perspective and considered the categories across content, purpose, platform and design.

In Chapter 7, Phases 3 and 4 of the human-centred design framework are presented. A prototype of a web-based resource guide was developed based on results from the focus group. In the final phase of the overall project, SPs evaluated the prototype resource guide as the end-user target group. SPs reviewed the prototype and provided feedback on the proposed content categories, overall design, website purpose, and platform via an online survey instrument.

This research appears to be the first study to evaluate the current practice of Australian SPs who work with people with dementia in order to assess their demands and needs. Results indicated that the management of dementia is still a neglected area of SP practice. Given that dementia is not considered extensively in curricula at a university level and guidelines to provide SP services in Australia are missing, the current research with the developed resource guide can be seen as a starting point for further investigation. Overall, participating SPs rated

the website resource guide as useful and supportive for their clinical practice, and there is great potential for the resource to grow further and add to current SP practice.

Chapter 1: Overview

1.1 Background

Dementia is an umbrella term used for several syndromes and symptoms typically involving cognitive changes caused by a number of diseases. Dementia is a rapidly growing global public health problem (World Health Organization [WHO], 2021a). Today, an estimated 55 million people worldwide live with dementia, and it is expected that the number will reach 139 million by 2050 (Alzheimer's Disease International, n.d.). Dementia is a progressive disease that affects mental abilities and brain processes (cognition). Cognitive changes can become severe over time and interfere with an individual's normal life. The American Psychiatric Association (APA, 2013) defined six cognitive areas which can be affected as a result of dementia: attention, executive functions, learning and memory, language, perceptual motor function, and social cognition. In addition to cognitive changes, responsive behaviours are also common in people with dementia (PWD), including depression, hallucinations, agitation, delusion, apathy, and sleep problems and disturbances of daily rhythms (Tible et al., 2017).

Symptoms of responsive behaviours often increase in severity with disease progression and can be major stressors for families and carers (Finkel, 2000; Lawlor, 2002; McKeith & Cummings, 2005; Radue et al., 2019). Many researchers have attempted to classify the symptoms and progression of dementia; however, the literature is inconsistent in approaches. While there have been notable changes in terminology, classification, stages, and symptoms over the years, the very early work of a psychiatrist, James Prichard, laid the foundation for the classification tools used today. Prichard (1837) described symptoms as memory loss, loss of reason, lack of comprehension, and loss of instinctive action. Further systems to classify dementia evolved based on Prichard's original scales. These were the Global Deterioration Scale (Reisberg et al., 1982), with seven clinical stages of Alzheimer's dementia, and the Clinical Dementia Rating scale (Morris, 1997), describing five stages from normality to severe dementia. The most contemporary and globally used diagnostic tool for dementia is the APA's *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; APA, 2013, 2022). This tool describes three broad stages for degenerative dementia: early stage, middle stage, and late stage. In the early stage, symptoms include forgetfulness and disorientation. With progression to the

middle stage, symptoms become more obvious and include increased forgetfulness and confusion, as well as difficulties with communication and changes in responsive behaviour. In the late stage, cognitive functions and physical abilities are severely impacted and PWD have an increased need for assistance and care (WHO, 2021a).

As noted earlier, dementia is an umbrella term used to describe a number of different conditions and syndromes related to memory loss and cognitive decline caused by various underlying diseases. In Australia, according to the prevalence data, there are presently an estimated 487,500 persons living with some form of dementia (Dementia Australia, 2018a). Overall, symptoms of different dementia types lead to deterioration of independence as they progress and PWD require constant assistance and support that responds to their individual care needs (Kolanowski et al., 2018). The different dementia types with symptoms, including affected language abilities, are described briefly in the next section.

1.2 Dementia Types

The most common type of dementia is Alzheimer's disease, first described by German psychiatrist Alois Alzheimer (1907). Australian figures indicate that Alzheimer's disease is present in approximately two thirds of dementia cases (Dementia Australia, 2018a). Alzheimer's disease is caused by amyloid plaques and neurofibrillary tangles throughout the brain which lead to a gradual build up and accumulation of proteins. These processes cause neuronal dysfunction in the brain and eventually brain cells start to die (Lane et al., 2018). Over time the damage in the brain has a functional impact on individuals that progressively worsens and interferes with activities of daily life such as cooking, self-care routines, orientation and mobility (Bucks et al., 1996). Deterioration in the ability to perform activities of daily living occurs in different ways and at different rates for individuals with the disease. Where tasks such as getting dressed can affect some people in the early stages, other individuals may become more dependent on assistance for personal care in the later stages (Giebel et al., 2015). The most notable changes in the early stages of the disease are deterioration of the person's ability to remember new information (Alzheimer's Association, 2016). In later stages, symptoms include further memory loss, confusion, and difficulties with spoken and written language (Rentz et al., 2013; Sperling et al., 2011). Language difficulties in Alzheimer's disease can affect all linguistic domains. People with Alzheimer's disease may have naming disorders, impaired comprehension, empty speech, and phonological and semantic errors (Bayles et al., 1992; Croot et al., 2000). Deterioration at microlinguistic levels of phonology, morphology,

syntax, and semantics, such as phonological and semantic errors, lead to problems at the discourse level and impact interpersonal interactions. The discourse-level problems may include excessive and incoherent talkativeness, repetitive content or deviation of conversation topics (Klimova et al., 2015).

The second most diagnosed type of dementia, accountable for 15%–20% of all cases in Australia, is vascular dementia (Dementia Australia, n.d.). This is a broad term for dementia connected with problems of blood circulation to the brain such as brain damage after stroke (National Institute of Neurological Disorders and Stroke, 2022). A recent stroke or a stroke history increases the risk of developing vascular dementia by 70% (Kuźma et al., 2018). Specific syndromes, such as Binswanger disease, can also cause vascular dementia. Binswanger disease is a clinical syndrome caused by abnormalities in the brain (Libon et al., 2004) and thickened and narrowed arteries (atherosclerosis) that supply the subcortical areas of the brain, affecting cognitive function and causing language difficulties and visual dysfunctions (Akiguchi et al., 1997; Caplan & Gomes, 2010). Progression of vascular dementia is often described as a gradual decline; however, dementia symptoms may occur quickly following a stroke (Mayo Clinic, n.d.). Vascular disease and Alzheimer’s disease often occur together due to a co-occurrence of vascular and degenerative processes associated with Alzheimer’s disease (O’Brien & Thomas, 2015). Investigating the link between strokes and the clinical expression of Alzheimer’s, Snowden and colleagues (1997) added an important piece of work to this area, suggesting that cerebrovascular disease may affect the presence and severity of the clinical symptoms of Alzheimer’s disease. Clinical criteria specifically for vascular dementia comprise a set of signs that patients must have, including memory impairment or a dysexecutive disorder¹ (APA, 2013, 2022). Overall, language deficits appear similar to those associated with Alzheimer’s disease (Vuorinen et al., 2000).

Lewy body dementia results from accumulation of abnormal deposits of the protein alpha-synuclein in the brain causing impairment of cognitive domains (Gomperts, 2016; Sanford, 2018). In the literature, Lewy body dementia has been the subject of considerable discussion as some research states that it includes two different syndromes that cause dementia: dementia with Lewy bodies (DLB) and Parkinson’s disease dementia (Z. Walker et al., 2015). Other research suggests that Lewy body dementia is part of a larger spectrum of Lewy body diseases with a variety of clinical presentations, including Parkinson’s disease (McKeith, 2007). At

¹ Problems in the ability to attend to or monitor internal and external information and adapt to complex and changing environmental stimuli (Hanna-Pladdy, 2007).

autopsy, Lewy body dementia is neuropathologically indistinguishable from dementia occurring in later stages of Parkinson's disease (Gomperts, 2016; McKeith, 2007). Both syndromes overlap regarding their clinical presentation and the subsequent management is similar. Symptoms may include visual hallucinations, movement disorders, decreased regulation of body functions, sleep difficulties, fluctuating attention, depression, apathy, and cognitive problems. The cognitive problems may affect overall speech rate and articulation, as well as grammar (Ash et al., 2012). Due to the similarity of symptoms, differential diagnosis of the syndromes can be difficult in the clinical setting (Capouch et al., 2018).

Frontotemporal dementia (FTD) was first described in 1892 by Arnold Pick, who described a patient with a rare dementing syndrome associated with left temporal lobe atrophy (Pick, 1892, as cited in Förstl, 2002). Compared to other dementia types, which affect several cognitive domains, FTD presents with severe language difficulties similar to aphasia caused by stroke or brain injury but with the underlying cause being frontotemporal lobe deterioration (Spatt, 2003). There are six clinical subtypes of FTD: (a) behavioural variant, (b) semantic variant primary progressive aphasia, (c) nonfluent agrammatic variant primary progressive aphasia, (d) corticobasal syndrome, (e) progressive supranuclear palsy, and (f) FTD associated with motor neurone disease (Finger, 2016). Initially, damage of the frontal lobes leads to changes in personality and behaviour (behavioural-variant FTD) whereas damage to temporal lobes causes a loss of language skills, called primary progressive aphasia (PPA; Botha et al., 2015). In the last few decades, primary progressive aphasia has been of particular interest in speech pathology literature. Mesulam (1982) used the term primary progressive aphasia first, stating that "PPA is a gradual and isolated impairment of word usage and comprehension" (Mesulam, 2001, p. 425). In subsequent years, an increasing number of cases with progressive language breakdown have been described in the literature. Snowden and colleagues (1989) documented loss of semantic comprehension in three different patients with the absence of other notable neurological or physical symptoms. This required a systematic qualification, which was proposed in 1992 by Hodges and colleagues and wherein language difficulties of PPA were categorised. In 1996, Grossman and colleagues described an additional form of progressive language disorder, called progressive nonfluent aphasia. Over approximately the last two decades, PPA was classified into subgroups based on imaging and linguistic profiles as either semantic dementia or progressive fluent/nonfluent aphasia (Grossman & Ash, 2004). However, using the existing categorisation, there were still cases that did not fit, and a third variant called logopenic progressive aphasia was documented (Gorno-Tempini et al., 2004). The first attempts to classify the different variants of

language deterioration and characteristics of PPA were not systematic. Therefore, a classification system was developed by a group of experts between 2006 and 2009 to ensure uniformity in diagnosis (Gorno-Tempini et al., 2011). Consequently, three variants have been decided on which have been adopted and used internationally since 2011 (Gorno-Tempini et al., 2011): (a) logopenic variant PPA, (b) semantic variant PPA, and (c) nonfluent/agrammatic variant PPA. Furthermore, classification of PPA variants is also used for specific diagnostic procedure (Epelbaum et al., 2021). However, applying different diagnostic criteria for each PPA variant “represents a significant challenge, even for experts” (Ruksenaite et al., 2021, p. 2), and some patients present with symptoms which are not covered in such classification (Harris et al., 2013; Sajjadi et al., 2012; Wicklund et al., 2014). Hence, attempts to specify PPA variants and subtypes with their different clinical presentation and symptoms increased (Neophytou et al., 2019), and there have been discussions around PPA variants, potential subtypes, and definition of a fourth variant for diagnostic procedure (Tippett, 2020). A further approach in the literature is the consideration of PPA as part of Alzheimer disease pathology. Besides frontotemporal degeneration, Alzheimer’s disease might affect anatomical features, leading to PPA (Mesulam et al., 2014). Given that there are different terminologies and classification of PPA besides frontotemporal degeneration, it is often referred as PPA syndrome (Harris & Jones, 2014).

Although dementia typically occurs in people over 65 years of age, it is well documented that dementia can also present in younger people. Alois Alzheimer described onset of dementia in a younger patient in 1911, using the term “Presenile Dementia” (Möller & Graeber, 1998). However, “early-onset dementia” or “younger-onset dementia” are more commonly used to describe dementia that occurs before the age of 65 (Giannakopoulos et al., 1996). Because dementia with onset at younger age may present as atypical, misdiagnosis is not uncommon (Tsoukra et al., 2021). Consequently, diagnostic services are inconsistent and delayed (Loi et al., 2020). The management of early onset dementia differs from that for older patients, as people under 65 years are often still working and may have parental carer responsibilities (Rossor et al., 2010). Additionally, early onset dementia presents challenges in providing appropriate care and facilitating wellbeing. Thus, acceptance, management of symptoms, and age-appropriate service provision are often problematic (Mayrhofer et al., 2018; Vafeas et al., 2020).

1.3 Cognitive Changes, Risk Factors and Prevention of Dementia

Subtle changes in cognition are common for people as they get older (Cole & Franke, 2017; Cole et al., 2019; Harada et al., 2013). When changes occur at a rate greater than expected

for a person's age and educational ability, the person may be diagnosed with mild cognitive impairment (MCI). MCI is described as the transitional phase between age-appropriate cognitive changes and dementia (Gauthier et al., 2006; Petersen, 2000, 2016; Petersen et al., 1999). While people with MCI have a higher risk of progression to dementia (Knopman & Petersen, 2014; Petersen, 2003; Petersen et al., 1999), the literature is discrepant about conversion rates from MCI to dementia. A meta-analysis of 41 cohort studies indicated that the annual conversion rate of people with MCI to dementia is approximately 5%–10% (A. Mitchell & Shiri-Feshki, 2009). Further, most people included in the cohort studies did not progress to dementia, even after a 10-year follow up. In contrast, in a longitudinal study with 105 individuals, 21.9% were diagnosed with dementia after a 3-year follow-up (Gabryelewicz et al., 2007). Although conversion rates vary, researchers have identified neuropsychiatric symptoms as potential risk factors in individuals, indicating the likelihood of conversion to dementia (Forrester et al., 2016). In addition to neuropsychiatric symptoms, cognitive function impairments seem to be important risk factors for the development of dementia (Acosta et al., 2018; Bidzan et al., 2017). Another risk factor is hearing loss, and a considerable amount of literature suggests that hearing loss, cognitive changes, and MCI are interconnected. Consequently, people with hearing loss are at higher risk for cognitive decline and developing dementia (Amieva et al., 2015; Chern & Golub, 2019; Deal et al., 2015, 2017; Hopper et al., 2016; F. Lin et al., 2011; Slade et al., 2020).

In light of potential risk factors, it is worth noting that early assessment and intervention has been shown to slow down or even stall cognitive decline in some patients and therefore progression to dementia can be avoided (Rozzini et al., 2007). It is known that clinical assessments can be used to predict progression from MCI (J. Kim et al., 2017). These assessments have been found to detect pathological cognitive changes even years before the onset of dementia, ranging from 5 to 10 years before dementia diagnosis (Amieva et al., 2005; Elias et al., 2000; Saxton et al., 2004). In particular, linguistic changes and deterioration in spoken and written language appear to be an early indicator of cognitive change (Beltrami et al., 2018; Calzà et al., 2021; Forbes et al., 2002; Kemper et al., 1989; K. Williams et al., 2003). This was indicated in the landmark longitudinal data from the Nun Study (Sharp, 1996; Snowdon, 2003). The data from the Nun Study showed that early life language ability was predictive of cognitive ability and later cognitive health in a study of 678 nuns in the United States. A higher language ability, measured by the amount of information they provided through written language samples in early life (19–22 years), was predictive of their cognitive health in

later life. Those with lower language ability at an early age had higher rates of dementia. Spoken language deficits such as changes of verbal fluency (Jorm et al., 2005) and an increased amount of voice breaks (Meilán et al., 2014) have been found to allow language-based identification of early linguistic abilities and to enable monitoring of language changes over time by experts.

Despite research supporting the detection of MCI and other potential risk factors for dementia, there seems to be an inconsistency and lack of guidance on timing of early detection of cognitive changes. However, prevention of cognitive decline and the onset of irreversible dementia remains one of the main concerns (Andrade & Radhakrishnan, 2009; L. Middleton & Yaffe, 2009; Mowszowski et al., 2010; Pickett et al., 2018; Shatenstein & Barberger-Gateau, 2015). Prevention is considered a more effective strategy than management of already-diagnosed dementia (Livingston et al., 2017) as it is well reported that various risk factors across the early, mid- and later lifespan promote cognitive decline and may lead to dementia in the long term. One area of investigation has been the impact of educational level in relation to prevention of cognitive and pathological changes associated with dementia (Ardila et al., 2000; Leibovici et al., 1996). Even though education level has an impact on cognitive function overall, it does not appear to be correlated with cognitive decline and conversion to dementia. According to R. Wilson and colleagues (2009), education was not connected with rate of cognitive decline. In another study, Zahodne and colleagues (2011) demonstrated that education affected overall cognitive performance but had no impact on cognitive changes and decline. Besides educational level, other factors in mid- and later life, such as hypertension, obesity, hearing loss, traumatic brain injury, alcohol misuse, smoking, depression, physical inactivity, social isolation, diabetes, and air pollution have been associated with increased risk of cognitive changes and dementia onset (Livingston et al., 2020). Many of these risk factors are modifiable through a conscious and healthy lifestyle in order to prevent cognitive decline and some types of dementia. Consequently, prevention involves health promotion activities that target healthy lifestyle and individuals at higher risk (Solomon et al., 2014; Winblad et al., 2016). Prevention strategies are categorised as primary prevention (prevent a disease before occurring), secondary prevention (early disease detection and intervention), and tertiary prevention (reduce symptoms and severity of a disease) (Kisling & Das, 2022). In the field of dementia, there has been a growing interest in primary prevention, with evidence supporting the implementation of strategies such as mental activity, physical activity, and lifestyle modifications (Hussenoeder & Riedel-Heller, 2018; Richard et al., 2009). This was exemplified in different studies. In a cluster-randomized trial, Richard and colleagues (2009) demonstrated that cardiovascular risk

factors in elderly people could be lowered and this resulted in a decreased risk for developing dementia. Eighty-seven percent of participants ($n = 3700$) had at least one cardiovascular risk factor that was responsive to intervention. A systematic meta-review verified that physical activity should be increased to prevent dementia, and other modifiable factors included social integration, education and lifelong learning, mental and cognitive stimulation and activities, a healthy diet, and reduction of nicotine and alcohol (Husenoeder & Riedel-Heller, 2018).

Another prevention strategy is cognitive training. In terms of pathological cognitive decline, several studies have explored the use of mental activities such as cognitive training on preservation of cognitive function. For example, computerised cognitive training has been identified as having a positive impact on brain function and preserving cognitive functions in individuals with MCI (Barnes et al., 2009; Lampit et al., 2014; Mendoza Laiz et al., 2018; Zhang et al., 2019). While all these studies demonstrated the positive impact of cognitive training, findings still seem to be inconsistent due to study design or the considered aspects or domains of cognition (e.g., memory, attention). Additionally, results indicated improvement only in the specific areas of cognition that were trained. There was not generalised improvement in other cognitive areas (Butler et al., 2018). Furthermore, implications about dosage strongly vary as different aspects, such as intensity and baseline levels, need to be considered. Therefore, a few studies have investigated the role of a multi-domain strategy, focusing on numerous factors of primary prevention of dementia. In 2014, as one of the largest and longest preventive trials, the Multidomain Alzheimer Preventive Trial (MAPT study) set the baseline (Gillette-Guyonnet et al., 2009; Vellas et al., 2014). Across 3 years, the MAPT study investigated 1,680 individuals who participated in a combination of interventions including nutrition, physical activity, and cognition. Even though the initial results of interventions were negative, subsequent analyses showed a positive effect on primary and some secondary outcomes, such as in performance in the Mini-Mental State Examination (MMSE; Andrieu et al., 2017). Another large randomised controlled trial was presented by the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER; Kivipelto et al., 2013). In this study, a 2-year multidomain intervention approach targeted numerous lifestyle factors (e.g., physical and cognitive activity). A total of 1,260 individuals, aged 60 to 77, received intervention ($n = 631$) or were assigned to a control group ($n = 629$). Results indicated that a healthy lifestyle (combination of healthy diet, exercise, and mental activity) was more effective in preventing cognitive decline among elder at-risk individuals (Strandberg et al., 2017). These trials have conveyed the importance of prevention and laid the foundation for further

investigation, such as the Systematic Multi-Domain Alzheimer's Risk Reduction Trial (SMARRT; Yaffe et al., 2019). In this ongoing trial, participants received personalised plans based on their individual risk factors, such as hypertension, diabetes, depressive symptoms, poor sleep quality, physical inactivity, and low cognitive stimulation. Due to the COVID-19 pandemic, the study protocol has undergone some changes, as monitoring of participants has been restricted.

There is translation to public health of such studies through communicating preventive strategies and their importance with regard to dementia. However, a public health approach and promotion of those primary prevention strategies have had limited success in tackling the growing prevalence of dementia in Australia, given that national numbers are increasing and any established strategies have not been successful (Slevin, 2021).

1.4 Assessment and Diagnosis of Dementia

Assessment for diagnosis of dementia is usually initiated by general practitioners (GPs) through monitoring current health status and potential risk factors for dementia (Patterson et al., 2008). Typically, GPs perform brief cognitive tests and laboratory investigations, such as blood tests and urinalysis, to exclude comorbidities (Feldman et al., 2008). Additionally, physical examination considers any neurological signs, such as loss of memory. This can also be complemented with structural brain imaging through computed tomography (CT) and magnetic resonance imaging (MRI) to look for any structural changes and abnormalities (Arvanitakis et al., 2019).

Brief cognitive tests screen for cognitive complaints, including difficulties with memory and word retrieval, and if any concerns or risk factors are identified, comprehensive neuropsychological testing will follow. Neuropsychological testing will deliver specific information on cognitive patterns of strengths and weaknesses (Jacova et al., 2007; Pasquier, 1999; Salmon & Bondi, 2009). A range of cognitive tests are recommended to distinguish between a normal function, MCI, and dementia (Feldman et al., 2008). Commonly performed cognitive tests include MMSE (Folstein et al., 1975), Clock Drawing Test (Hazan et al., 2018), Memory Impairment Screen (Buschke et al., 1999), Montreal Cognitive Assessment (Nasreddine et al., 2005), and the Addenbrooke's Cognitive Examination (Mioshi et al., 2006). These tests cover a range of cognitive domains, such as attention, working memory, executive function, and language (B. Cullen et al., 2007) and are typically performed by neuropsychologists or occupational therapists (Bennett et al., 2011; Burrell & Piguet, 2015; McGrath & O'Callaghan,

2014; Miller & Butin, 2000; Pasquier, 1999; Salmon & Bondi, 2009). Additional assessments conducted by a speech pathologist (SP) may also be necessary to capture the complexity of cognitive-communication and linguistic skills in order to detect deterioration of communication and language (Dooley & Walshe, 2019). Appropriate SP tests for PWD include the Arizona Battery for Communication Disorders of Dementia (Armstrong et al., 1996) or the Functional Linguistic Communication Inventory (Bayles & Tomoeda, 1994).

Diagnostic procedures aim to detect different levels of function (e.g., physical, cognition, and language) and therefore should be the responsibility of a multidisciplinary team. As is well-documented in the literature, a variety of professions should be involved in diagnosis of dementia as they add the ability to distinguish among different types of dementia and to identify comorbidities and symptoms for further care pathways (Grand et al., 2011; Ng & Ward, 2018; Page et al., 2008; Wolfs et al., 2006). Hence, memory clinics or centres where allied health professions collaborate play a crucial role in the diagnosis process of dementia. First described in the 1980s, memory clinics are nowadays accepted globally in order to assess and treat dementia (Jolley et al., 2006; Kelly, 2008). In Australia, the number of memory clinics has increased over the last 10 years in order to provide efficient access and early diagnosis (Mehrani et al., 2021). In 2021, the Australian Dementia Network published *Memory and Cognition Clinic Guidelines* to improve quality of services. According to these guidelines, comprehensive dementia assessment should be performed by various professionals including GPs, neuropsychologists, and allied health professionals such as SPs. People with cognitive difficulties are typically referred from GPs or community services or may be self-referred. Given the expected increase of dementia cases in the future, the role of these memory clinics is crucial in order to ensure further access to early assessment, treatments, education, and care plans (Mehrani & Sachdev, 2022). As a result of the assessment process, the person's stage of dementia is identified, which allows clinicians, the PWD, and their families to consider the type of care and intervention required and to plan for the future (Lima-Silva et al., 2021).

1.5 Pharmacological Intervention

Since the late 1980s, pharmacological treatments for dementia have been established and continuously developed (Fleming & Evans, 1995; Sloane, 1998). Currently, four different types of drugs are available to treat symptoms of dementia: donepezil, rivastigmine, galantamine, and memantine (Gan et al., 2021; Nguyen et al., 2021). These drugs attempt to either prevent synaptic breakdown or provide improved communication between nerve cells (Rodda & Carter,

2012) with the aim of improving or slowing down progression of deterioration in cognitive abilities. Unfortunately, existing drug treatments do not prevent progression of the disease or reverse brain damage (Cummings et al., 2017). Additional drugs may be prescribed for PWD to address responsive behavioural symptoms of dementia and may include antidepressants, antipsychotics, mood stabiliser, stimulants, sedative-hypnotics, or melatonin (Fink et al., 2020; Madhusoodanan & Ting, 2014; Ooms & Ju, 2016).

To date, the effectiveness of pharmacological treatment options is inconsistent because dementia types and symptoms vary for each individual (Wong, 2016). Additionally, medical management of dementia may not directly improve or change the symptoms of dementia. Therefore, non-pharmacological approaches are also recommended by experts as a preferred intervention option to reduce responsive behavioural symptoms (Austrom et al., 2018; Kales et al., 2014).

1.6 Non-Pharmacological Intervention

Non-pharmacological interventions for PWD include face-to-face therapies using cognitive and behavioural strategies to minimise symptoms and assist with maintenance of function and independence (S. Douglas et al., 2004). These strategies facilitate principles of conditioning and learning that aim to reduce or eliminate challenging behaviours, for example, through reality orientation strategies or reminiscing about past events and experiences (S. Douglas et al., 2004). Alternative therapies, such as aromatherapy, art therapy, or light therapy, are also categorised as non-pharmacological interventions. These alternative interventions can be implemented by family members and carers in home-based environments or residential care settings to calm distressed patients (Scales et al., 2018). According to Zucchella and colleagues (2018), non-pharmacological treatment options include cognitive intervention; occupational, psychological therapy; complementary and alternative medicine, including aromatherapy, music therapy, or art therapy; and training in the use of different technological devices, such as information or communication devices. They all aim to address physical and mental health and wellbeing, as well as environmental aspects which may contribute to distress in PWD (e.g., lighting and noise). Regarding support of mental wellbeing, psychotherapy can help PWD to adjust to responsive behavioural symptoms of dementia (Cheston & Ivanecka, 2017; Cheston et al., 2003; Junaid & Hegde, 2007; Tibble et al., 2017). Complementary or alternative therapies in dementia care include many different therapeutic strategies and may also include sensory

stimulation of PWD by using aromatic oils (Ball et al., 2020), adjusted light schemes (Hanford & Figueiro, 2013), or music stimulation (Martinec & Lera, 2018).

In terms of functionality, occupational therapists can support PWD to complete daily tasks such as cooking or getting dressed. Occupational therapy may improve functioning of PWD in daily tasks, which reduces the burden on the caregiver (Graff et al., 2006). Central to the discipline of occupational therapy is also the provision of cognitive therapy, which overlaps with speech pathology in the domains of cognitive-communication disorders (Meyer et al., 2021). This is further described in Chapter 2.

As experts in movement and function, physiotherapists support PWD to maintain and improve movement and muscle strength, mobility in bed, balance in sitting or standing, and gait activities (Pomeroy et al., 1999). Physical exercise can help PWD to keep overall physical function (Lam et al., 2018) and may also improve daily life and independent functioning (Pitkälä et al., 2013).

According to Bessey and Walaszek (2019), non-pharmacological interventions should be individualised and implemented even before pharmacological treatment options are considered. Overall, non-pharmacological treatment options address the complexity and variety of symptoms by providing holistic and individualised support to PWD.

1.7 Person-Centred Management of Dementia

The causes, symptoms, and progression of dementia are highly individual and variable; therefore, a person-centred approach is crucial to manage the complexity of the disease and to promote the personhood and wellbeing of PWD. The person-centred theory was initially described by Carl Rogers in the field of psychotherapy (Rogers, 1951, as cited in Hobson, 2019). In 1992, Kitwood and Bredin conveyed the concept of social-psychological theory in the area of dementia care. Person-centred care in dementia aims to support individual needs and preferences to maintain quality of life for as long as possible for PWD and their families (Bellchambers & Penning, 2007; Hunter et al., 2016; Sanderson, 2003). Principles of good dementia care include positive person work, which include 1) Recognition, 2) Negotiation, 3) Collaboration, 4) Play and appropriate Activity, 5) Giving, 6) Stimulation to stimulate the senses, 7) Celebration, 8) Relaxation, 9) Validation, 10) Holding, 11) Creation and 12) Facilitation (Kitwood, 1997). Such principles provide a form of interaction on different levels and enable a person to express themselves. All principles consider major elements, such as “a value of human lives, regardless

of age or cognitive ability; an individualised approach, recognising uniqueness of the person living with dementia; positive Social psychology in which the person living with dementia can experience relative well-being” (Røsvik et al., 2013, p. 156). Clinicians working with PWD have the responsibility to implement such principles to create a trustful basis as part of any intervention and to promote quality of life. In recent decades, a considerable amount of research literature has emerged to define quality of life for those diagnosed with dementia (Bowling et al., 2015; Howard & Rockwood, 1995; Hurt et al., 2008; Hvidsten et al., 2018; Kisvetrová et al., 2021; Korczyn & Davidson, 1999; Moyle et al., 2011; Ready & Ott, 2003; Selai & Trimble, 1999). In summary, available literature regarding quality of life strongly suggests that the individual level of living well and comfort should be prioritised. A major aspect of ensuring wellbeing and keeping individual personhood in care of PWD is person-centred communication. Rather than focusing on difficulties and impairment, person-centred communication focuses on individual strengths and resources to support PWD and help them to retain communication (Downs & Collins, 2015). “The linguistic elements of person-centred dementia communication are defined as language-based strategies that promote communication goals of reciprocity, clarity/coherence and continuity when communicating with individuals with dementia” (Rourke et al., 2022, p.1598). Such elements play a central role when delivering person-centred care to promote quality of life.

Given that quality of life is a subjective feeling and based on personal perception, several instruments have been developed to assess quality of life in dementia. These include the Dementia Quality of Life instrument (DQoL; Brod et al., 1999), the Dementia Quality of Life measurement (DEMQOL; S. Smith et al., 2005), and the Quality of Life in Dementia scale (QUALID; Weiner et al., 2000). The DQoL and DEMQOL are instruments that directly assess a patient’s perceived quality of life. There is also a DEMQOL-Proxy instrument, wherein questions are reported by a carer (Mulhern et al., 2013). The QUALID is targeted at caregivers for rating quality of life in people with late-stage dementing illness.

Despite some discrepancies and debates in defining specific key criteria and domains of quality of life in PWD, research has considered the importance of physical, mental, and social wellbeing in PWD, as well as the inclusion of extensive support networks, whether on a community level or through involved social and allied healthcare providers. Through the abovementioned quality of life instruments, positive and negative aspects can be assessed in order to improve and adapt person-centred care. However, these instruments assess the individual dynamics of health, environmental, and personal factors only to a certain degree as

questions vary considerably in depth. Hence, a more comprehensive framework is needed to capture all components of health, environmental, and personal factors.

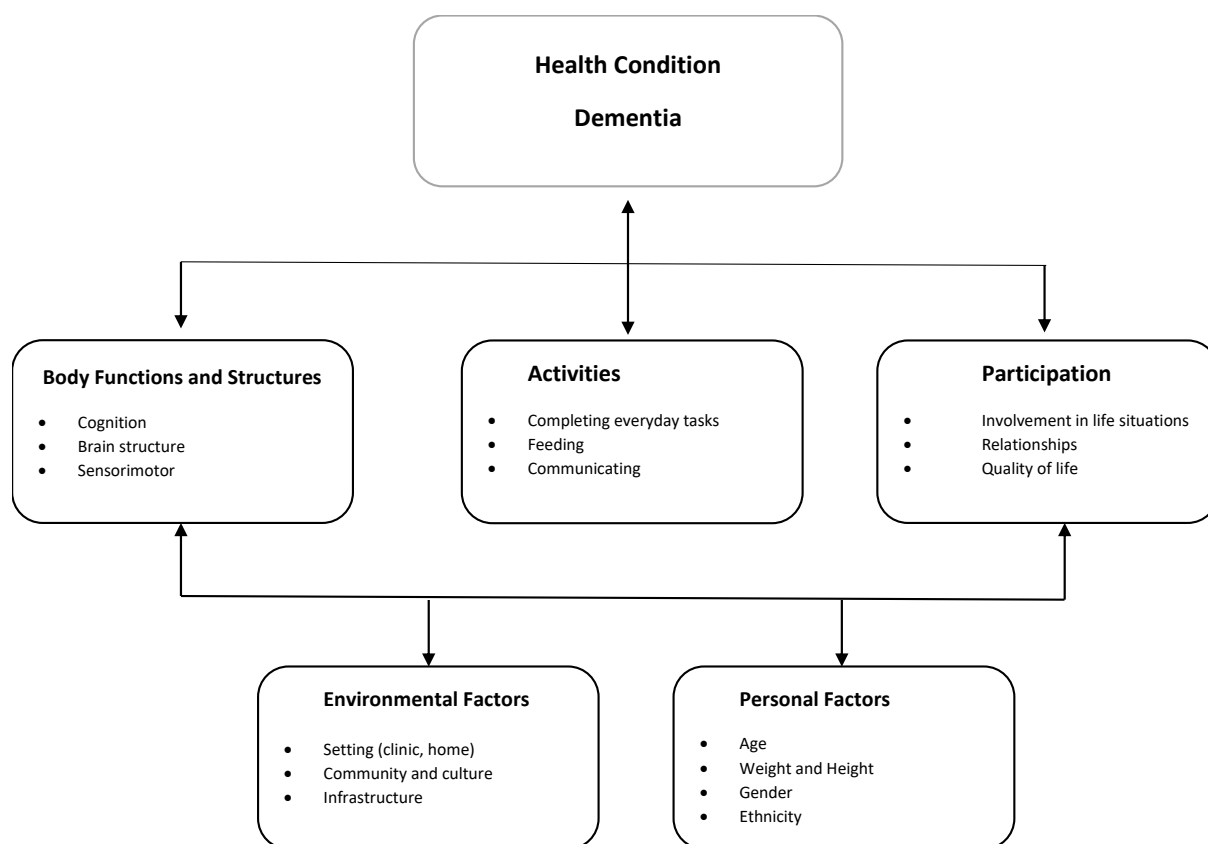
1.8 International Classification of Functioning, Disability and Health, and Dementia

In May 2001, the WHO endorsed an international standard to describe and measure health and disability, called the International Classification of Functioning, Disability and Health (ICF; WHO, n.d.). The ICF provides a framework for conceptualisation, measurement, and classification of functioning for health conditions (Haglund & Henriksson, 2003; Heerkens et al., 2006; Howe, 2008; Kearney & Pryor, 2004; Schwab & Zeleznik, 2020; Threats, 2010). The ICF is based on a psychosocial model that considers the body, its structure and function, activity and participation, and contextual factors of a person. The relationship and interaction of the domains within the model aim to describe the impact of disease on an individual. The first domain includes the components of functioning and disability, and the second domain considers contextual factors; together, the domains aim to measure functioning of an individual in a society, despite any diagnose and impairment. The ICF views the level of functioning of an individual as an interaction between health factors, environmental factors, and personal factors. The contextual factors include external and internal factors. External factors include social attitudes and structures, architectural circumstances, legal and social structures, as well as environment and climate; internal factors consist of gender, age, coping management, and social support (WHO, n.d.).

The framework has been applied to the management of dementia in order to facilitate and maximise person-centred care in all stages of the disease (Badarunisa et al., 2015; Byrne & Orange, 2005; Hopper, 2007; Muo et al., 2005; Murphy & Boa, 2012; Park et al., 2020; Scherer et al., 2012). The ICF framework can be used as a tool to define and profile overall health status in PWD, and related aspects of activity and participation (Badarunisa et al., 2015; Muo et al., 2005). This helps to identify social and individualised needs for an improved standard of care (Park et al., 2020). Due to its multifactorial considerations, the ICF framework supports SPs in their decision-making to redefine the level of improvements for rehabilitation (Hopper, 2007). Furthermore, the ICF framework can be used to engage clients actively and empower and involve them in decision-making (Murphy & Boa, 2012; Scherer et al., 2012). Besides its focus on the PWD, the ICF framework is a helpful tool for planning and implementing training programs around communication for families and carers of PWD (Byrne & Orange, 2005). Figure 1.1 demonstrates how dementia as a health condition affects levels of function.

Figure 1.1

Dementia in the ICF Framework



Note. ICF = International Classification of Functioning, Disability and Health (WHO, n.d.).

1.8.1 Functioning and Disability in Dementia

In functioning and disability, two components are considered: body functions and structures, and activities and participation (WHO, n.d.). As described above, dementia is characterised by a decline in memory and cognitive domains caused by underlying diseases and symptoms. The diseases and symptoms impair functional abilities in PWD. As a consequence, the capacity of PWD to engage in social, leisure, occupational, and daily activities is affected to different extents for each individual. Both components – body functions and structures, and activities and participation – are interrelated and influence the wellbeing of PWD (Chung, 2004).

1.8.2 Contextual Factors in Dementia

Contextual factors in the ICF model include environmental factors and personal factors. The physical, social, and attitudinal environment has a significant effect on PWD and influences functioning and disability (Hopper, 2007). The influence of physical environment on wellbeing

and performance of PWD has been well documented. According to Chaudhury and Cooke (2014), decreased physical and cognitive abilities in PWD make them more sensitive to environmental factors, such as design and room interior. Further, the social environment has an impact on PWD, as support, interaction, communication, and engagement from and with family and carers influence activity and participation considerably (Teitelman et al., 2010). Attitudinal characteristics of the environment include potential stigma for PWD, including lack of inclusion, respectful language, and lack of dementia-friendly resources (Swaffer, 2014). All these environmental factors influence PWD on a personal level. Personal factors are the second type of contextual factors in the ICF framework. These factors are individual attributes that are independent of the PWD's disease and symptoms and include among other factors age, gender, life history, beliefs, experiences, and habits (Threats, 2007), which influence the management of dementia and person-centred dementia care planning (Hunter et al., 2016; van der Steen et al., 2014).

1.8.3 ICF Components in Person-Centred Dementia Care

To consider functioning, disability, and contextual factors in terms of dementia, a holistic approach consisting of collaborative care to address long-term management of disease is required (Dreier-Wolfgramm et al., 2017). Such collaboration can be provided by a multidisciplinary network wherein team members vary and come from various allied health, medical, and social professions and services (Grand et al., 2011) and provide high-quality dementia care (Cartwright et al., 2015). Professions include, but are not limited to, GPs, nurses, occupational and physical therapists, and SPs (Galvin et al., 2014). Collaborating enables professionals to work efficiently together with PWD on the development of shared goals, as well as providing improved coordination of care as part of non-pharmacological treatment options (Richters et al., 2018). SPs add their professional expertise to multidisciplinary treatment plans, addressing cognitive communication, feeding, and swallowing as part of a holistic and person-centred approach.

1.9 Summary and Conclusion

Dementia is an umbrella term for a variety of underlying diseases and syndromes that lead to a progressive decline in cognitive functions and impact an individual's ability to perform daily and independent activities. This chapter has provided an overview of the different types of dementia caused by various syndromes and diseases. Common dementia types include

Alzheimer's disease, vascular dementia, Lewy body dementias, and frontotemporal dementias. In recent decades, early diagnosis of dementia has been of interest in research, as diagnosing MCI early on and preventing the onset of irreversible dementia is still a priority. Dementia is a complex disease that requires multidisciplinary assessment and intervention. Current pharmacological treatments for dementia may help to improve symptoms; however, non-pharmacological treatments provide a more individualised and person-centred solution for PWD, their carers, and their families. Given that symptoms and progression of dementia are highly individual, a person-centred approach is necessary to consider individual needs and preferences for quality of life for as long as possible. By considering domains from the ICF framework, the strengths and needs of PWD can be identified to provide and adapt adequate treatment. Treatment options include speech pathology, cognitive intervention, occupational and psychological therapy, and may also include complementary and alternative medicine. They all aim to address physical and mental health, as well as individual wellbeing as a key criteria of quality of life in PWD. Hence, not only do body structure and functioning matter, but also contextual factors such as environmental and personal factors need to be considered as proposed and conceptualised in the ICF framework.

In Chapter 2, the SP's role in working with PWD and their families and carers will be explained by discussing aspects and principles of evidence-based practice.

Chapter 2: Speech Pathologists' Role in Working With People With Dementia

Speech pathologists (SPs) are autonomous allied health professionals who have comprehensive expertise in communication and swallowing, and communication and swallowing needs, across an individual's lifespan (Speech Pathology Australia [SPA], 2022). SPs assess, diagnose, and intervene through using prevention strategies and treatments for people with communication and swallowing difficulties and disorders. It is the SP's role to facilitate individual goals regarding communication and swallowing, to minimise any impacts and occurrence of communication and swallowing difficulties, and to enhance participation in individuals (SPA, 2022). This means that SPs are required to provide care that is ethical in light of evidence-based practice to support the individual abilities of PWD to their highest level during the course of dementia. This chapter discusses how SPs work with PWD and their families and carers following principles of evidence-based practice.

2.1 Evidence-Based Practice

SPs have a responsibility to deliver the highest standard of services to ensure that a client gets the greatest benefit of any speech pathology services (SPA, 2021). Consequently, SPs need to integrate the best existing evidence from research and other sources into their clinical practice. Such evidence-based practice aims for a combination of (a) clinical knowledge/expert opinion, (b) scientific evidence, and (c) client and caregiver values to ensure that SP services benefit an individual's needs and beliefs (American Speech-Language-Hearing Association [ASHA], n.d.-b).

As part of clinical decision-making, SPs consider and research external scientific evidence, including quantitative and qualitative data, by using frameworks for their selection of evidence and evaluation and rating systems for studies or forms of evidence (SPA, 2021). SPs' experiences and personal preferences may influence the implementation of evidence-based practice (Roddam & Skeat, 2010). Their expertise is crucial to determine whether external evidence is appropriate for clients, and how that evidence should be used (SPA, 2021). A further integral aspect of evidence-based practice is client preferences: understanding individual goals, principles, perceptions, desires, and concerns of clients, their families, and their caregivers. These preferences inform approaches to intervention to consider meaningful outcomes for clients (SPA, 2021). In terms of dementia, SPs need to use evidence-based

practice to consider the individual and unique needs of their clients, integrating family members and caregivers in their practice, as well as identifying and evaluating evidence from studies. The evidence base for SP interventions in the management of dementia is increasing, and considers expert opinions, scientific evidence and client/caregiver values. Previous studies have investigated evidence-based practice in dementia in Australia and the UK, including their area of practice and referral patterns to SP services (i.e. how they were referred, by whom, and for what reasons) (Hopper et al., 2007; Volkmer et al., 2019; 2020). Looking at the Australian context, Taylor and colleagues (2009) explored the emerging service provision for frontotemporal dementias, specifically primary progressive aphasia, in the state New South Wales in Australia. Results from their survey showed that back then only a small number of clients with frontotemporal dementia were referred to SP and respondents indicated the need for further information for clinicians in order to provide appropriate support clients and their carers (Taylor et al., 2009).

Additionally, clients and caregiver values as an evidence-based level in the area of dementia keeps undefined and it is unclear, if and how people with dementia are seeking SP services.

2.2 Application of ICF Principles in SP

As discussed in Section 1.8, the ICF framework allows for a holistic view of a person and has been implemented in SP practice. In Australia, it is embedded in the *Professional Standards for Speech Pathologists in Australia* (SPA, 2020b). Internationally, SP bodies include the ICF as a continuing standard of practice and outcome measurements (ASHA, 2016; Royal College of Speech and Language Therapists [RCSLT], 2014b; Speech-Language & Audiology Canada [SAC], 2010). Considering the SPA Code of Ethics (SPA, 2020a), SPs support individuals to maximise their communication and swallowing functions with the aim of improving their quality of life. This is considered with an “awareness of the broader context of human rights of the individual” (SPA, 2020a, para. 3), such as identified in the WHO ICF framework (WHO, n.d.). To date, the framework is guiding SP practices and is used by sub-specialities (Washington, 2007) such as aphasia (Simmons-Mackie & Kagan, 2007; Wallace et al., 2017; Worrall et al., 2011), dysarthria (Dykstra et al., 2007), traumatic brain injury (Hughes & Orange, 2007; Larkins, 2007), and dementia (Badarunisa et al., 2015; Byrne & Orange, 2005; Hopper, 2007). The use of the ICF as a framework in SP allows for improved decision support, determining care pathways, harmonisation of care, education, and constant quality improvement (Palmetto, n.d., as cited in

Cornett, 2010). Consequently, SPs need not only to address body structures and functions which may affect communication and swallowing and feeding, but also to contemplate contextual factors holistically in their services (Howe, 2008).

SPs provide rehabilitation through interventions that are “designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment” (WHO, 2021, What is rehabilitation? section, para. 1). Whereas traditionally the term rehabilitation emphasised re-ablement or restoring function (Cations et al., 2017), in the context of a progressive disease, rehabilitation focuses on empowerment of individuals to operate maximally within the setting of their individual capacity and current wellbeing state (Clare, 2017). More precisely, considering dementia, Wynn and Khayum (2015) conceptualised the term “habilitation”. Habilitation does not focus on restoring any function but rather on individual strengths and personal interests that are considered when implementing compensatory strategies, memory aids, environmental modifications, and training of family members and caregivers. This is implemented by SPs by developing treatment plans with a focus on (a) cognitive-communication and associated language difficulties, and (b) swallowing and feeding difficulties, while considering mutual goals from the multiple perspectives of the PWD and their families, and members of the care team (Idol et al., 1994). For example, practising holding cutlery and applying swallowing cues at mealtimes combines perspectives from occupational therapists and SPs. Furthermore, in applying tailored multicomponent interventions that consider individual strengths and interests of PWD, function and participation in desired life activities is maximised (Khayum & Rogalski, 2018).

There are two main intervention types for individuals with dementia: direct and indirect (Clark, 1995). SPs apply direct interventions for the following reasons: to preserve communication abilities and muscle strength for swallowing, to prevent deterioration, to equip PWD with skills for the use of swallowing manoeuvres and communication and memory aids, and to maintain daily participation (Duncan et al., 2019; Hopper et al., 2015; Medical Advisory Secretariat, 2008). Indirect interventions provide strategies to modify and improve an individual’s environment and can include education of family members and caregivers, counselling, and support by providing or facilitating adequate resources (Hopper, 2001; Mendez & Cummings, 2003). In most cases, a combination of direct and indirect interventions provides the highest level of effective support for the individual with dementia (Egan et al., 2010) and there is no one-size-fits-all approach for the various dementia types.

2.3 Cognitive-Communication Disorders Associated With Dementia

Dementia affects cognition and associated language or communication difficulties can occur even in the early stages of the disease (Amieva et al., 2005; Banovic et al., 2018; Kong et al., 2019; McCullough et al., 2019; Robinson et al., 2015). Given that the language system cannot be separated from the whole cognitive system, deficits in cognitive processing associated with dementia lead to difficulties in processing language and affect comprehension, discourse and written language (reading and writing). These types of language difficulties are classified as cognitive-communication disorders and impact participation and activities of PWD. SPs manage cognitive-communication disorders through prevention, helping to slow down progression, improving symptoms through intervention, and promoting activity and participation to increase wellbeing and quality of life (Bayles & Tomoeda, 2013; McCullough et al., 2019). In the literature, different terms are used to address cognitive treatments, such as cognitive stimulation, cognitive rehabilitation, or cognitive training. These different terms do not convey important differences of various existing concepts and applications of treatment options. According to Clare and Woods (2004), general strategies can be used to enhance cognitive and social functioning, including engaging the PWD in group activities and discussions. In contrast, cognitive training usually involves guided tasks that consider memory, attention, language, or executive function. The term cognitive rehabilitation is more extensive, as it acknowledges that dementia involves “changes and needs at the biological, psychological and social levels” (Clare & Woods, 2004, p. 393).

Cognitive therapy can improve brain function by stimulating neuroplasticity (Caeyenberghs et al., 2018; Juárez-Cedillo et al., 2020; Kleim & Jones, 2008; Spector et al., 2003). SP intervention provided at stages of dementia may halt or delay the progression of the disease through facilitating neuroplasticity (Bayles & Tomoeda, 2013; McCullough et al., 2019). By applying different intervention strategies, SPs may also enhance wellbeing of individuals with dementia and their carers through improved communication (Swan et al., 2018). Given the progression of dementia, the role of SPs is to facilitate maintenance of functioning and support participation and engagement by emphasising personal relevance (Hickey & Bourgeois, 2009). In order to do so, SPs may use a range of external aids, which include memory wallets and books (Bourgeois, 1990, 1992, 1993), planners, calendars and schedules, written reminders, memo boards, notepads, sticky notes, or a designated place for an object (Lanzi & Bourgeois, 2020; Lanzi et al., 2017). Such external aids are implemented as compensatory communication tools to adapt the environment of PWD to ensure person-centred care (Lanzi et al., 2017). Furthermore,

assistive devices such as “high-tech computer-based and speech-generating devices” can be implemented to support PWD with communication difficulties (Bourgeois et al., 2010, p. 8). Such devices provide different stimuli for communication when interacting and socialising with people in their environment and their families and carers.

2.3.1 Direct Cognitive-Communication Intervention Strategies

As part of direct intervention strategies to address cognitive communication, typically linguistic stimulation techniques are used and can include spoken, graphic, and written cues or computers (Beales et al., 2016; Bourgeois et al., 2015; Egan et al., 2010; Mahendra, 2001; Payne, 2014). Direct interventions can be categorised as either impairment-based or functional approaches. In impairment-based approaches, SPs offer tailored strategies that are based on the individual language and cognitive deficit profile of PWD (Des Roches et al., 2015). A functional approach focuses on individual strengths of the PWD, and strategies aim to improve daily-life performance and quality of life (Warchol, 2006). Studies have investigated evidence of the effectiveness of both these approaches; however, evidence levels strongly vary, and efficacy for severity of disease, which could impact on effectiveness, is limited. A critique of the evidence is provided below.

Impairment-Based Approaches: Learning Activities and Methods

Spaced retrieval training is a learning activity in which the clinician asks stimulus questions and aims to support PWD to recall information over longer time (Bird & Kinsella, 1996; Camp et al., 1996; McKittrick & Camp, 1993). These questions can include information (e.g., date of birth) or just a daily strategy (e.g., looking up a schedule). The intervals between each question and response are systematically lengthened during the training (Bjork, 1988; Karpicke & Bauernschmidt, 2011; Landauer & Bjork, 1978; Storm et al., 2010). The initial case studies on the effectiveness of spaced retrieval training were conducted by Abrahams and Camp (1993), and the first study included a 77-year-old woman. The second study included two women aged 76 and 82 with dementia (McKittrick & Camp, 1993). These case studies found that participants successfully learned to name objects in their environment with the training and maintained treatment gains when followed up two weeks later. The outcomes of spaced retrieval training in these case studies were positive and meaningful for the individuals’ daily living and highlighted the benefits of direct SP intervention (Brush & Camp, 1998). Since the initial reports by Camp and colleagues, further research on the effectiveness of spaced retrieval has been conducted. Hopper and colleagues (2005) conducted a systematic review, summarising thirteen articles about

spaced retrieval training. All reviewed studies, which were descriptive studies, were classified with an evidence level of either II² or III³ descriptive studies and indicated that spaced retrieval training improves learning and retention of trained information and skills (Hopper et al., 2005). The positive impact of spaced retrieval training has also been demonstrated in other relevant daily situations, such as eating and drinking. Lin and colleagues (2010), as well as Benigas and Bourgeois (2016), demonstrated that spaced retrieval training as direct intervention is supportive for PWD during mealtime intake, wherein different compensatory swallowing and eating behaviours (e.g., change of posture, such as chin tuck) were facilitated through verbal assistance.

Another learning strategy used in SP is the errorless learning approach. The focus of this approach is to prevent participants from making errors while learning (new) important information. A target response is always presented by the therapist to support the patient with an appropriate stimulus (E. Middleton & Schwartz, 2012) and, for example, includes the answer of an anniversary or a specific time for medication to remember. This approach was initially implemented for people with disabilities, amnesia, and brain injuries (C. Cullen, 1976; B. Wilson et al., 1994) and has also been discussed as an effective treatment for acquired communication disorders such as aphasia (Conroy et al., 2009; Fillingham et al., 2003; Lambon Ralph & Fillingham, 2007; Patra et al., 2022; Thiel & Conroy, 2014).

Errorless learning intervention was trialled with an individual with dementia, who demonstrated positive results in recall and retention of information (Clare et al., 1999). As a result, further multiple single case studies were conducted, where six participants were included with early-stage dementia (Clare et al., 2000). In this study initial neuropsychological assessment and a 6-month follow up was conducted and each participant received tailored intervention, using a multiple baseline or applied behaviour analysis single case design. The results indicated that participants improved in daily memory tasks, and some of them retained information (recalling names) over intervals of a week between the sessions.

The vanishing cue method is another treatment approach used with people with brain injuries and memory impairment (Abel et al., 2005; Leng et al., 1991; Nettleton & Lesser, 1991). This approach uses graphic and written information to stimulate language. Initially, the first letter of words is provided as a cue for the information. Then, these word fragments are systematically removed until the individual can retrieve the information in the absence of cues (Glisky, 2011). According to Mimura and Komatsu (2010), the vanishing cue method helps to

² Level of evidence II = evidence from a randomised controlled trial.

³ Level of evidence III = evidence from controlled trials without randomisation.

facilitate recall precision for name associations. However, other reports suggest the effects of the vanishing cue method are not significant enough, and presentation of the cues may lead to more inaccurate responses and require numerous learning trials (Kessels & de Haan, 2003). Haslam and colleagues (2010) investigated whether the vanishing cue method by itself or in combination with errorless learning is more effective when used with healthy individuals. In the study, the adequacy of errorless learning and the vanishing cues were combined in order to figure out which strategy facilitated the best memory performance. Participants (with Alzheimer's disease: $n = 22$; healthy control: $n = 60$) had to solve single and double tasks; for double tasks they were required to split their attention simultaneously. Participants made significantly fewer errors when combining both strategies, and these results indicated that a combination of both methods is significantly better than vanishing cues in isolation.

Especially for patients with PPA, implementation of impairment-based approaches show promising results. As discussed by Pagnoni and colleagues (2021), impairment-based approaches as language treatments improve oral and written naming in PPA patient. Therapeutic models consider a person-centred approach, ideally, they use individual pictures of items, and focus on remediation and rehabilitation, especially in the earlier stages of PPA (Volkmer et al., 2020). Such models include word retrieval interventions (Jokel et al., 2014; Savage et al., 2012), which use repetitions, prompts and instructions by clinicians (Henry et al., 2019).

Functional-Based Approach: Stimulation, Activation, and Environment

Multisensory stimulation works by using various tools and materials (e.g., sounds, different textures, visuals) to stimulate one or more senses and to provoke a (verbal) reaction. This, for example, could include a photo of lavender and lavender aroma oil in order to create a base for further interaction. According to Baker and colleagues (2001), the activation of senses such as smell, taste, hearing, vision, and touch boosts awareness and attention. As part of a randomised controlled trial with 50 patients with moderate to severe dementia, Baker and colleagues (2001) demonstrated that multisensory stimulation had a positive effect on communication skills as participants were more engaged and communicated spontaneously, and lengths or utterances increased. While this method has not demonstrated any long-term effects, it can be a useful source of positive stimulation to support PWD during the day (Baker et al., 2003).

A frequently used multisensory tool is a “memory wallet”, which includes pictures of sentences relating to personal belongings, familiar places, or family members to support an individual with dementia (Lanzi et al., 2018). Bourgeois and colleagues demonstrated that people with severe dementia can effectively use external memory aids to improve the quality of conversations with family members or carers (Bourgeois & Mason, 1996; Burgio et al., 2001). The aids were used by PWD to help them remember personal topics, as well as by carers to start conversations with PWD. Such aids may include photos about family and friends, familiar places, and important events. As these aids can be implemented in different settings, they provide individual and personal stimulation to PWD in their environment.

Another approach that involves multisensory stimulation is reminiscence therapy. Reminiscence therapy is a popular intervention strategy used for PWD and is based on recall and discussion with another person about past events, activities, and personal experiences, using different supporting materials (Cotelli et al., 2012). Typically, the therapy focuses on evoking memories, stimulating mental activity, and improving comfort by using videos, photos, or other objects. Reminiscence therapy can be delivered in person, or photos and videos can be presented on technological devices. Even though this therapy method shows promising results and improved communication skills in individuals, comparison of results is difficult as therapy sessions are tailored to individual needs and not standardised (E. Kim et al., 2006; O’Philbin et al., 2018).

The Montessori Method uses functional activities or routines to create a supportive environment by focusing on individual interest. The Montessori Method includes several steps: (a) identifying an activity of interest that meets remaining skills, (b) making use of familiar (real life) materials and objects, (c) arrangement of materials and objects, (d) demonstrating the activity, (e) breaking down the activity into manageable parts, and (f) encouraging the individual to self-correct and complete the activities themselves (Malone & Camp, 2007; Orsulic-Jeras et al., 2001). The implementation of Montessori-based activities has shown improvements in levels of engagement, cognitive performance, and social interaction (N. Douglas et al., 2018; Mahendra et al., 2006). SPs can implement the Montessori Method by presenting language as brief verbal or written cues or instructions, but also to prompt questions and verbal utterances by PWD. Chosen activities and materials are based on individual and meaningful activities and roles, considering individual communication capabilities, personalised cues, support frameworks, and environmental supports (Cartwright & Oliver, 2015).

2.3.2 Indirect Cognitive-Communication Intervention Strategies

Indirect interventions are delivered by training and counselling of family members and caregivers of PWD by promoting linguistic modifications (Bayles et al., 2020). It is known that family members frequently experience the care for a relative with dementia as an extremely stressful burden (Connell et al., 2001; Rabins et al., 1982). Consequently, a variety of programs have been developed for family caregivers. The aim is to reduce caregiving stress levels, improve health and wellbeing of caregivers, and enable at-home care for PWD for longer periods. The programs range from peer support groups to counselling and skill training. According to Beales and colleagues (2019), support programs in a group setting are the most frequently implemented indirect strategy, as they can provide education and training to support families with communication. SPs provide information about linguistic modifications to help PWD, family members, and carers to improve aspects of communication to promote wellbeing and safety for the individual with dementia (Burgio et al., 2001; Smith-Conway et al., 2012). Comprehension and attention in PWD can be increased by their communication partners reducing speech rate, using simple vocabulary and short sentences, increasing use of facial expressions and appropriate gestures, and using clear and direct speech (Jootun & McGhee, 2011). Savundranayagam and colleagues (2007) examined communication-enhancing strategies for PWD. The study included scripted staff–resident communications with different complexity levels for two dining situations with 71 long-term-care staff participants. Afterwards, conversation competency and perceptions of the residents were compared and rated. The results indicated that simplified and personal language, including clause simplification and repetition, enhanced conversations with PWD (Savundranayagam et al., 2007). Several other studies indicated how important caregiver and staff training is to communicate effectively and enhance communication skills (Bourgeois et al., 2004; Burgio et al., 2001; Haberstroh et al., 2009).

Communication Partner Training

Eggenberger and colleagues (2013) supported the importance of communication training as it has a positive impact on quality of life and wellbeing of an individual with dementia. Published communication booklets and guides, such as the “Let’s talk” guide from Dementia Australia (2018b), aim to support carers of PWD. However, Done and Thomas (2001) noted that people who attend communication training workshops gained much more knowledge about communication compared to those who only accessed information from a booklet. This was

measured pre-intervention (before workshops and booklets were implemented) and six weeks after intervention through a developed assessment (Assessment of Awareness About Communication Strategies). Other multimedia delivered programs (e.g., “MESSAGE”; Broughton et al., 2011) showed promising training results as carers of PWD gained knowledge about communication and difficult communication situations, and confidence to provide care (Conway & Chenery, 2016).

Environmental Modification

Environmental modification is another indirect strategy and helps to improve communication by creating a safe, person-centred environment (Manasco, 2016). The environment can be modified according to an individual’s needs (e.g., colour and visual perception and hearing abilities) to highlight helpful stimuli, reduce distractions, and improve functioning. This may include the use of written signs, labels, and table settings (Gitlin & Corcoran, 1996; van Hoof et al., 2010). Furthermore, Brush and colleagues (2002) stated that environmental modifications, such as table settings, improve meal intake in PWD, as any distractions are minimised. Although such environmental modifications are person centred and therefore have an impact on behaviour rather than cognitive processes, they can improve quality of life of an individual with dementia (Cooper et al., 2012; Schwarz et al., 2004).

Assistive Technologies

Assistive technologies may help PWD to maintain independence as well as support SPs, carers, and families when communicating with PWD. To date, many computerised and technology-supported systems have been specifically developed to support PWD to communicate on a daily basis and to make therapy accessible (Alm et al., 2007; Carós et al., 2020; Lazar et al., 2014). The range of assistive technologies can be categorised into those used to (a) promote safety, (b) improve communication, (c) provide multisensory stimulation, and (d) enhance memory (Cahill et al., 2007). In the literature, the usefulness of technologies for PWD is still debated, as they might not be appropriate due to a potential digital divide, the individual technological literacy of the elderly, and sociocultural aspects (Vollmer Dahlke & Ory, 2020). Other studies showed that technologies were well accepted and perceived as helpful by PWD and carers (Guzman-Parra et al., 2020; Holthe et al., 2018). Devices and technologies can be used as positive stimuli and can be adapted as reminders on a daily basis; in addition, such devices or technologies lead to a better result when a PWD is already familiar with them, for example, phone/smartphones, tablets, smart watches, clocks, and calendars (Bayles et al.,

2020). Furthermore, Astell and colleagues (2010) suggested that a touch-screen system with prompts enhances communication and relationships between caregivers and PWD. According to Lorenz and colleagues (2019), assistive technologies should support PWD to maintain skills and compensate for lost abilities. Compared to other fields of dementia research, current studies focusing on assistive technologies are difficult to compare as they use a variety of technologies and designs, including low-tech or higher-tech devices (Topo, 2008).

2.3.3 Summary of the Evidence for Cognitive-Communication Intervention

The literature critiqued above may be relevant to any type of dementia, depending on the individuals' specific symptoms and their personal and environmental factors. These factors impact on the presentation of cognitive-communication abilities differently. However, the evidence base of each approach applied to different dementia types is still limited. As stated by Swan and colleagues (2018), there is evidence that especially direct intervention strategies for people with moderate–severe dementia may improve or maintain communication function and are beneficial for quality of life of those living with dementia. Considering the progression of dementia with potential deterioration of symptoms and an increase in dependence, interventions offered need to suit the individual and their circumstances. Thus, direct intervention, including both impairment-based and functional approaches, better addresses the needs of PWD in the early stages. Nevertheless, intervention should always prioritise quality of life as part of a person-centred approach, as there seems no strategic framework or procedure for considering a specific approach. Moreover, it appears that the previously described complexity and modalities of dementia types make a standardised methodological approach even harder, and SPs need to be flexible by potentially combining or switching their approaches.

2.4 Feeding and Swallowing Difficulties Associated With Dementia

In addition to managing communication disorders, SPs also have a role in ensuring PWD can swallow fluids and solid foods safely to maintain nutrition. Neurophysiology of feeding and swallowing is a complex phenomenon involving relation between sensory and motor actions before food enters the oral cavity to complete the swallow (Humbert et al., 2009). According to Matsuo and Palmer (2008), more than 30 nerves and muscles are involved in volitional and reflexive activities to manage food passage from the oral cavity to the stomach while protecting the airway from any food or liquids.

The normal swallowing process is described in four stages: oral preparatory stage, oral stage, pharyngeal stage, and oesophageal stage. In the oral preparatory stage, a feeding utensil (e.g., fork or spoon), fingers, cup, or straw is used to place food into the mouth, which is then chewed before swallowing; this does require taking food from a plate and transferring it to the mouth using hand-to-mouth motions (Matsuo & Palmer, 2008). Following the preparatory stage, the bolus is moved voluntarily from oral cavity into the oropharynx. In the pharyngeal stage, the bolus moves from the oropharynx into the oesophagus, then it moves through the oesophagus and into the stomach as part of the oesophageal stage. The phases of the swallowing process are controlled by message from brain stem, peripheral reflexes, and sensory feedback via the pharynx and oesophagus (Lang, 2009).

Dementia is defined by neuroanatomical changes in different areas of the brain, including abnormalities affecting muscle and nerve function of the swallowing process (Rogus-Pulia et al., 2015); therefore, swallowing and feeding problems are common as the disease progresses. Neuroanatomical changes affect both the involuntary process of swallowing and the ability to self-feed (Sura et al., 2012) and are the result of behavioural, sensory, or motor difficulties (Easterling & Robbins, 2008). According to Parker and Power (2013), perceptual and spatial difficulties occurring in PWD cause difficulties in any phase of swallowing, and apraxia can induce difficulty in performing voluntary actions, such as opening the mouth to cutlery or taking more effort to move food from front to back area of the mouth. In late stages of the disease, individuals may forget regular food intake and have difficulties recognising food and necessary tools and performing eating actions such as opening the mouth to a spoon or moving food to the back of the mouth (Parker & Power, 2013). This also increases the risk of aspiration pneumonia, choking, and dehydration and malnutrition (Saitoh, 2008). The degree of severity depends on the underlying neurophysiological changes and characteristics of each type of dementia and disease progression; hence, prevalence of such problems is imprecise. It is estimated that 45% of PWD who are institutionalised have swallowing and feeding difficulties (Easterling & Robbins, 2008). Considering the social aspects of dining, such as socialising with family and friends during meals, difficulties in feeding and swallowing impact participation and activity of affected people adversely (Ekberg et al., 2002; Farri et al., 2007; Leow et al., 2010). Consequently, management of difficulties around feeding and swallowing involves various strategies, considering body function and structure and contextual factors. Indirect strategies include exercises to improve oromotor or laryngeal control, whereas direct therapy strategies are implemented to change swallow physiology (Logemann, 1991). Within treatment

of feeding and swallowing, it is common to combine direct and indirect treatment approaches to improve outcomes (Drulia & Ludlow, 2013). SPs carefully implement direct and indirect strategies to improve feeding and swallowing safety in PWD, such as compensatory and behavioural swallowing strategies, sensory enhancement strategies, environmental and cognitive strategies, oral hygiene, tube feeding, and preventative approaches. Common strategies for both approaches are described briefly as follows.

2.4.1 Intervention Strategies: Swallowing and Feeding

Compensatory and Behavioural Swallowing Strategies

Compensatory and behavioural swallowing strategies are implemented to adjust the biomechanics of swallowing stages by redirecting bolus flow; however, these strategies do not change swallow physiology directly (Easterling & Robbins, 2008; Rogus-Pulia & Robbins, 2013). Swallowing can be facilitated through postural adjustments such as chin tuck towards neck, head rotation, head tilt, head back, and side-lying positions, which aim to control gravity for the bolus flow (Rogus-Pulia & Robbins, 2013; Speyer, 2011, 2017).

Sensory Enhancement Strategies

As the swallowing process includes different sensory stimuli to trigger the swallow, the literature considers different sensory enhancement strategies that may be effective to facilitate oral and pharyngeal swallowing. This may include dietary modification and oral or olfactory stimulation to facilitate oral and pharyngeal initiation of the swallow (Rogus-Pulia et al., 2015). Dietary modification, wherein different parameters of food texture are adjusted, such as viscosity, volume, temperature, and/or acidity of the bolus, can help to ease and facilitate swallowing (Speyer et al., 2010). Additionally, spicy, sweet, and sour foods can increase sensory input (Easterling & Robbins, 2008). Thermal-tactile oral stimulation is a common strategy used by SPs for other populations with swallowing and feeding disorders; however, it does not show any promising results in swallowing patterns of PWD in an inpatient care setting (Olchik et al., 2020).

Environmental and Cognitive Strategies

Environmental modifications, such as lighting and table setting, improve functional abilities in PWD and result in a better oral intake (Brush et al., 2002). Other environmental modifications include the use of visual and written cues or decorating the table in a homelike

manner (Brush et al., 2006). Cues presented as a repetitive recall, such as in spaced retrieval or errorless learning (see section 2.3.1), can also be adapted during mealtimes in order to increase food intake in PWD (Camp et al., 2012; Wu et al., 2014). Furthermore, Montessori-based activities are effective in increasing food intake (Wu et al., 2014) and improving social interaction and mealtime experience (Cartwright et al., 2022).

Oral Hygiene

Oral hygiene is a relevant aspect that should be embedded in the management of any feeding and swallowing difficulties. Due to changes in eating habits and cognitive abilities to perform oral hygiene independently in PWD, SPs assist with and provide education about oral hygiene. As food modification and lack of oral hygiene leads to bacterial colonisation, there is greater risk of developing aspiration pneumonia (Furuta & Yamashita, 2013; Ortega et al., 2014; Yoon & Steele, 2007). Another risk factor requiring oral hygiene is that PWD may pool food in their mouth and/or forget to swallow (McGinley, 2015), which represents an increased risk for choking. Oral care strategies include mechanical cleansing to remove food debris and the use of toothpastes and other chemical agents along with interdental brushes and gauze (Lim, 2018). Performing oral hygiene with PWD will not only promote health and safety but also provide the opportunity for SPs to examine and monitor oral status and function continuously (Furuya et al., 2020).

Tube Feeding

Especially in the later stages of dementia, tube feeding is frequently implemented to prevent aspiration pneumonia and to avoid malnutrition and dehydration. However, tube feeding has not been shown to be an effective treatment. Neither aspiration nor functional status improve; on the contrary, tube feeding leads to other adverse effects. This includes making PWD feel uncomfortable (Finucane et al., 1999; Peck et al., 1990), as well as affecting overall participation in social and interpersonal structures (Brotherton & Judd, 2007; J. Douglas et al., 2017). Furthermore, it has been found that PWD with feeding tubes do not survive any longer than people who are not tube fed (Chernoff, 2006; S. Mitchell et al., 1997, 1998). In a cohort study with 5,266 participants with chewing and swallowing difficulties, participants who were tube fed had a significantly poorer survival rate than those without feeding tubes (S. Mitchell et al., 1998). According to Chernoff (2006), there seem to be no significant benefits of tube feeding for PWD. Part of an SP's role in feeding and swallowing is to provide education to individuals, families, carers, and other health professionals about the effectiveness of tube

feeding in PWD; therefore, they should “contribute to the ‘diffuse’ impetus to begin tube feeding” (Finucane et al., 2007, p. 206).

Continuous Monitoring

Given that difficulties in swallowing and feeding present an increased risk for aspiration, pneumonia, choking, and malnutrition, changes should be monitored early on (Altman et al., 2013). It is equally important to gather information from family members as well as from the individual’s performance during assessment. Assessments used for dysphagia in PWD are often derived from a stroke population and include bedside assessment of swallow efficiency with various food and fluid consistencies to decide if a risk of laryngeal penetration or aspiration is evident (H. Smith et al., 2009). A videofluorographic swallowing analysis may be implemented, especially in more advanced patients, to assess swallowing and to initiate and monitor therapeutic and compensatory techniques (Palmer et al., 2000).

2.4.2 Conclusion: Swallowing and Feeding Difficulties

The conceptual model that underlies the management of swallowing and feeding difficulties in PWD should be person-centred and incorporate adequate availability of food, appropriate resources and tools, sufficient environmental resources, personal relationship to others during mealtime, partaking in activities, and consistency of care for the PWD (Murphy et al., 2017). By providing individual intervention, nutritional intake can be improved and complications prevented (Wieseke et al., 2008). According to Speyer (2017), some of the strategies described above require a person’s unrestricted cooperation and the ability to follow and comprehend complex instructions from SPs, which is not possible for people with severe cognitive limitations. Furthermore, when making decisions about oral feeding, the person’s individual health status needs to be considered as safety of oral intake must be prioritised (Speyer, 2017). Consequently, choosing and combining appropriate strategies prioritises safety and also considers feeding and mealtime pleasure in order to respond to an individual’s needs and social participation. These strategies can be facilitated through a consistent mealtime routine, providing small meals or finger food, and practising good oral health (Easterling & Robbins, 2008). Furthermore, a collaborative relationship between carers, families, and SPs is crucial to provide adequate management of dementia (Johnson et al., 2000). As part of this collaboration, SPs aim to support personal desires and continued oral feeding as long as possible to promote quality of life (Berkman et al., 2019).

2.5 Summary and Conclusion

As part of their professional and evidence-based practice, SPs work with PWD to provide assessment and intervention as individualised and person-centred services, relying on their expertise and considering evidence. A vast body of literature documents direct and indirect intervention strategies and approaches for cognitive-communication and swallowing disorders. The abovementioned intervention strategies for cognitive-communication disorders and swallowing and feeding difficulties relate to various stages of dementia and address the strengths, needs, and desires of PWD on different levels. Through disease progression, area of focus, and intervention-type changes, and SPs need to reassess and adapt intervention goals by considering ICF components. Evidence regarding isolated direct or indirect intervention strategies exists; however, there is no systematic guidance or description for implementing these strategies given the complexities of individual needs of PWD. The role of SPs as part of their professional expertise within dementia is extensive, as it includes assessment and monitoring early on and provision of intervention across progression of dementia. Language and swallowing impairments in dementia are well documented. Nevertheless, it keeps unclear if SPs are practicing at all at this level in all stages of dementia. Given its different varieties and symptoms, a multidisciplinary approach is recommended to address individual needs of PWD. As each profession adds different aspects of expertise to a collaborative practice, a more person-centred approach can be applied. Despite knowledge of the value of a multidisciplinary team approach in the management of dementia, the extent to which clinicians practising in this area implement the various strategies and the stages at which they are involved with PWD is unclear, as it is not well described in the literature. Therefore, a scoping review of professional and interdisciplinary guidelines and recommendations was performed to identify the SP role in the management of dementia from the perspective of the SP profession as well as other allied and medical health professions. The scoping review is presented in the next chapter.

Chapter 3: Guidelines for a Speech-Language Pathologist Role in Dementia Care: A Scoping Review

In the previous chapter, the SP role was described as part of non-pharmacological treatment options and strategies in the management of cognitive-communication disorders and feeding and swallowing difficulties. As various dementia types occur progressively and affect an individual's body function, and activity and participation levels, management of dementia should be addressed by a multidisciplinary team. SPs have different roles at different stages of the disease; however, it is not clear what the best practice is. Across different international documents by professional bodies, SPs' scope of expertise highlights their clinical and educational role in the management of dementia, including early diagnosis, intervention, and prevention of dementia (ASHA, n.d.-a; RCSLT, 2014a; SAC, 2017; SPA, 2015). The scoping review included in this chapter critically appraises professional documents, including guidelines and position statements, in the management of dementia. Existing international guidelines, policies, and position statements are explored to determine how the role of SPs in the management and care of PWD is identified from a professional and interdisciplinary perspective. The review takes the form of a manuscript submitted to the *International Journal of Speech-Language Pathology* on 12 August 2022, which is currently under review. The authors and their contribution to the manuscript are provided in Table 3.1. All authors reviewed the results and approved the final version of the manuscript.

Table 3.1

Manuscript Authors and Contributions

Author	Contribution
--------	--------------

Elisa Choudery	Conceptualisation Study design Data collection Data analysis Drafting and revision of manuscript
Sally Hewat	Conceptualisation Study design Data synthesis Drafting and revision of manuscript
Elizabeth Spencer	Conceptualisation Study design Data synthesis Drafting and revision of manuscript

3.1 Manuscript Submitted to the *International Journal of Speech-Language Pathology*

Beginning on the following page is a copy of the manuscript submitted to the journal. References cited in this manuscript are included in the reference list for the thesis. Appendices for the manuscript are included in Appendix A. In accordance with the journal guidelines, the term speech-language pathologist (SLP) is used in the manuscript.

Guidelines for a Speech-Language Pathologist Role in Dementia Care:

A Scoping Review

Elisa Choudery^{1;2}, Sally Hewat¹, Elizabeth Spencer¹

¹University of Newcastle

² Swiss University of Speech and Language Therapy

Keywords: Dementia, Guidelines, Standard Practice

Abstract

Purpose: Speech-Language Pathologists (SLPs) are professionals who contribute to the management of dementia. Despite a vast amount of literature on the management of dementia for health professionals, the SLP role is unknown. This scoping review explores how the SLPs role is described from a professional and interdisciplinary perspective in existing guidelines and recommendations.

Methods: A scoping review was conducted using the PRISMA framework. Guidelines, position statements and recommendations for the management of dementia in allied health and SLP were located. Additionally, a hand-search across professional organisation websites was performed, to locate unindexed documents.

Results: The full-text review resulted in 20 documents that met the inclusion criteria. Five documents were specifically written for SLPs. Other documents from health professions referred either to the roles of SLPs in assessing and treating language deterioration and swallowing issues or made reference to impacts of dementia on language and swallowing.

Conclusions: Reference to the role of SLP in dementia management in the majority of guidelines for dementia is limited. The SLP profession may need to clarify its role in the management of dementia first to raise awareness among healthcare practitioners and policymakers to ensure inclusion of SLPs in the management of dementia.

Introduction

Dementia is a neurodegenerative disease affecting a person's cognitive function and daily activities. Due to an ageing population, it is expected that dementia rates will increase drastically over the next decade (Livingston et al., 2020) increasing pressure on the health care system and allied health service provision worldwide. To support people with dementia (PWD) and address individual symptoms and needs, non-pharmacological interventions are an effective adjunct to pharmacological (drug) treatments. Non-pharmacological interventions focus on promoting quality of life and address cognitive abilities, behavioural changes as well as deterioration in other function changes including communication, and swallowing and feeding (Douglas et al., 2004). Speech-Language Pathologists (SLPs) are experts in assessing and facilitating intervention for communication and swallowing and can contribute as key members of dementia care teams.

Depending on individual needs, strengths and functions, SLPs may provide PWD indirect and/or direct intervention strategies. These strategies may include functional and meaningful activities to facilitate communication (Hopper et al., 2015), as well as compensatory and behavioural strategies to address swallowing and feeding (Easterling & Robbins, 2008). Cognitive-communication intervention uses a variety of learning strategies, written and/or verbal cues and instructions (Hopper et al., 2013) and are delivered in a group or individual setting (Swan et al., 2018). Usually, SLPs combine cognitive-communication strategies, for example as conversational prompts and cues, to address mealtime concerns and support PWD with eating and swallowing (Benigas & Bourgeois, 2016). This ensures an individual approach, based on personal and individual needs. A main resource of person-centred approaches are family members and carers, who play a crucial role in caring for PWD. Therefore, education and provision of support through training for carers of PWD is integral to the overall management of dementia (Denning et al., 2017). Education and training may include communication partner training, a common indirect intervention strategy that incorporates and supports those caring for PWD actively in the therapy process (El-Wahsh et al., 2021). Training communication partners of PWD can be helpful to maintain a successful interaction and social life (El-Wahsh et al., 2021) by modifying a carers' behaviours when interacting (e.g., speaking pace) and the environment (e.g., reducing distractions) (Hopper, 2001). SLPs consider potential needs and individual resources for the treatment, to facilitate transfer into a person's environment and maximize the impact on quality of life.

Focusing on an individual and person-centred service delivery, SLPs apply their clinical expertise in light of principles of practice, evidence, ethical aspects and guidelines. Clinical guidelines are “systematically developed statements to assist practitioner about appropriate health care for specific clinical circumstances” (Field & Lohr, 1990, p. 50) and include recommendations for the target group by providing a critique of the evidence to recognize the most effective interventions to improve desired health outcomes for patients (Feder et al., 1999). Clinical practice guidelines can help establish standards and pathways for care of PWD and their families or carers through incorporating evidence-based practice (Ngo & Holroyd-Leduc, 2014).

In addition to clinical guidelines, there are a number of documents that either substitute or complement guidelines, such as position papers. A position paper is “a formal, usually detailed written statement, especially regarding a single issue, that articulates a position, viewpoint, or policy, as of a ... organization” (Dictionary, n.d.) and a “good” guideline can be defined as a valid, usable and reliable tool which leads to enhanced patient outcome (Terrace, 2003). Professional organisations develop clinical guidelines or position statements to update members about best practice guidelines for particular clinical populations. Position papers are not as comprehensive as guidelines; however, they do provide an overview on a topic and highlight areas of service provision and responsibility of clinicians. Therefore, position papers differ to clinical guidelines in purpose as the advice within such documents varies, and the evidence base is not as comprehensive as in a guideline (De Boeck et al., 2014). Additionally, the quality for the methodology used for currently available position statements is not clearly defined. Thus, position statements may be considered suboptimal in addressing specific questions about practice as they may be potentially biased, lack depth and may be based on evidence which was not gathered in a systematic approach (Cooke & Gould, 2013).

In 2005, Bayles and colleagues discussed the need for clinical guidelines for SLPs management of dementia and discussed that the increase in dementia caseloads necessitated a clearly defined role for SLPs working with this caseload (Bayles et al., 2005). As a result, a committee was formed and included organisations, such as the Academy of Neurologic Communication Disorders and Sciences, the American Speech-Language-Hearing Association and its Special Interest Division 2, and the Veterans Administration. The purpose of the committee was to issue evidence-based practice guidelines specifically for SLPs who work with individuals with dementia. The guidelines were written for SLPs and aimed to address the needs of people with Alzheimer’s disease; the guidelines were published as a series of articles

including evidence-based recommendations for specific speech therapy approaches. As these publications are now more than 10 years old, they were not included in the review.

In Australia, the need for improved guidelines for SLPs working with PWD was highlighted in 2012. Speech Pathology Australia Association (representative body of SLPs in Australia) provided a submission to the House of Representatives Standing Committee on Health and Ageing (SPA, 2012). In this submission they highlighted the SLPs role in early diagnosis and intervention and how provision of SLP services in the early stages can contribute to improved quality of life in the management of dementia. This was considered by SPA in the following three years, where they embedded information about working with PWD in aged care and mental health guidelines (SPA, 2015; 2018). In 2019, SPA made formal submission to the Australian Royal Commission into Aged Care Quality and Safety, providing structured feedback in response to key areas, such as communication and swallowing difficulties and the role of SLPs in clinical practice. With formal submission to the Australian Royal Commission into Aged Care Quality and Safety, structured feedback highlighted the restricted access of PWD to SLP services (SPA, 2019).

More recently, in March 2017, the Royal College of Speech and Language Therapists (RCSLT) submitted as part of a health, social care and sport committee an inquiry into the draft of Welsh Government dementia strategy, stating that allied health professions, including SLPs, have a key role in the management of dementia. The demand for inclusion of prevention and early intervention, rehabilitation and reablement, palliative care, the allied health key role and the importance of supporting communication, swallowing and feeding was addressed (Welsh Parliament, 2017).

In summary, there have been numerous attempts by SLP organisations to raise awareness of the contribution that SLPs can make to care of PWD. This includes raising awareness of how SLPs can contribute, how they can assess and provide intervention for communication, swallowing and feeding, both amongst the public and with allied health and medical professionals working with PWD. To date, we do not know the extent to which the role of SLPs has been incorporated into clinical practice guidelines and position papers for other professionals working with PWD. This is important because dementia requires a multidisciplinary team approach to ensure optimal care and independence for PWD, carers and families to ensure quality of life for as long as possible. To date, information about SLPs and their practice in dementia care has not been reviewed in existing professional and multidisciplinary guidelines and recommendations.

Therefore, this scoping review was conducted to identify and explore characteristics or factors related to the management of dementia (Munn et al., 2018) and to map available documents and content of documents for dementia (Pham et al., 2014) in relation to SLP practice addressing communication and swallowing needs of PWD. Hence, the aims of this review were to identify and describe how speech pathology is included in clinical practice guidelines, recommendations and position statements for the management of dementia.

Supporting this aim, four subquestions were identified to identify the role of speech pathology in assessment and management of dementia: (1) In what stage(s) of the disease was SLP involvement specified/recommended? (2) What information about SLPs role in assessment of PWD was included? (3) What information about SLPs role in communication and language was included? (4) What information regarding SLPs role in swallowing and feeding was included?

Methods

A scoping review was conducted to capture recommendations and key concepts. To ensure replicability, PRISMA-ScR guidelines were applied (Tricco et al., 2018) and the protocol for this scoping review was registered on 30 October 2020 on the Open Science Framework (<https://osf.io/35ty8/wiki/home/>).

Inclusion Criteria and Search Strategy

This review included clinical practice guidelines, position paper and statements addressing the non-pharmacological management of dementia, including diagnosis and assessment of symptoms, treatment strategies and approaches, and multidisciplinary care plans. The review included full-text documents available in English from January 2010 and December 2021, written for dementia in general (e.g., not focused on a specific dementia type) and not considered as part of any comorbidities (e.g., intellectual disabilities). As the management of dementia is an overlapping area of a range of professions (e.g., neuropsychologists, occupational therapists, and SLPs), search terms were kept broad to capture documents from as many allied health professions as possible. Search terms included [Dementia] OR [Alzheimer's] OR [Cognitive Impairment] AND [Guidelines] OR [Recommendations] OR [Position Statements]. The following electronic bibliographic databases were searched: Cumulative Index to Nursing and Allied Health Literature (CINAHL), EMBASE, PubMed, PsycINFO, and SCOPUS. As numerous guidelines and position statements are not published

in peer reviewed journals, a hand search was also conducted by the first author to capture relevant documents. This search included websites of national and international dementia associations, and professional speech pathology/speech therapy associations from English speaking countries. Reference lists within identified documents were also checked. Even though one of the search terms included Alzheimer's as a specific dementia type, the aim of the search was to identify documents that referred to dementia (onset at any stage) as an umbrella term rather than to a specific type of dementia.

Identification and Selection of Documents for Review

Following the search, references identified from the databases were uploaded to www.covidence.org, a software platform. Duplicates of references were removed and titles and abstracts were then screened by the first and third author for assessment against the inclusion criteria for the review. Sources were then retrieved in full and assessed in detail. Reasons for the exclusion of documents that did not meet the inclusion criteria were listed for reporting purposes.

Initially, 6084 documents were identified using the search terms, and 43 additional documents were retrieved following a hand-search by the first author. From 6127 documents, 1374 duplicates were removed. A further 4543 documents were excluded following review of the title and abstract and/or table of contents. 210 documents on Covidence were assessed for eligibility by another member of the research team. The first author read all documents and excluded 190. Twenty documents were identified for inclusion in the scoping review. See Figure 1 [Figure A1 in Appendix A] for a summary of the identification and selection process.

Data Extraction

The data was extracted by the first author and key information was recorded for each document. No quality appraisal or standard criteria instrument was used to evaluate considered evidence within documents, as the review included documents, such as recommendations and position statements on a broad perspective. For each document, the following background information was extracted: author, year of publication, type of document (e.g., guideline, position paper), and the information sources used for developing their guidelines. Each document was read in full to review any reference to SLPs, or SLP practice, communication, swallowing and feeding. Specifically, information about SLPs role at different stages of the disease, SLP role in assessment and SLP role in management or support for communication,

swallowing and feeding difficulties was extracted and documented. Furthermore, any indications for non-pharmacological intervention strategies that were not mentioned as part of the SLP role but still relevant to the profession were identified and included, such as cognitive training strategies that are implemented for cognitive-communication.

Results

Twenty documents included in this review consisted of 10 guidelines, three position statement papers, two recommendation documents and five other documents. The other documents included a framework, a practice resource, a reference guide, a guiding resource and a guide for decision making. Retrieved documents were published between 2012 and 2019 and were issued by eight different countries, including Australia, Canada, India, Ireland, United Kingdom, United States, New Zealand and Singapore. One document was published for the European context. No were published in 2010, 2011, 2020, or 2021 that met the inclusion criteria. Out of the 20 documents, five were published by international SLP associations and bodies to provide information and guidance for SLPs. The remaining documents were written by a variety professions for use by variety of audiences including allied health and social care professionals and care staff, general and family physicians, and families and persons with dementia. An overview of all documents is provided in Table 1 [Table A1 in Appendix A].

Documents for Speech Language Pathologists

The five SLP documents differed in scope and provided different levels of detail about the SLP role when working with PWD but all recommended that SLP services be provided PWD at all stages of the dementia.

The most comprehensive guidance for service provision was provided through documents issued by the Royal College of Speech and Language Therapists (RCSLT; 2014; Taylor-Goh, 2017). The RCSLT guideline consisted of a core guideline and incorporated twelve clinical guidelines, including a chapter dedicated to mental health and dementia. An evidence table and endorsement from end users of SLP services, such as clients and their families, was also included (Taylor-Goh, 2017). An associated position statement by the RCSLT described the role of SLPs specifically in the management of dementia (RCSLT, 2014), outlining SLP involvement in assessment and diagnosis, intervention and treatment, training and research. Both documents highlighted the importance of early involvement of SLPs to enhance and maintain communication for as long as possible, focus on partnerships with carers, and train

PWD and caregivers. In terms of assessment, the RCSLT guideline and position paper listed core cognitive communication skills for inclusion in an assessment, such as verbal reasoning, attention and concentration, and short-term memory. Addressing swallowing and feeding, both RCSLT documents recommended that assessment of these areas are essential to identify risk and be conducted routinely as part of ongoing management of PWD. For intervention, the RCSLT guideline (Taylor-Goh, 2017), recommended that intervention should consider both verbal and non-verbal communication. Depending on the stages of dementia, the intervention strategies recommended were based on individual cognitive strength and weaknesses, and overall physical function. Intervention strategies included training for those caring for PWD, group language stimulation, working specifically on conversation, environmental adaptations and enrichment, and situational, visual and verbal cues in a mealtime context.

The Irish Association of Speech-Language Therapists (IASLT; 2016) and the Speech-Language and Audiology Canada (2017) both published position papers wherein SLP key responsibilities were described and an overview of a multidisciplinary team environment was included. The IASLT discussed the importance of a holistic SLP assessment, including assessment of physical functioning, social participation and activity. The importance of assessing communication and swallowing and feeding was discussed. Methods for assessment included using objective assessments (e.g., videofluoroscopy) and/or through standardised and non-standardised assessments. The Canadian position paper discussed the importance of assessment precise diagnosis, but did not specify detail regarding the methods of assessments. In terms of communication intervention, the IASLT document provided an overview of the SLP role in communication and language intervention and included information about different modalities (cognitive-communication, memory, sequencing, problem solving, and executive functioning). Within the Canadian document, it was pointed out that an evidence-based approach should be implemented to improve internal communication within care teams, and to improve quality of life. Specific content detailing types of intervention (i.e. direct or indirect intervention strategies for communication and language) was not included. Both position papers recommended that carers and family members should be part of the intervention, and the SLPs role in this is to provide counselling and collaboration to promote communication strategies and advice in terms of end of life care and management.

Waters and Sullivan (2012) provide guidance for evidence-based decision making for people with dementia regarding feeding, swallowing and nutrition considerations. Besides medical evaluation, the use of instrumental evaluations were described and recommendations

stated that these should be implemented in the early stages of dementia in the decision-making process. To address swallowing and feeding difficulties and deterioration, it was also recommended to consider attention deficits, behavioural issues, or poor self-feeding abilities to address overall food intake. Furthermore, they stated that cognitive status should be considered when intervening.

All of the five SLP documents provide general information about dementia rather than discussing the variants or types of dementias. The recommendations made were regardless of any specific dementia type and symptoms and was drawn on the knowledge and clinical expertise of the SLPs.

Other Documents for Variety of Target Audiences

Eight documents from other allied health areas and professions, such as physicians, social science, health care and nursing, and psychiatry, considered the SLP role as part of assessments and in providing non-pharmacological interventions. A summary of these documents is provided in Table 2 [Table A2 in Appendix A]. To answer the research subquestions, each of the areas identified within the documents are presented below in a narrative synthesis.

Stages of SLP Involvement

In these eight documents, symptoms and health concerns related to the progressive nature of dementia were included, and all documents highlighted the importance of early management of dementia. The specific SLP role and involvement at different stages of dementia was not explicitly considered in any of the documents. Only two documents indicated that involvement and referrals to SLPs in an early stage was essential in order to develop a treatment plan and to provide early intervention (Agency for Clinical Innovation, 2016; Group Health Cooperative, 2012).

SLP Role in Assessments

Six of the eight documents discussed the role of SLPs in performing assessments, especially performance of an early communication assessment. The Agency for Clinical Innovation (2016) recommended that SLPs perform comprehensive communication assessment and assess deterioration of swallowing and feeding to initiate further necessary actions and develop an individualised care plan. Foley and colleagues (2019) highlighted that SLPs identify communication difficulties for PWD and assess feeding, drinking and swallowing difficulties to

recognize potential risks for aspiration and health related consequences. The New Zealand Ministry of Health (2013) recommended that PWD should be referred to relevant services, including SLPs, to assess and monitor nutrition and communication abilities. Clinical practice guidelines and principles of care for PWD in Australia indicated the need for swallowing and feeding assessment, performed by SLPs (Guideline Adaption Committee, Cognitive Decline Partnership Centre, 2016). The Group Health Cooperative (2012) included that cognitive communication evaluation should be assessed by SLPs and repeated within 6–12 months, to monitor any changes. The Royal College of Psychiatrists (2018) recommended that access to SLP services should be included in service provision for PWD, further details were not included.

Communication and Language as Part of the SLP Role

Four documents (26%) referred to SLPs expertise and ability to contribute to intervention of communication and language. The Agency for Clinical Innovation (2016) recommended that SLPs provide early and individualised treatment to facilitate specific communication strategies for PWD, their carers and families. This included the use of memory and communication aids, individual reminiscence work, creating a communication-friendly environment, and advise on the use of modalities other than communication. Foley and colleagues (2019) recommended that SLPs should optimise communication skills of PWD and communication partners to minimise difficulties and to promote overall well-being. The New Zealand Ministry of Health (2013) mentioned the importance of access to specialised care, such as speech therapy, to develop appropriate communication and behaviour strategies. The Royal College of Psychiatrists (2018) included SLPs as key worker within multidisciplinary care in their recommendations. They stated that SLPs are involved in assessment of swallowing and speech impairments but provided no specific information about how to involve SLPs in the multidisciplinary team.

Swallowing and Feeding as Part of the SLP Role

Only four documents discussed SLPs in intervention to address swallowing and feeding. The specificity of recommendations within the documents for swallowing and feeding varied. The Agency for Clinical Innovation (2016) included a more comprehensive reference to SLPs role and swallowing, which included provision of guidance on texture modification, provision of swallowing strategies, promotion of routines and social aspects of mealtime, and liaison with other health care providers. Foley and colleagues (2019) indicated that SLPs manage feeding,

eating, drinking and swallowing to reduce severe health risks and to ensure oral intake is maintained for as long as possible. The Cognitive Decline Partnership Centre (2016) recommended in terms of swallowing and feeding to promote living well and palliative care. The guideline issued by the National Institute for Health and Care Excellence (2018) recommended involving SLPs if concerns regarding safe food intake arise.

Assessment, Diagnostic, and Intervention

All included documents from disciplines other than SLP recommended intervention strategies and/or assessment and diagnostic approaches that fit in the scope of SLP practice but were neither particularly signposted as such, nor did they specify which profession should implement them. These non-pharmacological recommendations included cognitive stimulation and/or training, communication and/or language strategies, as well as behavioural strategies. The Singaporean Ministry of Health (Nagaendran et al., 2013) made reference to environmental design features (e.g., personalisation in bedrooms) as well as reminiscence therapy. Additionally, individualised and/or group-based cognitive and stimulation to improve or maintain cognitive function, as well as quality of life were recommended (Nagaendran et al., 2013). Sadowsky and Galvin (2012) also discussed reminiscence therapy as part of a non-pharmacological approach. The National Institute for Health and Care Excellence (2018) recommended cognitive stimulation therapy and group reminiscence therapy, as well as providing training of adapted communication strategies to improve interacting with people in their direct environment. The Alzheimer Society Canada (2014) included an “All About Me” booklet and the promotion of a supporting and individualised physical and social environment within their key elements of person-centred care for PWD. The Cognitive Decline Partnership Centred (2016) indicated that multicomponent interventions, involving engaging and individualised activities, may include reminiscence therapy, promoting effective communication, and provision of training and education of staff and carers. Volkert and colleagues (2015) recommended the promotion of a pleasant environment to ensure PWD feel safe and comfortable. As these were guidelines on nutrition, text modifications, specific behavioural and communication strategies were considered as well to address specific needs as part of difficulties with swallowing and feeding.

A practice resource for general practitioners by the National Health Service England (2015) did not provide any recommendations for non-pharmacological interventions in particular. However, the provision of further services to improve quality of life of PWD was

considered, as well as assessment of cognitive function. This information is similar with the guideline by Galvin and Sadowsky (2012), which mentioned the performance of standardised cognitive assessments, and, if necessary, referral for it to specialist services. In addition to evaluation of cognition, Sadowsky and Galvin (2012) recommended evaluation of function and behaviour. The Alzheimer Society of Canada (2014) did mention that assessments should be individualised, to meet unique needs, no further information was provided. Aspect of individual needs was also considered by the Royal College of Nursing (2019), wherein person and carer needs should be assessed in conjunction with speech, language, and cognitive abilities. Nagaendran and colleagues (2013) provided more in-depth information about cognitive domains that should be evaluated in an assessment. This included aphasia, apraxia, and/or executive dysfunction. Shaji and colleagues (2018) recommended and cited specific cognitive assessment tools for PWD, such as Addenbrooke's Cognitive Examination (ACE) or Montreal Cognitive Assessment. Further, assessment of changes in expressive language, spontaneity and economy of speech, pressured and stereotypy of speech, echolalia, preservation and mutism were specified for assessing frontotemporal dementia (Shaji et al., 2018). Overall, only two documents by The Royal College of Nursing (2019) and Volkert and colleagues (2015) recommended assessments of swallowing and intake.

In summary, the 15 documents from other allied health professions considered the SLP role as part of assessment, non-pharmacological interventions and strategies. However, involvement was indirect and only general information provided. Even though symptoms and health concerns of dementia were consistently presented as progressive and the importance of early management of dementia was highlighted, the SLP responsibilities and roles at different stages of dementia were not specified. Early management was also highlighted in the performance of an assessment, especially the assessment of a communication. Only five documents from other allied health disciplines referred to SLPs in the context of communication and four considered SLPs in the intervention to address swallowing and feeding. Interestingly, nine documents included recommendations for assessment and intervention strategies that match in the scope of practice of a SLP, but did not explicitly refer to SLP.

Discussion

In this study, existing guidelines for allied health and medical professionals for the management of dementia were reviewed. Relevant documents issued by professional SLP organisations, as well as documents for other professions who are part of an interdisciplinary

dementia care team were identified and reviewed. A total of 20 were included in this review. The quality of each document differed in specifications and characteristics of level of details when working with PWD, and SLP specific documents varied in specificity and quality about the professional role in the management of dementia and therefore may lack the depth required to inform practice for clinicians. Furthermore, other professional position statements or guidelines on how to manage dementia provided limited or no information regarding the role of SLPs in multidisciplinary or interdisciplinary team management of people with dementia from the early to late stages. This is problematic as evidence indicates intervention, including speech therapy, in the early stages can ameliorate the impact of cognitive decline, increase independence and wellbeing through maintaining communication and activities of daily living for longer (Gauthier et al., 2021).

The RCSLT guideline (Taylor-Goh, 2017) provided the most detailed guidance for SLPs, and documented relevant outcomes, different levels of research evidence and the document was subject to peer review. Additionally, the RCSLT position paper provided a clear guidance on the provision of SLP services and collaboration within a multidisciplinary team. The IASLT (2016) and Canadian (2017) position paper gave an overview of the SLP responsibilities, but did not provide detailed guidance on SLP practice in the management of dementia. Interestingly, bodies from other countries, including North America and Australia, do not have specific documents to support SLPs when working with dementia at all. At this time, the American Speech-Language-Hearing Association provides a comprehensive dementia practice portal page (ASHA, n.d.-a) on their website. It includes information about dementia causes, symptoms and signs, and the SLP role and responsibilities with an overview of important assessment and intervention approaches. In Australia, current documents issued by Speech Pathology Australia are found as part of information written for the aged care sector and for mental health (2015; 2018). Given that the Australian documents are written as general papers, the role of SLPs when working with PWD is not described comprehensively enough to support SLPs to guide their practice. Consequently, SLPs need to seek additional guidance through research to enhance their clinical practice and providing best service outcome when working with PWD, their families, and carers. Furthermore, the advocacy of the overall collaboration in a multidisciplinary team was affected, as the SLP role was undefined.

Seven documents reviewed from other disciplines did not identify or discuss the SLP role within their recommendations. While the Singaporean Ministry of Health included recommendations for non-pharmacological treatments, details about how and by whom those

could be delivered were missing (Nagaendran et al., 2013). The Alzheimer Society of Canada (2014) provided recommendations on person-centred care for staff working in long-term care and also mentioned the importance of non-pharmacological treatment. SLPs were not specifically discussed in those recommendations. A similar situation occurred in the guidelines on nutrition (Volkert et al., 2015), where SLPs contribution was not discussed at all. Interestingly, practical guidelines for family physicians (Galvin & Sadowsky, 2012) mentioned the referral to specialist services for further cognitive assessments only but did not consider communication or swallowing. Four documents from other disciplines recommended facilitation of reminiscence therapy but did not mention the SLP as a profession who could implement that as part of their role in providing communication therapy. Reminiscence therapy is a well-used approach by SLPs to facilitate various activities wherein nostalgic recounts are created in order to encourage speaking and language production in PWD (Rose et al., 2020). While an early assessment with a timely diagnosis was a consistent concept within documents, documents lacked details for specific procedures applied to early, middle or later stage of the disease and did not provide significant detail about how these professions can work with SLPs. The current findings suggest that in documents targeted at other allied health professionals the SLP role in the management of dementia is considered, but not detailed enough in order to give other team members a good overview how SLPs could contribute management of dementia.

Review Limitations and Strengths

To our knowledge, this is the first study that has mapped the SLP role within guidelines for the management of dementia. Our search strategy involved five databases to find available guidelines and documents for the management of dementia and an additional comprehensive hand search of relevant grey literature. While the main focus of this scoping review was to capture information about the SLP from a multidisciplinary perspective, there are some limitations. The information reviewed was not evaluated across pre-specified criteria, consequently results are less defined as they were not subject of an evidence appraisal criteria tool. Therefore, the authors' interpretations are reflective and suggestive rather than conclusive (Ehrich et al., 2002). Furthermore, some of the reviewed documents were not accessed through an electronic database and it is possible, that other important documents were not identified and consequently not included. As only documents available in English were included, results could not be representative of guidelines and documents published in other countries and languages. Furthermore, documents that considered dementia as an umbrella term were included and

assumed homogeneity in approaches to all types of dementia. Specific types of dementia with their different needs in the management were not considered.

Conclusion

The results of this review indicate that documents by SLP bodies lack specificity about key responsibilities and roles in the management of dementia. Further, guidelines for multidisciplinary health and other allied health providers do not recognise the role of the SLP in supporting communication, cognitive communication and swallowing in PWD extensively.

On a professional level, this requires the development of corresponding professional SLP clinical guidelines by SLP bodies, which explain the scope of work and responsibilities, specific assessment and diagnosis procedures to inform implementation of potential assessment tools, and strategies with applicable tools in light of available evidence for the management of dementia. By including different expert and evidence levels in such documents, transfer in clinical practice can be facilitated and needs of key stakeholder can be considered. Further, development and implementation of guiding recommendations should consider specific referral paths as part of potential organisational barriers and cost implications. Once the SLP role in the management of dementia is well-defined through professional guidelines, other allied health and medical professions can be informed accordingly which result in SLPs being more involved in multidisciplinary teams by contributing to dementia care plans. On a long-term perspective, improved collaboration leads to better person-centred management of dementia and the review findings may contribute to future planning and development of professional and interdisciplinary guidelines for the management of dementia.

Declaration of Interest

The authors report no declarations of interest.

3.2 Summary and Conclusion

In this chapter, the procedure and results of the conducted scoping review were presented. Documents including guidelines, position statements, and papers were reviewed. Documents included those relating to the SP profession as well as those for other allied health professionals. A total of 20 were included in the review, and the quality of each document differed in terms of specifications and level of detail about working with PWD. Reviewed SP documents varied in specificity and quality regarding the professional role of SPs in the management of dementia and therefore may lack the depth required to inform practice for clinicians who work with PWD. Additionally, there was a lack of suggestions for specific services applied to different stages of dementia. This included recommendations of assessment and diagnosis, therapy, education, and research. Although the importance of early involvement was highlighted, the role of SPs was neither defined on a professional level nor considered clearly within other multidisciplinary documents. Overall, reviewed documents were not detailed enough to provide sufficient guidance for SPs, and the current role of SPs in the management of dementia remains unclear. This established the need for the present research applied in this thesis, wherein initially the SP role is explored, needs and problems are identified, and further solutions are generated to contribute to knowledge about the SP role in the management of dementia.

Chapter 4: Methodological Approach

In the previous chapter, results of the scoping review highlighted the dearth of information available to support SPs to work effectively with PWD. Overall, 20 documents were included in the review, including five documents specifically written for SPs. The included documents mainly discussed deterioration of language and malnutrition during the progression of dementia. The description of the SP role from a professional perspective differed from country to country, and current practice of SPs in Australia is still unclear. To identify and gain better understanding of Australian SPs' needs, perceptions, and concerns when working with PWD, this research has sought to capture the voice of SPs and to provide them with a solution for their professional needs. To do this, a human-centred design framework was applied (Giacomin, 2014). Overall, there were six phases in this research, which are described in this chapter as part of the human-centred design methodology. The applied human-centred design in this research combined academic-analytic activities with research through design of a final product for SPs.

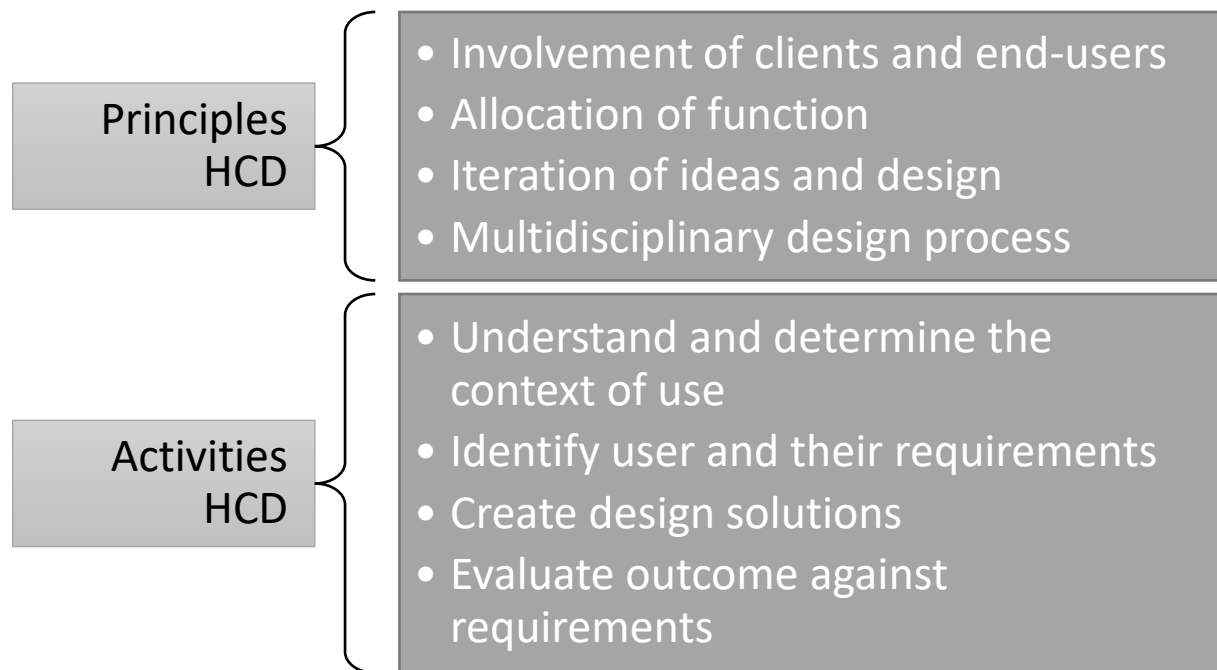
4.1 Human-Centred Design

Human-centred design (HCD), also known as person-centred design, is a method to actively involve end users in the design and development process by generating and adapting their individual needs to design and create an end-product (Giacomin, 2014). In the literature, the term HCD is often used interchangeably with user-centred design as there are similarities and overlapping approaches and frameworks. In this thesis, the term HCD is used throughout. Originally, HCD as an interactive design approach was introduced in the software industry in the late 1980s by Bill Moggridge (Moggridge & Atkinson, 2007). It has also been applied to manufacturing and engineering in response to the need to increase productivity (Maguire, 2001). HCD prospectively evaluates a variety of aspects which define the interaction between people and what they deal with (Tosi, 2020).

In 1999, the International Organization for Standardization (ISO) created and defined ISO 13047 to define the principles and activities involved in HCD. Such principles and activities are summarised in Figure 4.1 (ISO, 1999).

Figure 4.1

HCD Principles and Activities According to ISO 13047, 1999

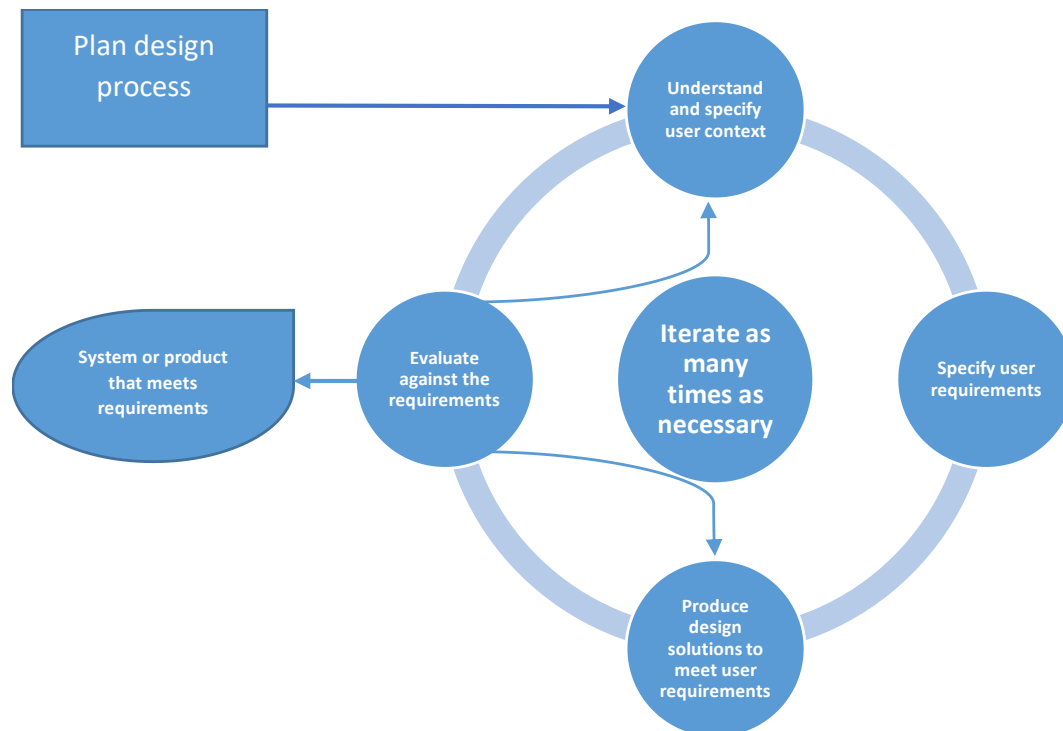


Note. Adapted from ISO 13407:1999: *Human-Centred Design Processes for Interactive Systems*, by International Organization for Standardization, 1999 (<https://www.iso.org/standard/21197.html>). Copyright 1999 by ISO. Reprinted with permission.

To date, ISO 13047 has been withdrawn and no further work and updates will be added, but it has been replaced by ISO 9241-210 (ISO, 2019). While in the past HCD was evaluated only, the updated version clarifies HCD by explaining methods, design activities, and principles in more depth (ISO, 2019). The underpinning principles and activities as shown in Figure 4.1 are still considered within the individual steps. These steps are illustrated in Figure 4.2, wherein the standard approach for user-oriented procedures in development projects is shown, and the focus is on targeted iterations of user-oriented activities depending on the level of knowledge achieved. Such procedure is a repetitive and flexible process as activities cannot be seen as sequences; rather, the design process is planned and iterated based on specific user requirements (see Figure 4.2).

Figure 4.2

The User-Centred Design Process According to ISO 9241-210 (2019)



Note. Adapted from ISO 9241-210:2019: *Ergonomics of Human-System Interaction — Part 210: Human-Centred Design for Interactive Systems*, by International Organization for Standardization, 2019. (<https://www.iso.org/standard/77520.html>). Copyright 2019 by ISO. Reprinted with permission.

In order to consider “all the user’s emotions, beliefs, preferences, perceptions, physical and psychological responses, behaviours and accomplishments that occur before, during and after use” of a product (Mirnig et al., 2015, p. 440), application of the principles and activities ensures attainment and application of knowledge about human beings and their interactions with their environment. This ensures that products and services fulfil their specific and individual needs and goals (van der Bijl-Brouwer & Dorst, 2017). To achieve this, HCD is a multistage design approach that ensures the knowledge, capabilities, and expectations of end users (in this case, SPs) are considered throughout the whole process, from design to development, implementation, and evaluation (Harte et al., 2014). Not only are end users embedded in the whole design process, they are still part of it after the process (Harte et al., 2014). This ensures that problems during the designing of a final product are eliminated and user frustration is prevented before launching it (Rubin & Chisnell, 2008). To date, there are different research activities that can be applied for HCD stages. They strongly depend on the specific outcome of a product and service, such as planning, context of use, requirements, design, and evaluation. For each outcome, different research methods can be applied (Maguire, 2001):

- planning: usability planning, cost–benefit analysis
- context of use: survey of end users, field study, user observation
- requirements: focus groups, scenarios of use, interviews
- design: brainstorming, storyboarding, paper prototyping
- evaluation: questionnaires, participatory evaluation, interviews

Each method provides either quantitative or qualitative data, informing each stage of HCD.

4.2 Application of HCD to Other Disciplines

Although HCD was initially a human–computer interaction approach, it has since been adapted and applied to various other disciplines, including health (Bazzano et al., 2017), education (Garreta-Domingo et al., 2018), and social science (T. Williams, 2020). The HCD approach has become an attractive way of researching within those disciplines, as it is a complex procedure considering user participation, expertise and experience (Boy, 2017). HCD has been used by educators to encourage students’ understanding of individual needs and to inspire them to collaborate in a more creative way, as they see a direct outcome of their work. Thanapornsanguth (2016) developed a project wherein teachers encouraged their students to contemplate and collaborate creatively in order to produce prototypes of their own social innovation products and ideas. This enabled them to express themselves, learn, explore, and experiment with new knowledge and boundaries. Students within this project passed through different steps to gather their ideas and test their prototypes, which allowed them to reflect and get feedback on their projects. In the end, they presented their final products, for example, an oil diffuser, and then received feedback from an audience. Within information technology for health, technology development embedded in an HCD approach is a well-known process (Robillard & Sporn, 2018) as it ensures that end-user representatives will be given the opportunity to implement their ideas to inform it (Clemensen et al., 2007; Pilemalm & Timpka, 2008). Moreover, it emphasises the patient’s voice and their experience in order to address issues and solutions within their context (Roberts et al., 2016). Frequently, it is applied to check readability and format of online health information. This study design, wherein end-user representatives are included, has also been applied in different studies for PWD that embedded an HCD approach. These, for example, included technology for a personal music assistant with individual playlists and music and picture albums (Peeters et al., 2016), dementia-friendly designs based within hospitals to improve self-care abilities of PWD (Kirch & Marquardt, 2021), or production of an advanced care plan for PWD (Denning et al., 2020).

Allied health professions specifically use HCD more frequently as an effective approach applied by a multidisciplinary research team to develop a creative but user-specific item or product. For example, in a study by Robins and colleagues (2010), a panel of professionals consisting of SPs and occupational therapists were asked to create different play scenarios with robotic toys for children with special needs. Experts outlined different scenarios for robot-assisted play, considering user groups (children with autism, mild mental intellectual ability, and/or severe motor impairments), social mediation, and play type (exercise play, symbolic play, assembling play, and play with rules). The robot-supported play ensured an appropriate play environment as determined by the expert panel. This aimed to prevent dependency and isolation of children with special needs.

Other studies have focused more on the technology outcome and included SPs as part of an augmentative and alternative communication training workshop by providing feedback and evaluating systems (Waller et al., 2005) or in the validation of a brain computer for people with acquired brain injury (Lynn et al., 2016).

Specific to dementia, the University of Queensland introduced the Florence project, which aims to research and design technology with PWD and their carers as involved experts in a multidisciplinary team setting (The University of Queensland, n.d.). The project includes PWD in the process as part of the panel, and incorporates computer science, interaction design, speech pathology, psychology, cognitive science, and occupational therapy to design communication technology to assist people living with dementia. The project included different steps such as the investigation of conversational dynamics of PWD and their carers (Atay et al., 2015) or measuring conversation of PWD and their carers (Chenery et al., 2016). One of the outcomes of the project was to introduce publicly accessible resources, describing key issues related to dementia.

With progression and advances of technology, SPs have embraced technology as part of their professional practice and included it in research methodologies. Augmentative and alternative communication systems have become standard practice in speech therapy sessions and are used in different areas (Beukelman et al., 2007; Bourgeois et al., 2010; Cress & King, 1999; Higginbotham et al., 2007; Light & Drager, 2007), implemented with devices such as tablets (Ballard et al., 2019; Furlong et al., 2016; Jesus et al., 2019) and specific apps (Dunham, 2011; Furlong et al., 2018; Wiles Higdon, 2015). Embedded within HCD, different areas of practice and technological standards have been explored, such as training of augmentative and alternative communication users (Waller et al., 2005), app design for speech sound disorder

interventions (Gačnik et al., 2018), voice output for communication aids (Hawley et al., 2012), and system architecture for feeding assessments via telepractice (Raatz et al., 2019). Such different areas demonstrate the flexibility of HCD wherein the user is the focus.

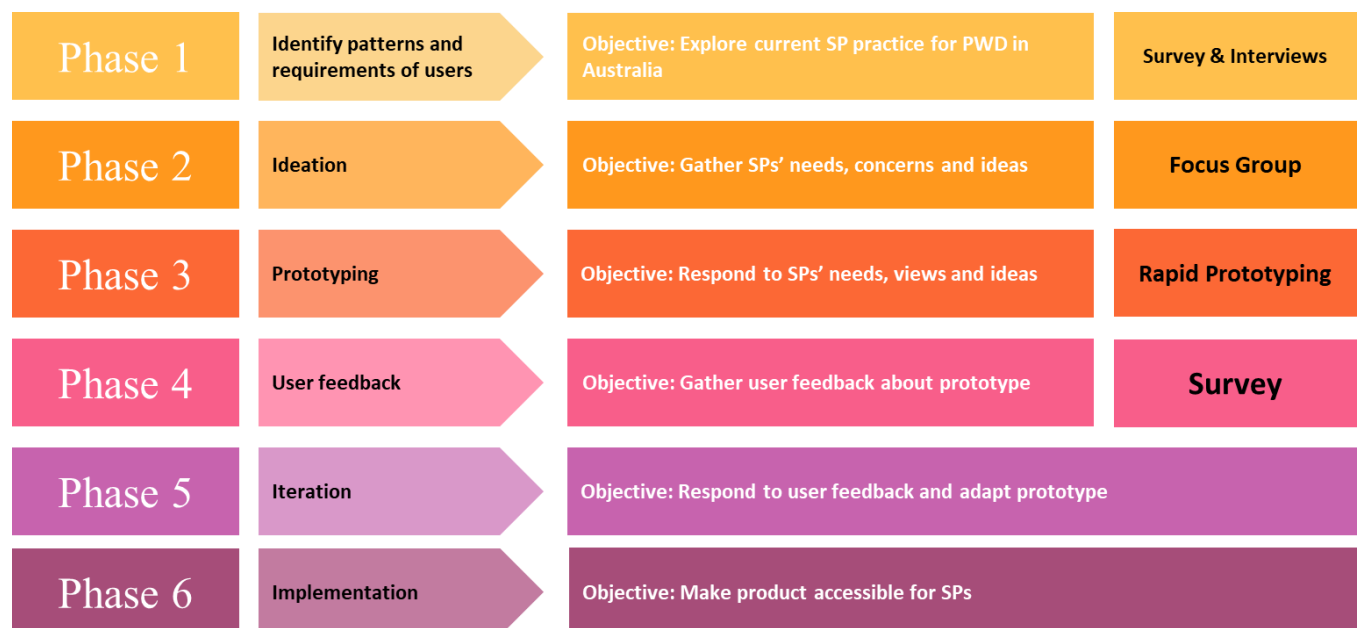
4.3 Research Design

This research project adapted different steps to identify and answer the SP end users' needs and concerns. As outlined above, an HCD framework was adopted which implemented a mixed-method design (Creswell et al., 2011). The purpose of mixing methods to establish current practice in Australia was for comparison (i.e., seeking to confirm and substantiate numerical data from an online survey with qualitative findings from interviews), reflection (i.e., seeking to give participants a voice to elaborate on themes and issues revealed), and to collect rich and comprehensive data (Wisdom & Creswell, 2013). Initially, an online survey followed by in-depth interviews were conducted to explore current practice of SPs who work with PWD. After that, a focus group was conducted to explore and consider SPs' opinions and views on a suitable resource to address their needs (Prior, 2018). Following the resource development, an online survey was conducted to evaluate it.

Overall, this project incorporated six phases, each with different research activities, as illustrated in Figure 4.3.

Figure 4.3

HCD Project Phases



Note. HCD = human-centred design; SP = speech pathologist; PWD = people with dementia.

4.3.1 Phase 1: Identifying Patterns and Requirements of Users

Through the initial studies in Phase 1, current practice and individual experiences of Australian SPs working with PWD were explored. Given the lack of consistent guidelines by professional SP bodies, and that the SP role within multidisciplinary documents varied, the scope of Australian SPs' service provision for PWD was unclear. The aim of this phase was to determine the context for service provision in order to identify practice patterns, focus areas (e.g., swallowing, communication), and factors that influence SP practice. SP practice with potential issues, as well as views of SPs, were gathered in this phase as part of a two-stage mixed-methodology study. Initially, an online questionnaire was administered to collect and analyse quantitative data of Australian SPs (see Appendix B for the survey information and questions). To increase validity of the data and gain in-depth qualitative data, face-to-face interviews were held in the second stage (see Appendix C for the interview material). By exploring the clinical practice of SPs, current practice for the management of PWD was identified and set the baseline for improvements and the ideation in Phase 2.

4.3.2 Phase 2: Ideation

In the previous phase, key patterns were emphasised and revealed potential concerns and needs of SPs. Such concern and needs were defined and informed this phase: the ideation. In this phase, SPs were informed of the results of the mixed-method study in Phase 1 and participated in a focus group. The focus group was a creative space wherein SPs gathered their ideas and views to address a problem and brainstormed solutions (see Appendix D for the focus group material).

4.3.3 Phase 3: Prototyping

In Phase 3, a prototype of a potential product (resource guide) to support SPs working with PWD was developed (see Appendix E). A rapid prototype process was implemented to allow fast adaption to any changes. The prototype was informed by ideas from Phase 2 and addressed SPs' professional needs, views, and ideas that were previously gathered.

4.3.4 Phase 4: User Feedback

In this phase, user feedback about the previously developed prototype was gathered. SPs who participated in the ideation process (Phase 2) tested and examined the prototype. Usability testing and evaluation of a product helps to identify areas of confusion and expose opportunities

for improvement (Wichansky, 2000). An online questionnaire was used for the evaluation as it provided anonymity as well as flexibility while reviewing the prototype. The questionnaire consisted of different question types to assess user experience and gain feedback (see Appendix F). This then informed revisions and adaptations to the prototype of the resource guide.

4.3.5 Phase 5: Iteration

In this phase, the user feedback from Phase 4 was analysed. Any issues and concerns identified by SPs were considered and the prototype was redefined. SPs also indicated how useful the prototype would be for their practice with PWD. Iteration in this phase enabled resolution and readjustment of the overall product.

4.3.6 Phase 6: Implementation

In the final phase, the prototype was ready to be implemented. Given that the overall design process, including content on the website, is not static, the end-product can be subject to updates. The iteration process (Phase 5) can be repeated if necessary and is a central part of the design thinking process. For this research, Phase 6 was the final phase of the study.

Chapter 5: Phase 1: Mixed-Method Study

As identified in the previously conducted scoping review (Chapter 3), there are no clinical guidelines on the role of SPs who work with PWD in Australia. Other Australian documents, such as position papers and recommendations, did not provide sufficient information for specific areas, such as assessment tools and intervention strategies. In comparison with international documents, the level of depth in guidance differed strongly. Consequently, the role of Australian SPs who work with PWD is still unclear and needs to be explored to identify current practice patterns. This was done through a mixed-method study consisting of two consecutive stages within the first phase of the HCD study. In Stage 1, an online survey was designed to explore SP practice in Australia. Stage 2 aimed to gain more in-depth data through interviews. This chapter initially discusses the research design, procedure, and data processing and analysis for each stage of the mixed-method study, then presents the findings.

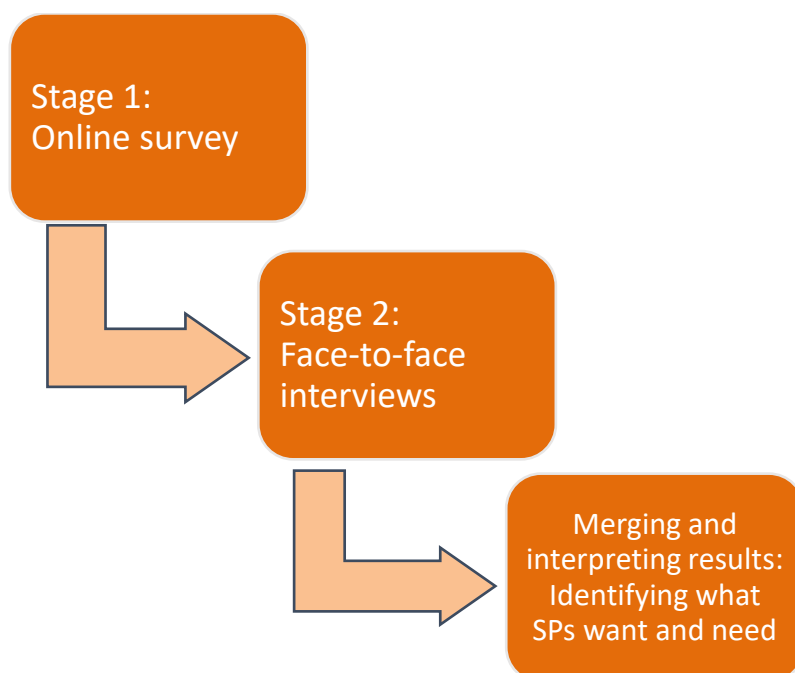
5.1 Research Rationale and Design

The aim of the mixed-method study was to answer the following question: What are the experiences and perceptions of SPs when working with adults with dementia and their carers? To answer this question, a series of subquestions were developed as the research question required both qualitative and quantitative data to be answered (Reams & Twale, 2008): (a) identify the scope of practice of SPs working with PWD, (b) identify factors that influence SPs' practice and decision-making for PWD, (c) determine the context for services that SPs provide for PWD, and (d) identify current SP service provision for PWD.

To answer these questions, both qualitative and quantitative approaches were employed to collect and analyse data (Creswell et al., 2011). According to Ivankova and Wingo (2018), mixed-method studies provide a comprehensive way to assess a problem from various perspectives. Overall, there are different ways to conduct a mixed-method study, either concurrently or sequentially (Leech & Onwuegbuzie, 2009). The study in this research consisted of two sequential studies. Initially, an anonymous online survey was developed and disseminated to gather Australian SPs' perspectives when working with PWD. Following analysis of the survey, face-to-face interviews were conducted with SPs to add more in-depth data to the survey results (see Figure 5.1).

Figure 5.1

Phase 1 Mixed-Method Study Stages



In this study, Stage 1 and Stage 2 were implemented consecutively, but data from both stages had equal weight in the analysis of results. This increased the validity of the data and reduced bias for a more accurate conclusion.

5.2 Ethics Approval and Ethical Considerations

Both studies in Phase 1 and the study in Phase 4 were approved by the University of Newcastle Human Research Ethics Committee (Phase 1 Stage 1 approval number: H-2019-0073; Phase 1 Stage 2 approval number: H-2019-0389; Phase 4 approval number: H-2021-0145; see Appendices B, C, and D for full details). Ethical considerations were addressed in line with the university's ethical approval. These included voluntary participation with the option to withdraw from the studies at any time. It was ensured that participants took part in both studies based on informed consent.

Survey participants were required to read the participant information statement and to indicate understanding by checking a box before they progressed to the survey with the main questions, ensuring their decision to participate was informed. Further, they had the option to skip any question in the survey they did not wish to answer or to exit from the survey before submitting it. However, submission of their survey responses by clicking “submit” at the

conclusion of the survey indicated implied consent. Submitted answers were not able to be withdrawn because all responses were anonymous and unidentifiable as no identifying information was collected. At the end of the survey, participants were asked if they were interested in being sent information about future research conducted by the researchers and/or participating or assisting with recruitment among their networks. Participants who indicated “yes” were linked to an additional separate page where they provided their contact details (name and email) to be listed on a secure database. This ensured there was no connection between the anonymous questionnaire and the personal details.

Interview participants were sent the information statement as a document via email before the interview was scheduled. To ensure they had read the statement, they signed and returned it to the researcher. Before starting the interview, if participants wished, the information statement was read to them again. In order to ensure voluntary participation, before starting the interview, it was explained that participants had the option to stop or withdraw at any time and without consequences. Questions they felt uncomfortable answering were skipped. Privacy and anonymity of participants and respondents was ensured through the following steps: (a) interview transcripts were allocated a number; (b) transcripts were made anonymous and did not contain any identifiable information in order to protect privacy; (c) audio recordings and consent forms were stored on the University of Newcastle OwnCloud server; and (d) all records will be stored electronically for a period of 5 years, after which time they will be deleted.

5.3 Stage 1: Survey

5.3.1 Survey Instrument

Previous studies in Portugal and Canada have explored the clinical practice of SPs with PWD, including their area of practice and referral patterns to speech pathology services, that is, how they were referred, by whom, and for what reasons (Hopper et al., 2007; Nóbrega et al., 2016;). However, given that there was no data on current practice in Australia, the survey was designed to fit in the Australian context. Questions were developed based on questions used in the international surveys and with reference to the SPA Code of Ethics (2020a), Scope of Practice (2022), and Clinical Guideline on Speech Pathology in Mental Health (2018). Given the information in these professional documents, it was still unclear if the role of clinicians in Australia was consistent with documented practice areas and how they perceived working with PWD. Therefore, an online survey was developed using LimeSurvey, an online survey tool

(www.limesurvey.org) which allows for anonymous data collection. An online format was used to ensure access for SPs working across Australia with PWD in an efficient time frame (Wright, 2017).

The first page of the online survey outlined the research procedures, aims, risk and benefits, confidentiality, participant rights, ethics information, and the chief investigator's contact details. On the last page of the survey, participants were thanked for their contribution and informed that the survey formed part of a larger study. They then had the opportunity to sign up with their name and email address for a database to get more information about future studies. To ensure anonymity in accordance with ethics committee approval, the database registration was placed on a separate webpage without any link to the previously completed questionnaire.

The survey was pilot tested within the research team and by two SPs who were not related to the research team. Questions were pretested and the SPs provided feedback on the user design, content, layout, and question-and-answer structure. Based on this feedback, changes were made to two questions by adding more choices to select from.

The questionnaire included 27 questions and covered five areas: (a) demographic information, (b) education and further training, (c) referrals, (d) diagnosis and intervention, and (e) service provision. Question types included single and multiple-choice questions, Likert scales, and open-ended questions to allow respondents to elaborate on their responses. Participants were also given the opportunity to answer “not sure” for many of the questions. All questions are included in Appendix B. The areas and questions are further described as follows.

Demographic Information

Five demographic questions were included to collect essential data to contextualise the answers of the participants in terms of experience and setting. The first question asked about the current employment status of participants with single-choice options of full time, part time, casual, fixed-term contracts, or other (please specify). They were asked to indicate their level of experience, with five options to choose from (ranging from less than a year to more than 15 years' experience). Participants were asked about the setting they worked in, which was delivered as a multiple-choice question with options of private practice, public or private hospital, inpatient or outpatient rehabilitation, community health, disability service, residential aged care, university clinic, or community health care centre. They also had the option to choose “other” to give details about their work setting if it was not listed. Another question asked if

they were working in a team, with three options to choose from: sole practitioner, small team (less than 5 people), and large team (more than 5 people). The final question asked about the state they were working in. As this survey was only disseminated in Australia, all Australian states and territories were included to choose from to identify survey distribution.

Education and Further Training

Five questions gathered information about participants' education and any specific training in dementia. Participants were asked if they had additional training or professional development in the field of dementia after the completion of their speech pathology degree. Only the participants who chose "Yes" as an answer were forwarded to four more questions in this section. Those included a question about the type of training they had undertaken, such as postgraduate studies, seminar, conference, congress, or workshop. Participants were then asked in a single-choice question if the training was specific to speech pathology. They were able to indicate "Yes", "No, just general information about dementia", or "No, specific to another area of dementia management (e.g., palliative care/providing carer education)". The following multiple-choice question focused on the types of dementia covered in their training, such as Alzheimer's disease, frontotemporal dementia, vascular dementia, dementia with Lewy bodies, or an overview of dementia only. The final question in this section asked participants to indicate if they got much practical knowledge out of the training, with options of yes, no, or not sure. This question aimed to identify the depth of the training undertaken.

Referrals

In this section, questions about referral patterns to SP services were asked. The first question asked participants to indicate from whom they usually received referrals. This was a multiple-choice question and options included GP, neurologist, neuropsychologist, dementia care advocacy groups, nursing staff, other allied health professional, self-referral, and family referral. Participants were asked if the referral numbers had changed over the last 3 to 5 years based on their own experience. This was a single-option answer with four choices: decreased, unchanged, increased, or not applicable (N/A). Participants were also given the option to comment on their choice. The followed multiple-choice questions asked about the information they typically received when assessing a PWD. Options included full medical report (e.g., mental and physical state), MRI or imaging information or report on imaging, aged care assessment, cognitive screening and assessment, or other (e.g., no information at all) with comment option. The subsequent question was represented as a Likert scale asking in which

stage of the disease they usually received their referrals. Participants had to choose for each stage (early stage, intermediate stage, late stage) whether they received referrals never, rarely, sometimes, most of the time, or always; N/A and comment options were also included. The final question in this section gave participants the option to indicate the main reasons identified for the referrals they received. Choices for this question were language disorders, speech disorders, reduced intelligibility, swallowing difficulties, voice disorders, difficulty in the breathing control, cognitive issues identified by the individual with dementia (e.g., memory difficulties, word finding difficulties), or problems identified by the carers or family members; N/A and comment options were also included.

Diagnosis and Intervention

There were six questions in this section. Initially, participants were asked about their roles when assessing PWD. In this multiple-choice question, 16 options were provided, ranging from early contribution to the dementia diagnosis to speech, voice, and swallowing assessments. The next question asked about the average number of clients the participant assessed and/or treated per year. Even though this might have been a hard question to answer, the question was included to give an approximate number of PWD who were treated in each setting. The answer options were kept general: less than 5 clients, 5–10 clients, 10–15 clients, or more than 15 clients. “Not sure” and “N/A” options were also provided. The following question asked about the therapy focus. Using a Likert scale, the question asked about swallowing and feeding in one column and about communication in another column. The scale provided participants with the following options to answer how often their therapy was focused on the respective areas: never, rarely, sometimes, most of the time, always, and N/A. Another question in this section asked about their approach to goal setting and included the following single-choice options: traditional, functional, social, N/A, or not sure. The following single-choice question asked about the types of interventions that were provided most frequently: direct, indirect, group intervention for PWD, group intervention for PWD and their carers, N/A, or not sure. The final question in this section asked participants about their confidence level when working with PWD. This question was presented as a Likert scale with the following ratings: poor, fair, good, very good, excellent.

Service Provision

The five questions in this section covered information about participants’ service provision. Although the demographic section included a question about their work team, in this

section participants were asked more specifically if they worked as part of a dementia-care team. Participants could select between the options of a multidisciplinary or transdisciplinary team, an SP team, a medical team, or that they worked as a sole practitioner. Participants who indicated working as part of a team were directed to the following question, which asked who typically was involved in that team. This was a multiple-choice question and included 12 options: carer, nurses, case manager, social worker, physiotherapists, occupational therapists, diversional and recreation therapists, dietitian, physician, psychologist, medical specialist, and other (with comment function). Participants were then asked about other services they provided for PWD as part of their professional role. The columns covered the following areas: case management, education and training, advocacy, and research. Using a Likert scale, participants were able to indicate for each column if they provided this type of service never, rarely, sometimes, most of the time, or always. Finally, participants were asked if they thought information was available to support SPs in working with PWD and their carers. This was a single-choice question with options of yes, no, or unsure. Participants who answered “Yes” were then asked an open-ended question about what kind of information they used.

Final Open Question

The final question of the survey was an open-ended question asking participants if there was anything they would like to add. This was a non-mandatory question with the opportunity to leave a comment in a text box.

Database

After answering the final question and submitting the survey, participants were asked if they would like to sign up to a database to receive further contact. The database was intended to collect contacts who were willing to be emailed regarding future research and assistance with recruiting for Stage 2 (the interview stage) of the mixed-method study. Interested participants were asked to click on a separate link to keep previously submitted answers anonymous. The database collected consent to be contacted and their names and email addresses.

5.3.2 Survey Recruitment and Procedure

The selection criteria for the survey were identified at the beginning of the survey, with the primary inclusion criteria being experience in working with PWD and currently practising in Australia. Snowball sampling was used as a recruitment method to encourage responses from a large sample (Heckathorn & Cameron, 2017). This included network-based sampling via

email. SPA and SP interest groups were contacted directly via email, asking for support in distributing the survey among their networks. These included, for example, dementia or adult rehabilitation groups. Additionally, SPs from the SPA member list on the website were contacted, targeting SPs who indicated dementia as their area of practice. The email included a summary of the research project with the survey link and provided the participant information statement as an attachment. Recipients were encouraged to share the survey link among their networks. The survey link was also submitted to Dementia Australia with a request that they add it to their website to invite interested people to participate in the study. To increase visibility of the survey, the research flyer was posted with the survey link on a variety of social media pages, such as Twitter and LinkedIn. A reminder email was sent out after three weeks as well as a repost on social media. The online questionnaire was open for participation for 6 weeks in May and June 2019.

5.3.3 Survey Data Analysis

Survey responses were collected through LimeSurvey, an online survey tool, and were then directly imported to an Excel spreadsheet for analysis. As discussed in Section 5.3.1, the survey contained both categorical and open-ended questions, and descriptive analysis was conducted by frequency distribution of each question. Therefore, the survey provided both quantitative and qualitative data. This included affirmative and non-affirmative responses for individual questions, which were divided by the total number of responses to receive percentages for each option. Open-ended questions were analysed using content analysis.

5.4 Stage 2: Interviews

In Stage 2 of Phase 1, semi-structured face-to-face interviews were used as they offered both structure and flexibility, which allowed participants' ideas to emerge (Robson, 2002). Additionally, they complemented the previous survey questions and allowed triangulation of data, as in the previous survey the majority of questions were closed questions (Adams, 2015). Therefore, interviews were conducted using predetermined open-ended questions to allow a conversation between interviewer and interviewee (DiCicco-Bloom & Crabtree, 2006). The predetermined questions in this study were set as part of an interview guide (see Appendix C), were developed in consultation with the research team, and consisted of seven main questions and probes. The guide as a framework ensured thematic consistency of emerging themes, objectivity, and trustworthiness of the results (Kallio et al., 2016) but was also designed "to

encourage depth and vitality and to allow new concepts to emerge” (Dearnley, 2005, p. 22). Given that the interviews collected qualitative data only, the guide was a necessary tool to ensure consistency throughout.

5.4.1 Interview Recruitment and Procedure

In the previously conducted survey, participants were given the opportunity to sign up to receive further contact from the research team. Overall, five SPs signed up to be contacted after registering. They were sent a study invitation with the request to share it within their networks. Furthermore, posts on social media (Facebook, LinkedIn, and Twitter) were distributed to increase visibility of the study. Twelve participants were recruited and interviews were held during February and March 2020 and were conducted and recorded via Zoom (version 4.6.), a cloud-based telecommunication tool. Recordings were downloaded and saved to OwnCloud, a cloud-based storage server.

Based on the conversations that arose, the researcher veered from the guide where relevant. Iterative questioning was used to clarify meaning during interviews, to ensure there were no misunderstandings of content. Notes were taken during and after the interview as a recommended procedure (Whiting, 2008). Before commencement of the interview, participants were reminded not to identify themselves or share identifying details (e.g., workplace). All interviews were transcribed by the student researcher and any unintentionally mentioned personal information was anonymised. Before the interviews were transcribed, participants were assigned a number to de-identify them. Selected quotes from participants used in this thesis are presented after removal of formulaic language to enhance readability (e.g., fillers “um”, “er”, and “you know”). Once the transcripts were finished, they were sent out via email to all participants as part of the member-checking process to check for accuracy and to ensure validation from participants (Birt et al., 2016; see Section 5.4.3).

5.4.2 Interview Data Analysis

The analysis of data was guided by Terry and colleagues’ (2017) explanation of thematic analysis. The practice-based conceptualisation proposed by them includes six phases: (a) “familiarising with the data”, (b) “generating codes”, (c) “constructing themes”, (d) “reviewing potential themes”, (e) “defining and naming themes”, and (f) “producing the report” (Terry et al., 2017, p. 8).

All interviews were transcribed by the researcher to gain familiarisation with the data. For further analysis, transcripts were read over a number of times to become more familiar with the data, and initial thoughts were noted. Transcripts were copied from Word documents into an Excel spreadsheet and analysed by coding the meaning units. Initial codes were identified for each interview through line-by-line analysis using Excel spreadsheets for each participant. Given that thematic analysis does not underlie any pre-existing framework, it can be used to explore different concepts (Braun & Clarke, 2006). Graneheim and Lundman (2004) described a table design for thematic analysis, which was adapted to represent identified codes, subthemes, and themes within the data set in this research. Table 5.1 shows an example from an excerpt of a participant interview with the initial coding outcome for the second phase of the thematic analysis.

Table 5.1

Initial Coding Outcome Example – Excerpt From Participant Interview SP7

SP7 interview excerpt	Initial coding outcome
So as a profession, I think ... that we should be able to provide [as] early intervention as possible. So ... if we ... are able [to] be	Provide early intervention
referred to by whoever is diagnosing a dementia and they should be educating the family	Referrals to SP services
immediately of what speech pathology can offer. And that we have referral options ... and of course we know that people with dementia may not need us for a while down the track. But if we can get that education in very very early, then ...	Diagnostician educate about SP services
people are aware of the options, they're aware of changes and they know what to look at ... so we can provide ideas and strategies in that point in time and then ongoing monitoring ... and if we are not needed until ... three years down of the track, that's fine ... but if we're needed sooner, then we're available as well. So we can help book the speech services.	Referral options
	Early diagnosing increases awareness of upcoming changes
	Providing ideas and strategies early on
	Enable ongoing monitoring early on
	Booking SP services early on if needed

5.4.3 Validity, Reliability, and Trustworthiness

The paradigm and procedures used to establish credibility and trustworthiness in this study included member checking (viewpoint of study participants), triangulation (viewpoint of researcher), and the audit trial (viewpoint of readers and reviewers), as described by Creswell and Miller (2000). Results from the online questionnaire were triangulated with the interview data. Researcher bias was taken into account by including use of transparency in the analysis process, which involved an audit trail (Excel spreadsheet and Word table). Included were the

number of each participant (e.g., participant SP1), date, length of the interview, and if they wanted to read through their transcript afterwards. The transcript was inserted into an Excel document with a unique sheet for each participant to initiate coding. Handwritten process notes made on the interview guide about the reasoning process were involved in coding. A further part to ensure trustworthiness of the study was member checking, which was implemented after transcribing verbatim when participants were invited to view transcripts for accuracy. Nine of the 11 interviewees chose to do this, and no changes were made. Data triangulation was conducted in the analysis process. Transcripts were checked before coding, and subsequent codes, subthemes, and themes were scrutinised by the student researcher and supervisors. Team consensus was obtained on a regular basis as part of the study process. Transcripts were read by the supervisors to gain familiarity with discussed content. The researcher and supervisors met three times to discuss coding through discussions of themes and subthemes.

5.5 Survey Results

5.5.1 Participants

A total of 71 participants submitted the online survey. This section presents the results from the first two sections of the survey.

Demographic Information

Table 5.2 summarises the demographic information of the survey participants.

Table 5.2*Demographic Information of Survey Participants*

Employment status and working experience			
Employment status:	%	Working experience:	%
Full time	61	< 1 year	8
Part time	27	1–5 years	31
Casual	8	6–10 years	25
Fixed-term contract(s)	3	11–15 years	15
Other	1	> 15 years	20
Setting and size of team			
Setting:	%	Size of team:	%
Private practice	31	Sole practitioner	14
Public hospital	55	Small team	38
Private hospital	13	Large team	48
Inpatient rehabilitation	21		
Outpatient rehabilitation	15		
Community health	10		
Disability service	4		
Residential aged care	14		
University clinic	6		
Community health care	1		
Other	6		
Location by state or territory			
Location:	%		
New South Wales: 13	18		
Victoria: 28	39		
Queensland: 8	11		
Western Australia: 10	14		
South Australia: 8	11		
Tasmania: 2	3		
Northern Territory: 2	3		
ACT: 0	0		

The table shows that over half the SPs who participated worked full time (61%), while 27% worked part time. The minority worked on a casual basis (8%), under fixed-term contracts (3%) or other (1%) work agreements. The largest percentage of respondents (39%) worked in Victoria, followed by New South Wales (18.3%) and Western Australia (14%). In terms of their experience, 31% reported 1–5 years working with PWD, followed by 25% who had worked for 6–10 years in the management of PWD; 15% had between 11 and 15 years of experience and 19% reported more than 15 years of experience in working with PWD. The majority (47%)

worked in a large team (with more than 5 people), while 38% indicated working in a small team, and 14% worked as a sole practitioner.

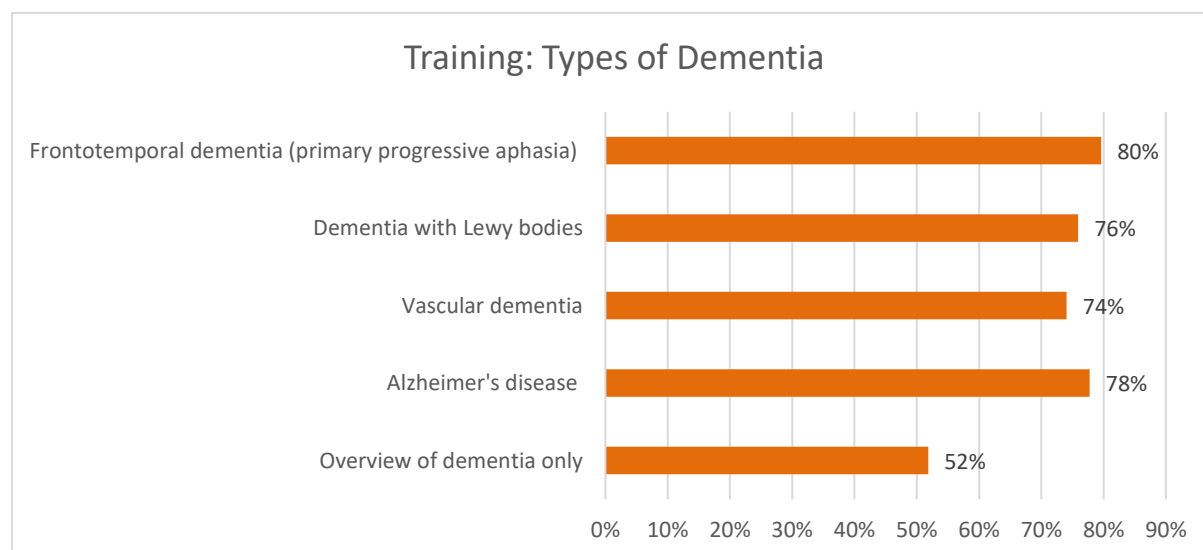
More than half (55%) of the sample worked in public hospital settings and about one third (31%) worked in private hospital settings. Twenty-one percent worked in inpatient rehabilitation and 15.5% worked in outpatient rehabilitation. Only 1% worked in disability care settings.

Education and Further Training

Seventy percent ($n = 50$) of all participants had further training in the management of dementia after graduating with an SP degree. From those who had further training, the majority (74%) had completed workshops, followed by seminars (38%). Sixteen participants (30%) ticked “other” and clarified their answer in a text box: 12 participants had completed online courses, two participants had completed internal (continuing) professional development, one participant was meeting regularly with more senior clinicians, and one participant was completing a PhD in dementia. Of those who had training in the area of dementia, 42% ($n = 21$) indicated that the dementia training was specific to SP practices. Figure 5.2 shows the different dementia types that were covered in the participants’ further training.

Figure 5.2

Types of Dementia Covered in Participants’ Further Training



5.5.2 Clinical Practice

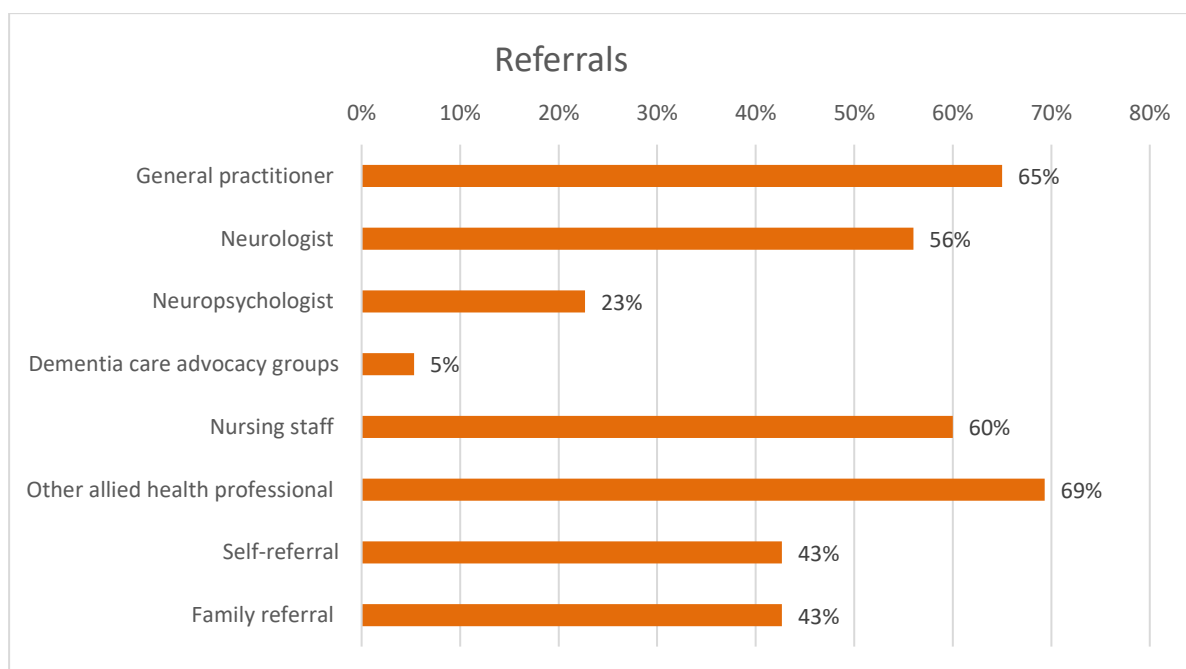
This section presents the results from the remaining sections of the survey, all of which related to the participants' clinical practice.

Referrals

The majority of referrals to SPs were received from other allied health professionals (69%), GPs (65%), and nursing staff (60%). Only 23% of participants indicated receiving referrals from neuropsychologists, and very few (5%) from dementia care advocacy groups. Figure 5.3 summarises the referral patterns.

Figure 5.3

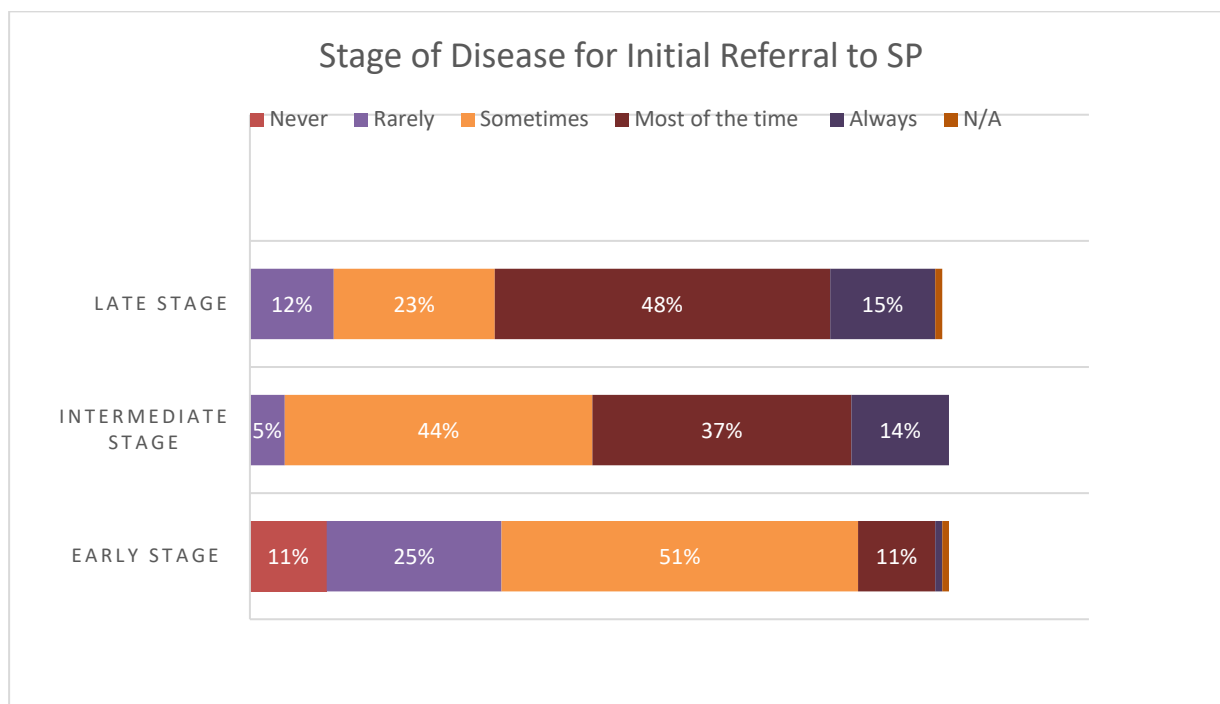
Referral Patterns



The majority of participants reported initial referrals of PWD in the late or intermediate stages of the dementia disease and that they only sometimes or rarely received referrals when clients were in the early stage. This can be seen in Figure 5.4.

Figure 5.4

Stage of Disease for Initial Referral to SP

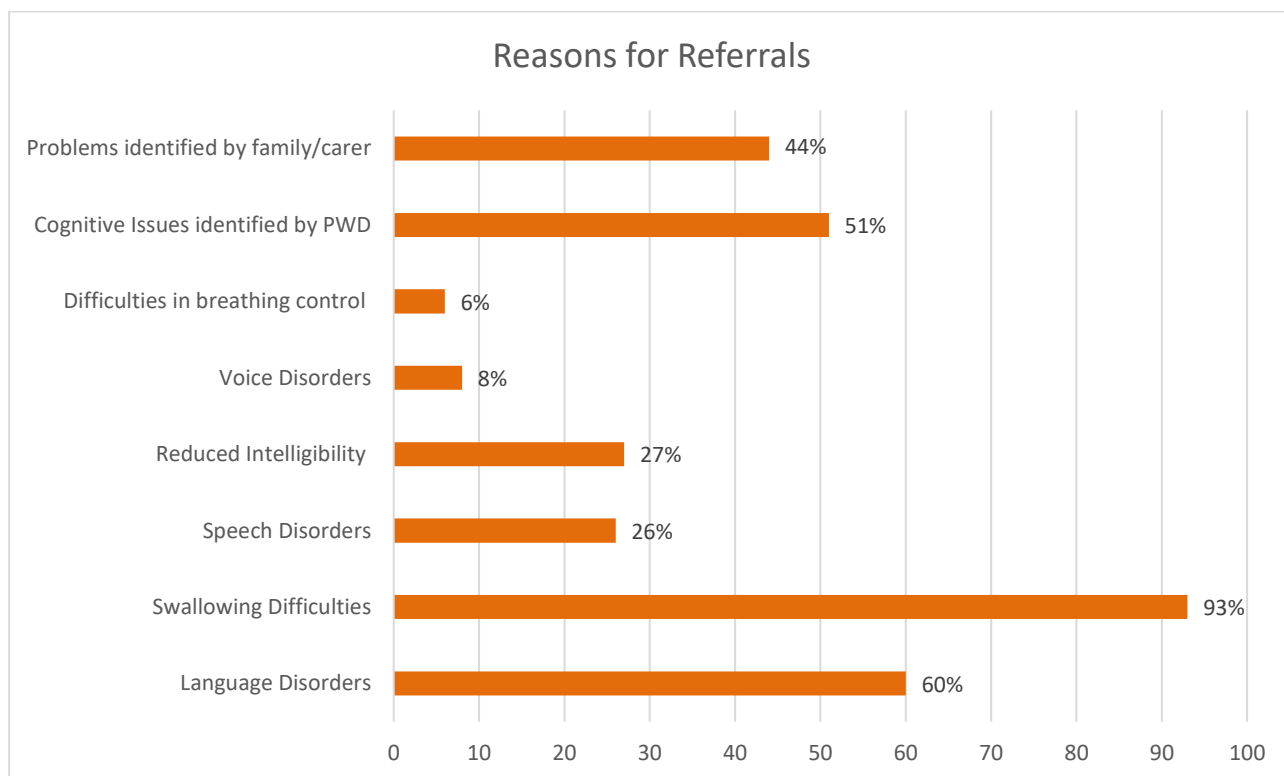


More than half the participants indicated they had experienced an increase in referrals of PWD in the past 3–5 years (52%) and provided various reasons for this, including an increase in awareness of how SPs can contribute to the management of dementia. Three participants commented specifically on the increase in referrals for dysphagia management in the last stages of the disease. The level of detail provided with each referral varied, as most participants had access to a cognitive screening and assessment as part of the referral (54%; $n = 38$), the full medical report (51%; $n = 36$), or MRI/imaging information or reports on imaging information (41%; $n = 29$). About one third of participants (32%; $n = 23$) had access to aged-care assessments. However, 39% ($n = 28$) reported receiving no additional information at all with the referral. Ten participants (14%) chose “other” and added a comment. Eight commented that they had full access to patient data with all information. Two participants indicated that information on referrals varied considerably in terms of detail.

Regarding the primary reasons identified for the referrals (see Figure 5.5), 93% of participants indicated swallowing difficulties, followed by language disorders (60%). About half (51%) of the referrals were due to cognitive issues identified by the PWD, while 44% were due to problems identified by the family or carer. Voice disorders (8%) and difficulties in breath control (6%) were rarely a reason for the referrals.

Figure 5.5

Reasons for Referrals

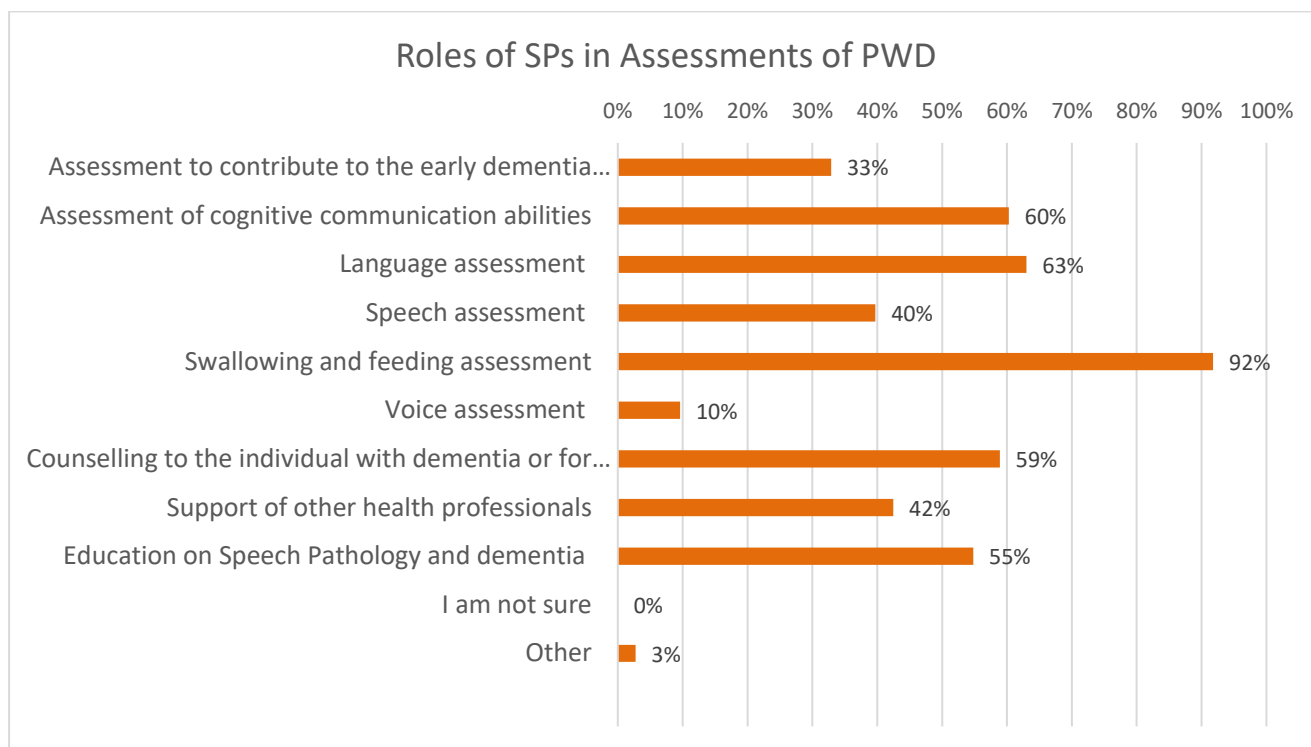


Diagnosis and Intervention

As shown in Figure 5.6, most participants (92%) reported that they mainly assessed swallowing and feeding, followed by language assessments (63%) and cognitive-communication assessments (60%). Other common roles of SPs in assessment of PWD were providing counselling to the individual with dementia or for carers and family members (59%), providing education on SP and dementia (55%), and supporting other health professionals (42%). It can be seen from Figure 5.6 that swallowing and feeding assessments significantly stands out as the role performed by most participants.

Figure 5.6

Roles of SPs in Assessments of PWD



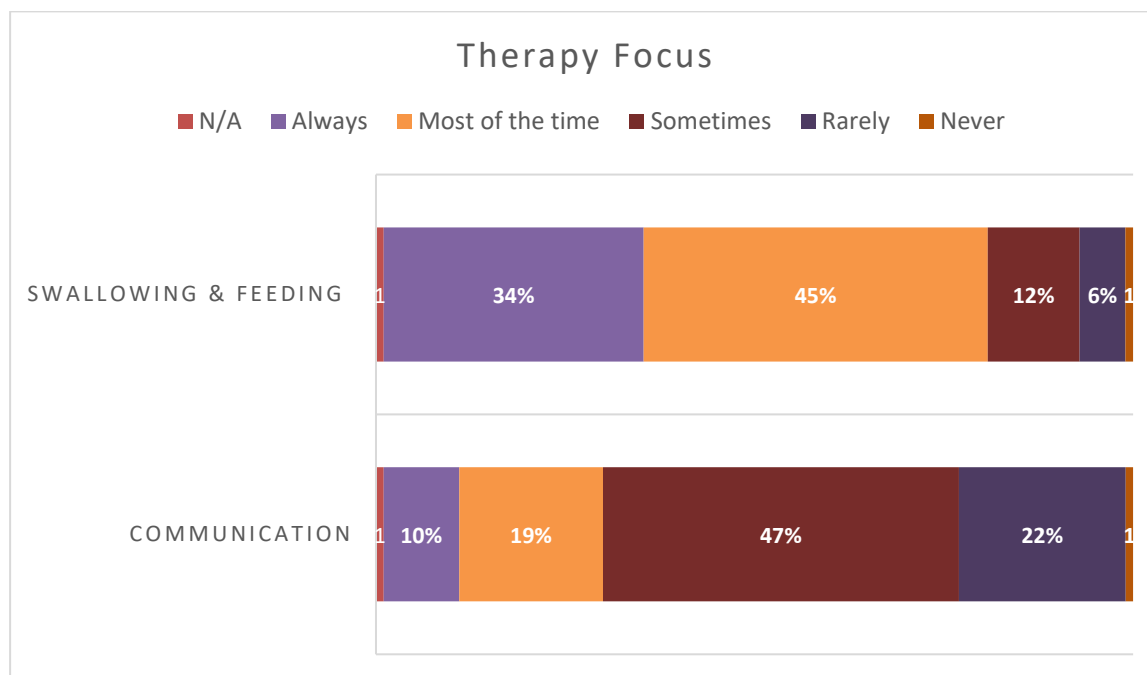
Note. One participant chose “other” and stated: “Ideally, I would like to offer all these areas.” SP = speech pathologist; PWD = people with dementia.

Treatment

Thirty-eight participants (53%) reported treating on average more than 15 PWD yearly; 19% indicated they treated 5–10 clients, and 15% treated 10–15 clients. Only 7% reported treating fewer than 5 clients per year. Four participants (6%) were not sure.

A comparison of the two major areas for therapy (communication, and swallowing and feeding), shown in Figure 5.7, revealed that 79% of participants focused on swallowing and feeding always (34%) or most of the time (45%), whereas only 29% focused on communication always (10%) or most of the time (19%). Given that a larger number of participants worked in a hospital setting (see Table 5.2 above), these numbers can be connected to the setting participants worked in, as for example, acute admission was indicated for other reasons (e.g., falls).

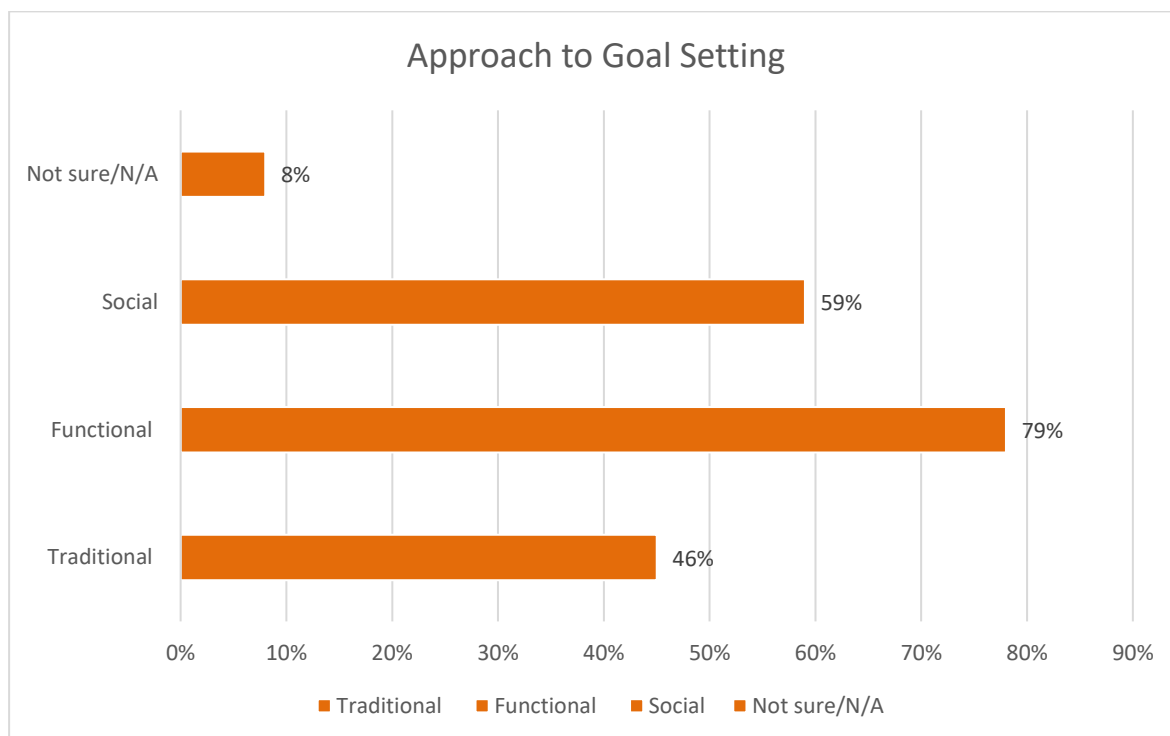
Figure 5.7
Therapy Focus



Participants were asked to indicate their approach to goal setting for their treatment of PWD and more than one response possible (see Figure 5.8). Fifty-six participants (79%) reported their approach to goal setting as functional, that is, aimed to minimise the individual's limitation in daily activities; 33 participants (46%) chose a traditional approach, that is, minimising difficulties and improving the affected abilities based on an individual deficit profile; and 42 participants (59%) selected a social approach, that is, minimising barriers in the individual's participation in the community through methods such as communication partner training.

Figure 5.8

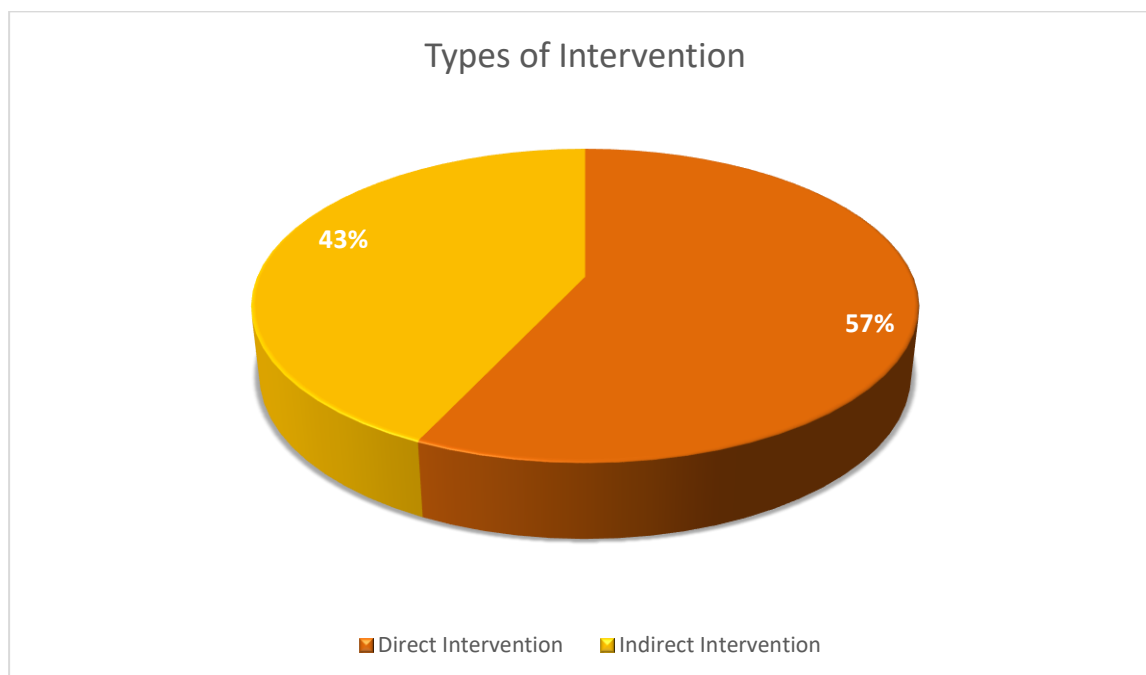
Approach to Goal Setting



With regard to types of intervention (see Figure 5.9), 41 respondents (57%) indicated they most frequently provided direct intervention with the PWD to preserve communication abilities, prevent further deterioration, equip them with specific skills for the use of aids, and maintain daily participation. Thirty participants (43%) indicated they most frequently worked indirectly by providing strategies to modify and improve an individual's environment and educating family members and caregivers. No respondents indicated that their most frequent form of intervention was to provide intervention in a group setting, whether with the PWD or with their carer(s).

Figure 5.9

Types of Intervention



SPs' Confidence Level in Working With PWD

Participants were asked to rate their confidence level in working with PWD using a rating scale with five levels (from 1 = *poor* to 5 = *excellent*). Fifteen participants (21%) rated their confidence level as excellent, 25 participants (35%) rated their confidence level as very good, and 23 participants (32%) rated their confidence level as good. Only eight participants (11%) rated their confidence as fair, and no respondent indicated they had a poor level of confidence.

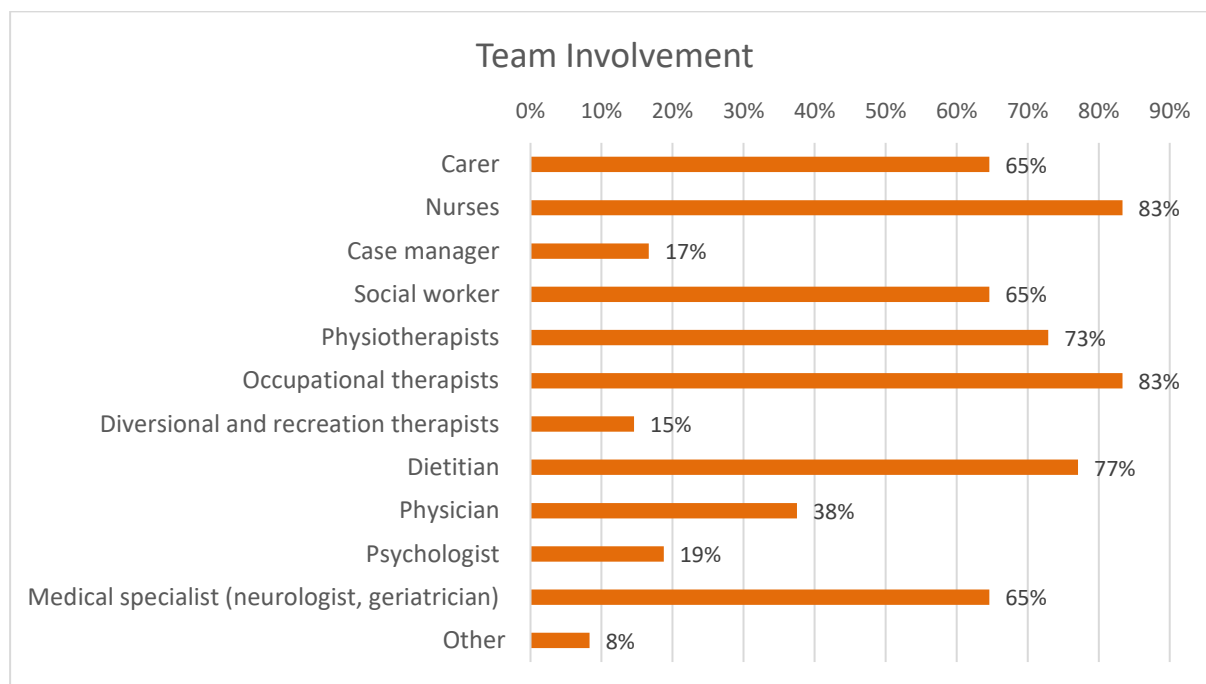
Service Provision

Forty-two participants (59%) indicated they worked as part of a multidisciplinary team, while 19 (27%) were working in an SP-only team; five (7%) indicated they worked specifically with medical team guidance, while the remaining five worked in a sole practitioner role.

Participants who were working as part of a multidisciplinary team were asked to indicate who else was typically involved in that team. A summary of team members typically involved is provided in Figure 5.10. Most participants working in a team reported that the team included carers, other allied health professionals, nurses, and medical specialists.

Figure 5.10

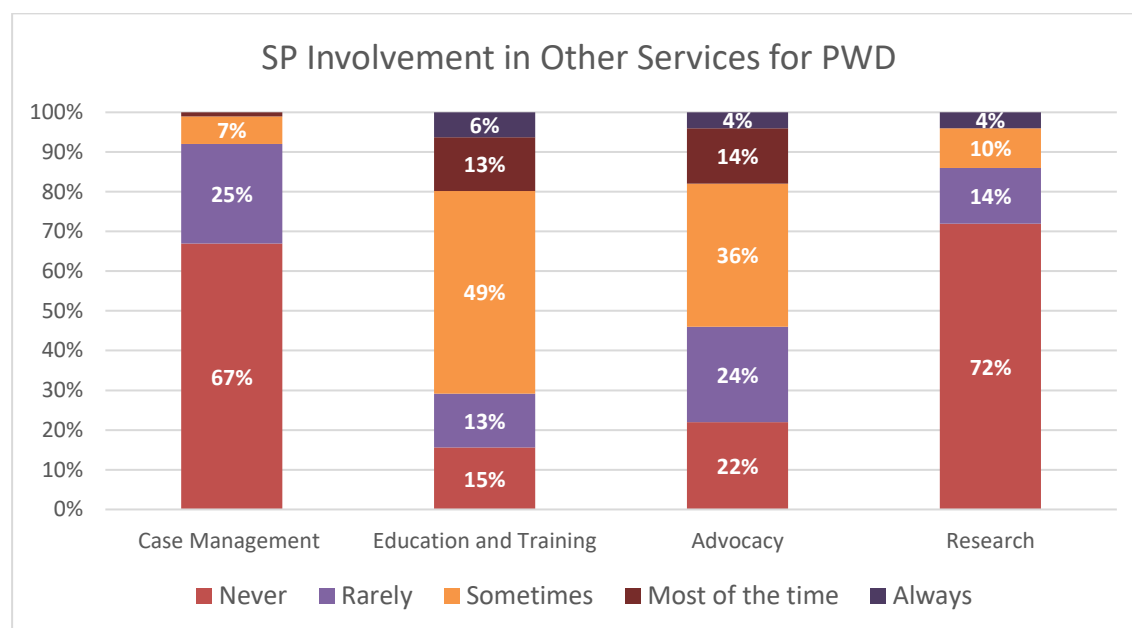
Team Involvement



With regard to other services provided by SPs, the majority of participants indicated they were rarely or never involved in case management or research. However, the majority of participants were sometimes, most of the time, or always involved in education and training for students, families, and other health professionals and in advocacy regarding the needs and rights of PWD. Figure 5.11 illustrates the results for this question.

Figure 5.11

SP Involvement in Other Services for PWD



Note: SP = speech pathologist; PWD = people with dementia.

Information and Resources to Support SPs Working With PWD

The majority of participants (69%) indicated that there was not enough information and resources, such as literature and guidance, to support their work for PWD; 19% were not sure, and only 11% reported that the given information was enough. Regarding the sources of information used, participants indicated a range of information sources, including available research papers, massive open online courses (MOOCs), brochures, blogs, and websites such as dementia.org.au. Additionally, participants reported using international guidelines to inform their clinical practice, such as the RCSLT guidelines, and exchanging knowledge and networking with colleagues as part of internal workshops and expert opinions.

5.5.3 Summary: Survey

The survey results gave an insight into Australian SPs' practice when working with PWD. Overall, SPs' involvement, especially in the early stage of the disease, was limited or restricted to swallowing and feeding only. Although the majority of participating SPs reported feeling confident when assessing and treating communication and/or swallowing and feeding issues in PWD, access to comprehensive information in this area of practice was difficult. Furthermore, overall awareness of others of the SP role in the area of dementia was limited. Participants indicated that there was not enough information and resources readily available to support their clinical practice with PWD.

5.6 Interview Results

5.6.1 Participants

Twelve participants across Australia consented to participate in Stage 2 of the mixed-method study, which consisted of semi-structured face-to-face interviews. One interview failed to record properly, as the participant's microphone was not working properly and the audio quality was impacted for further transcription. Overall, 11 interviews were recorded and eligible for transcription. Participants worked across a variety of settings with PWD, including private practice, clinics and hospitals, and community services, with different caseloads. Some of the participants had done some professional development, such as courses and seminars, to further their knowledge when working with PWD. Table 5.3 gives an overview of the demographic information about the interview participants.

Table 5.3

Demographic Information of Interview Participants

Participant	Setting	Caseload	Professional development
SP1	Private practice	Progressive neurological conditions	X (None)
SP2	Public hospital and private practice	Mixed caseload, geriatrics	Seminar
SP3	Acute and rehabilitation	Dysphagia and cognitive-communication impairment	X (None)
SP4	Cognitive Dementia and Memory Service (CDAMS)	Patients with suspected dementia	International conferences
SP5	Hospital	Acute ward	University of Tasmania MOOC
SP6	Hospital	Geriatrics	University of Tasmania MOOC
SP7	Hospital	Mixed caseload, geriatrics	Internal PD course, speech pathology course
SP8	Hospital	Geriatrics	University of Tasmania MOOC
SP9	Community and aged care	Geriatrics	University of Tasmania MOOC, Dementia Australia 3-day workshop
SP11	Hospital, community and aged care	Mixed caseload, geriatrics	Speech Pathology Australia seminars, Coursera John Hopkins University course, University of Tasmania MOOC
SP12	Hospital	Geriatrics	Course on behavioural management of PWD

Note. SP = speech pathologist; MOOC = massive open online course; PWD = people with dementia.

5.6.2 Themes

Following the initial coding phase of the thematic analysis (Terry et al., 2017; see Section 5.4.2) assigned codes were identified and grouped together with other similar codes into subthematic categories on a different spreadsheet. Subthemes were then reviewed and organised into main themes. In the penultimate stage, themes were named and defined based on the subthemes. Five themes were identified from the data, assigned by the research team to describe the subthemes (see Table 5.4).

Table 5.4

Themes and Subthemes From Interview Data

Theme	Subthemes
Factors affecting SP management in working with PWD	SP specific training in dementia Clinical experience of SPs Professional exchange with other SPs Therapy tools and approaches Dysphagia assessment and management prioritised Minimum cognitive-communication management Communication in PWD Clarity of role of SPs in the management of dementia
Regulatory/time constraints for provision of services for PWD	Impact of policies and guidelines Decision-making on behalf of PWD Advocating for PWD Impact of time regulation Referrals Setting for services Medical notes and reports
Person-centred practice approach for PWD	Residential care workers of PWD Implementation of communication strategies for PWD Importance of building rapport with PWD SPs implement person-centred approach SPs as part of a multidisciplinary team Approaches to goal setting
Education and engagement of carers and families	Importance of family inclusion Education of families SPs educating allied health professionals Coping among families, carers, and PWD
Challenges of working with the diversity of presentation, severity, and characteristics of dementia	Behaviour of PWD Morbidity and co-morbidities of PWD Cognitive functions of PWD Impact of delirium on intervention Characteristics of complexity of dementia caseloads

Note. SP = speech pathologist; PWD = people with dementia.

The themes are described in relation to the data as follows.

Theme 1: Factors Affecting SP Management in Working With PWD

Eight subthemes were identified in this category, wherein participants stated that several factors influenced working with PWD. These included training in dementia gained after graduation, how their clinical experiences influenced working with their caseload, professional exchange with other colleagues, and therapy tools and approaches they were using.

The majority of participants had undertaken some specific training in dementia after their degree. One frequently reported online training was the MOOC through the University of Tasmania.

I found that course in particular helpful to an extent ... it was more targeted at care staff specifically in aged care. ... it was really ... quite basic. ... I felt that I could contribute potentially more ... with my professional and personal experience. (SP9)

Participants indicated the need for more specifically tailored courses with greater detail about information relevant to SP practice and therefore they reported conducting independent research through accessing relevant literature online. Participants stated they used grey literature to gather more specific information or to compensate for lack of knowledge.

I think we use Google as a starting point and then we shift for quality from there. (SP8)

Participants discussed how their clinical experience shaped their work with their caseload. All of them indicated that they enjoyed working with PWD and creating therapy goals for them. However, there was accord within all interviews that participants were not able to implement their knowledge to its full potential, as they felt they were not involved in the treatment for the individual as early or as much as they could have been.

So as a profession, I think that we should be able to provide [as] early intervention as possible. (SP7)

Often I feel a bit helpless and feel if we had been involved earlier, potentially we could have provided more education or ... strategies ... (SP9)

Another factor affecting SPs managing PWD was the exchange with other SPs. Participants rated the exchange with colleagues as valuable, as they had different levels of experience and were able to discuss cases.

There's a group of speech pathologists in Victoria who specialise in dementia and we have a community of practice. So we get together once every two or three months to discuss

issues relating to the management of dementia by speech pathologists. We discuss complex cases and we ... it can be in regular email contact as well, supporting one another through those things. (SP4)

Furthermore, social media was mentioned as a valuable tool to get in contact with other SPs or get involved in discussions.

... that's why I like Speech Pathology Australia Facebook page [and] be[ing] involved in those discussions ... or even just reading and feeding back people's experiences in gathering ideas to how to tackle some of those more tricky situations. (SP9)

As PWD tend to present with individual symptoms and behaviours, intervention focus varies. Participants reported that interventions were personalised depending on the different stages of the disease journey. This influenced chosen therapy tools and approaches when working with these cases.

I've great plans just to design some easy English kind of resources, with picture supports and just ... to simple communicating. (SP9)

I think the most common one that springs to mind is just the basic communication board. (SP5)

Moreover, some SPs reported using technology devices if patients were able to access and use them.

Occasionally we do have people that can use higher tech devices to communicate as well. (SP1)

What I actually love in working with people with dementia is alternative or augmentative communication systems ... or a picture change communication system. (SP2)

Additionally, the setting influenced the choice of therapy tools and approaches. Whereas participants working in community care and private practice were able to implement different kinds of strategies by using items like photos or devices, participants working in acute settings used a different kind of approach to implementing strategies, such as group meetings.

People need to not just sit in their room and waiting to have therapy; anyone with a dementia or delirium I invite into that conversation group. (SP7)

A pattern shared by participating SPs working in acute care could be seen during analysis. As there were not many appropriate therapy opportunities in the acute setting, broader approaches were adopted to fit the vast majority of patients.

Participants described that PWD were referred in most cases for dysphagia assessments and intervention only. One reason for this was the setting participants worked in and necessary resources.

Generally, a lot of the referrals we get for clients with dementia in the community are just for swallowing assessment. (SP9)

Mainly we deal with dysphagia ... as it relates to these patients and that is assessment and then support with their diet and fluids. We don't have a lot [of] capacity at the moment, unfortunately, for communication in this context. (SP8)

Besides the setting and necessary resources, participants described that their overall practice was also influenced by compliance and status of patients.

Communication is not really thought of at all ... it's more how can we support them ... the resident or the patient to understand why we are there. (SP6)

A few participants reported that due to increasing numbers with early onset dementia, referrals for communication had started to increase.

Most people are being referred to speech pathology for a dysphagia assessment, but I have noticed in the last little while really just with early onset dementia, that I have started to see a few of those clients through NDIS ... and that those clients have been referred more for communication ... (SP3)

Besides dysphagia being a priority, all participants agreed that communication as a therapy focus was still included indirectly, even though it was not part of the referral.

SPs were confident while talking about their practice when working with PWD and highlighted the importance of their extensive expertise. Consequently, they knew what to expect when working with these cases and how to provide adequate services. However, all participants indicated that there was a lack of awareness of the SP role in the management of dementia among other allied health professionals. Furthermore, low public awareness of the SP role in the management of dementia influenced participants' areas of responsibility.

I'd say for some people there's a very small understanding of the profession and then even within the context of geriatrics as well, but we do try to do a lot of regular education about our role. (SP8)

Our profession is shaping up to be one that mentions dysphagia with a bit of communication on the side and I'm ... very much of the opinion that we need to put as much efforts on the communication as we do on the dysphagia. (SP7)

Lower public awareness influenced collaboration with other professions who were part of the dementia core-care team:

I feel like generally GPs have an understanding of our role, but I don't feel that we communicate as effectively as we could. Generally I will ... write a report that all gets sent to the GP, [but] I don't think I've ever heard back from a GP. (SP9)

Theme 2: Regulatory/Time Constraints for Provision of Services for PWD

This theme emerged after participants discussed how regulations and time constraints affected their provision of services for PWD. Views of current policies and guidelines, and how they influenced clinical practice when working with PWD, were discussed. Lack of guidelines were also discussed:

... in Australia there are clinical guidelines for dementia care. None of them mention speech pathology apart from in swallowing. (SP2)

Additionally, participants indicated that current policies and specifications do not include enough flexibility to provide individual services for PWD.

If we ran out of hours, if we ran out of allocated money, then we have to go through this rigmarole of having change approved before the specified period of change ... (SP1)

Such specifications influenced the overall intervention, and participants indicated the need for more guidance.

I think we can have all the good ideas and plans in the world but I think the support needs to come from higher up. (SP1)

As a consequence of policies and regulations, participants needed to advocate for PWD regularly. This included helping PWD to access more services or resources, such as funding. Advocating for their patients required some of the participants to make decisions on behalf of PWD, which was perceived as difficult.

... so we have sometimes to advocate quite heavily for the medical team to look at this other part what's going on. (SP7)

Sometimes we get asked to come in and sort of help the OTs [occupational therapists] and the md-team [multidisciplinary team] distinguish between different things in their presentation with a view to capacity and decision-making, but I think for everybody it's a really difficult area ... (SP8)

The majority of participants agreed that the types of referrals restricted the way they intervened, given that most SPs received referrals for dysphagia only and intervention for communication was not prioritised due to individual funding. It was also mentioned that referrals for rehabilitation got declined.

We have certainly had some patients declined for rehab because of their diagnosis of dementia ... and you think what sort of difference it would have made to their life if they'd been given the opportunity. (SP5)

Participating SPs reported that time is a valuable resource when working with PWD. Compared with other types of cases, participants reported that they would like to be able to spend enough time with PWD and their families. Additionally, participants reported that intervening with PWD takes additional time, putting pressure on resources.

With this particular population you really don't want to rush things. ...you want to spend the time with them. (SP5)

The time that it takes to have a basic conversation with someone with dementia is far longer than someone without dementia. So that alone requires additional time. (SP3)

Work settings also affected the type of services SPs provided for PWD. All participants reported that this impacted on their clinical work and reported large variation in service provision across different work settings (e.g., acute, rehabilitation, and community care settings).

I think capacity is a bit more limited in the acute setting, because there's so many distractions and it's a new environment for them in terms of setting up a reliable communication system or something of that nature. (SP3)

While some participants highlighted the benefits of working in the home environment due to comfort for the PWD, the difficulty of scheduling services in the home environment was noted.

I have had to make appointments to catch people who notoriously would go away every week I was visiting, to arrange them to be there, but ... unfortunately it's sort of pot luck if they're asleep ... (SP9)

The majority of participants reported the importance of medical notes and reports to support their practice and to provide adequate SP services for PWD. In order to make a definitive assessment, medical notes and reports give clinicians an impression of the patient. However, participants who worked in community and aged care indicated that accessing information about a patient and their medical history varied and was quite restricted.

You need to work in aged care or sometimes in communities with very limited detail. (SP9)

Participants working on hospital wards reported having unrestricted access to medical reports and notes. However, given information about a client did not always include accurate details.

They come in because they've had a fall or whatever it is ... their previous medical history is written in the notes, and I can't count the amount of time that dementia is either not written in a previous medical history but they actually do have dementia, because I go back and have a look on the records and can find [it] in another admission that was previously written. (SP3)

Theme 3: Person-Centred Practice Approach for PWD

This subtheme summarises the factors that influenced clinicians adopting a person-centred approach, considering individual needs and preferences of PWD. Participants stated that allied health professions are often not aware of the services and roles SPs have in the management of dementia. They suggested that educating staff about the SP role in order to provide a person-centred approach was necessary. Furthermore, participants reported that involving staff was useful to fill some knowledge gaps and to provide intervention.

I will utilise ... the staff members who also know these people better and maybe knew them when their level of function was a little higher. (SP1)

One of the main aspects raised in the interviews apart from dysphagia management was the implementation of adequate communication strategies for PWD. SPs reported the importance of providing some strategies for staff and carers to involve them.

The communication partner training ... is a great way to identify strengths and weaknesses. (SP2)

However, participants working in aged care facilities reported that implementing person-centred communication strategies and involving staff and carers was unlikely due to given referrals.

It would be great to go back the next day and focus in communication ... or having a session with the family on the phone ... anything else apart from eating and drinking, it's going on for this person ... but it's just not happening. (SP6)

SP5 added that time limitations affected the therapeutic relationship:

It's often quite ... quite limited. You don't really have much ... as much time to build that longer therapeutic relationship. (SP5)

All participants reported that PWD with their individual needs were placed in the centre of their services.

We work with a focus on comfort and preferences rather than just straight-out rehabs perhaps. (SP8)

Another participant added that, in order to provide a person-centred approach, a full healthcare team is needed.

... taking into account in particular people with dementia ... their likes and dislikes, their interests, and making it really person centred ... like a holistic approach with a full healthcare team ... (SP9)

Building rapport to address individual needs was identified by participants to establish a baseline for intervention. However, participants reported that building rapport with PWD needed time and was sometimes quite limited due to cognitive impairment.

It can be really hard to get them on the same page as you ... you can't really explain what you're doing. But that's, you know, that is something that I say is really challenging. (SP5)

The majority reported working as part of a multidisciplinary team and indicated the value of it when providing services for PWD. In particular, the relationship with occupational therapists was mentioned by participants, as professional borders overlapped when providing intervention for PWD.

The occupational therapist and I work quite closely together in terms of providing that dementia intervention. (SP3)

All participants highlighted the focus on individual preferences in terms of a person-centred approach. This included using different tools (e.g., picture cards) to probe and support goal setting. Furthermore, goals emerged during conversations with the PWD and their carers.

I have used pictures previously to try to assist with determining goals. But usually just a combination of conversation with the person with dementia and with their carers to come up with a plan. (SP3)

Theme 4: Education and Engagement of Carers and Families

All participants mentioned the importance of engaging and educating families when working with PWD. They reported families were helpful to assist with detailed information,

especially for patients with progressed dementia. Moreover, families acted as a link between the SP and PWD in different stages of the intervention.

I've got no other information, so I'm relying on the family to fill in those plans for me.
(SP9)

Given that families were such an important link between participants and PWD, coping issues among family members affected goal setting and how PWD were approached.

Sometimes I find with goal setting it can be a bit tricky, in particular with some family members, who maybe are having some adjustment and coping issues and having those discussions about realistic expectations. (SP9)

Additionally, participants discussed the support they could provide to families and communication partners of PWD.

I think it's important that we remember that at different levels as speech pathologists we can help families. (SP7)

To provide support, participants mentioned referring families to other sources to obtain education, such as grey literature or online courses.

There's the Dementia Australia website ... [it's] great for resources. I often suggest the Wicking Centre ... in Tasmania ... there's a massive open online course ... I often suggest that 'cause I think it's just a great resource to improve their understanding. (SP2)

Moreover, family education meant much more for participants. Especially in progressed stages of the disease, educating the family served as an indirect intervention strategy.

And sometimes indirect [intervention] could be just simple family education. (SP2)

In addition to family education, other allied health professional play a crucial role when working with PWD. Implementing education sessions, targeting allied health professionals in aged care facilities, hospitals, and rehabilitation were described by a few participants, mainly to educate them about key communication strategies.

I have provided education sessions on a broad perspective to nurses within the acute setting, within the inpatient rehabilitation setting, about what are the key communication strategies to communicate with someone with dementia. (SP3)

Theme 5: Challenges of Working With the Diversity of Presentation, Severity, and Characteristics of Dementia

In the final theme, participants spoke about factors that represented a challenge when working with PWD, such as the different dementia types, severity of symptoms, and characteristics. As changes of behaviour in PWD are quite common, participants reported how these changes affected service provision. This can complicate intervention processes but indicates even more that SPs are a crucial part of caring for PWD as changed behaviour interacts with communication breakdown. Participants working in hospital settings reported that they were seeing PWD who were admitted to hospital due to other co-morbidities. As a result, the medical team focused on rehabilitating them physically to get them back to their baseline.

They've come with a bones and hip, but there's still the medical team that focus on the bones and hip and rehabbing them and getting them back to where they were (SP7)

As cognitive functions may progress and are severe enough to interfere with daily activities, participants agreed that cognitive functions had an impact on their work.

Sometimes their cognition can impact their ability to understand, and maybe their cognition isn't super and so that's why they're with us and what we're trying to do. (SP8)

Another perceived challenge participants highlighted was that PWD are a neglected part of the community.

To me they're just a really misunderstood population of people. ... they have their own life experiences and they're still a person, which unfortunately a lot of people in the community seem to forget. (SP9)

Participants also raised the issue that PWD do not receive adequate and timely access to SP services due to their diagnosis.

It's just "oh they're not escalating" so we won't need to see them ... it's the whole path that speech pathologists need to offer as a standard ... (SP7)

5.6.3 Summary: Interviews

Overall, eleven interviews were transcribed and analysed in Stage 2 of the mixed-method study conducted in Phase 1 of this research. Codes were identified within the transcripts and organised into subthemes, which were then categorised into five themes. These themes were (a) factors affecting SP management in working with PWD; (b) regulatory/time constraints for provision of service for PWD; (c) person-centred practice approach for PWD; (d) education

and engagement of carers and families; and (e) challenges of working with the diversity of presentation, severity, and characteristics of dementia. All interviewees had undertaken specific training in dementia to support their clinical experience. Depth of training varied, and its value for clinical practice was only met to a certain extent. In relation to the previously collected survey data from Stage 1, participants confirmed that SPs' clinical practice is mostly centred on dysphagia assessment and management, whereas cognitive-communication is minimally considered. Overall, clarity of the SP role in the management of dementia was limited, and participants stated they did a lot of education and advocating. This limitation of the SP role affected referrals they received and had an impact on the setting of intervention and time regulations for services. As part of their clinical practice, participants highlighted the importance of a person-centred practice approach to allow individual implementation of strategies, build rapport with PWD, and consider the person as the centre of a multidisciplinary team and residential care workers. In Theme 4, the importance of families and carers as part of the intervention was raised. Theme 5 summarised a variety of challenges of working with PWD, such as behavioural problems of PWD, the morbidity and co-morbidities of PWD that affect cognitive functions and overall intervention, and the complexity of dementia as a whole.

5.7 Discussion and Conclusion: Survey and Interviews

In this chapter, a national survey explored current practice and perceptions of Australian SPs. In a previous conducted study in Portugal, Nóbrega and colleagues (2016) found that clinicians had limited clinical practice when working with PWD. In response, they addressed the need for more dementia-specific content in undergraduate and postgraduate curricula, including practical training. Furthermore, Nóbrega and colleagues pointed to the need for broader advocacy of professional roles and activities in this area in the management of dementia. The survey in this research gathered data about Australian SP involvement in different stages of dementia, as well as particular practice patterns and involvement in the management of dementia alongside other allied health professions. SPs' current practice was mostly focused on swallowing and feeding, and the majority who submitted the survey received referrals of PWD mostly in the intermediate or later stages of the disease. To build on the survey data gathered, more in-depth data were collected through semi-structured face-to-face interviews. The interview questions were based on the previous survey areas and enabled participants to reflect on their experiences and perceptions when working with PWD. Participants stated that their role included monitoring and assessment of swallowing and

feeding and cognitive communication, as well as education provision and management of language and communication issues. SP responsibilities strongly varied and depended on the setting and requested services from providers. Applying principles of good dementia care, however, seemed to be a priority of all participating SPs. The importance of an individualised approach was highlighted, including the importance of a partnership between PWD and clinicians, acceptance of the reality of PWD, and to enable PWD to achieve minor and major goals. Even though participating SPs were not asked directly about person-centred principles, they felt the urge to discuss these principles as part of their responsibility and provided services. Overall, person-centred care principles seemed to be the basis of any intervention to facilitate quality of life.

Overall, there seemed no consistent service provision across different settings. Furthermore, SPs emphasised the importance of involvement and correspondence with other allied health professionals and the PWD's carers and family members, which was not always given. SPs noted that there seemed to be limited public awareness of the role of SPs in the management of dementia, which impacted adequate service provision. Additionally, SPs reported that dementia is only taught as part of the university curriculum to a certain extent. Consequently, clinicians needed to undertake further training after graduation as well as extensive researching of information. Given that currently there are no guidelines to direct Australian SPs in the management of dementia (see Chapter 3), the survey and interviews reflected that current practice includes lots of researching of resources and information for service provision in dementia. These findings suggest several courses of action for professional practice and policy. The design and implementation of public documents should be the focus of professional bodies and other relevant public leaders, to address the needs of a variety of stakeholders. Additionally, protocols should be developed to ensure that PWD get access to SP services early on and to improve interdisciplinary and multidisciplinary. On a professional level, dementia as a holistic area of practice should be included in university curricula to a greater extent. Post-graduate professional development should be maintained to ensure knowledge is current in this rapidly developing area of practice.

These results prompted further inquiry into what kind of resources and information SPs access, how they use them, and how to facilitate access to resources and information to provide adequate services for PWD. In the next chapter, SPs will be part of an expert panel to gather their needs, ideas, and potential solutions to facilitate their practice when working with PWD.

Chapter 6: Phase 2: Ideation

In the previous chapter, the current practice of Australian SPs was explored and issues as part of their clinical practice were identified. Results from the survey and themes that emerged from subsequent interviews highlighted the lack of sufficient resources and information to guide the clinical practice of SPs. Issues were identified in service provision, which mostly occurred in the later stages of dementia and focused on swallowing and feeding rather than cognitive communication. Moreover, other allied health professionals as well as families and carers had different levels of knowledge about the role of SPs in the management of dementia. SPs reported that part of their practice after graduating included completion of further training, as well as researching for further information and resources. This issue is further addressed in this chapter as part of Phase 2 of the HCD approach. SPs participated as experts in focus groups to express their ideas, needs, and feedback around a helpful solution to guide their clinical practice when working with PWD. This prompted further inquiry into what resources could support clinicians in assessing resources and information easily in order to provide adequate services for PWD. The following research question guided the study in this chapter: What would be a clinically useful (digital) resource for SPs to facilitate and support their clinical practice and dementia-related services? Further subquestions were developed to answer this: (a) What resources would SPs like included in a web-based resource? (b) How does a resource guide target the needs of SPs? (c) In what context or setting will SPs use a resource guide? (d) To what extent is the developed resource guide helpful? and (e) What content should be covered in a resource guide? To formulate ideas in the ideation phase, two focus groups were held. The procedure and results for this phase are reported in this chapter.

6.1 Research Method

In this phase of the project, a qualitative research design consisting of focus group interviews was used. This method was chosen to obtain data from the target group directly rather than from a representative sample of this population (Nyumba et al., 2018). The contribution of focus group discussions as methodology is ideal, as participants get the opportunity to discuss their unmet and met needs by formulating their personal point of view (Acocella, 2012). Furthermore, since the purpose of this study was to gain insight into the SP perspective, focus group methodology is a well-suited tool for generating consumer feedback for the development of a new product or prototype in order to determine its pros and cons (Greenbaum, 1998) and to

draw directly upon participants' ideas, views, and experiences (Minichiello et al., 2004). The focus group environment enabled participants to interact with each other (Wilkinson, 1998) and to express their thoughts and feelings freely by interacting in a group context rather than one-on-one interviews (Plummer-D'Amato, 2008; Wilkinson, 2005). The focus group sessions were held online via Zoom in order to make participation accessible and flexible for participants across Australia. Questions from the interview guide were purposefully applied when appropriate to facilitate an easy flow within the discussion (Krueger & Casey, 2002). The questions were worded in a more active way to impact the discussion in a profound and more enjoyable manner (Colucci, 2007) and sought information about what resources SPs considered important when working with PWD, such as online resources (MOOCS, printable information sheets, etc.), international professional guidelines, and available assessments for PWD. In addition, an outline for an online resource was discussed in order to address a user-friendly design. Content areas were covered using primary open-ended questions (e.g., "What are your thoughts on this?"), probe questions, and follow-up questions (e.g., "What are the pros and cons of ...?"). The focus group guide is included in Appendix D.

6.2 Participants

Invitations to recruit participants were sent out via email to individuals who had registered in the database as part of the survey (see Section 5.3.1). The emails asked the database contacts to share the invitation within their network of colleagues to enable snowball sampling (Etikan et al., 2016). Recruitment posts were also published on social media channels (LinkedIn, Twitter, and Facebook; see Appendix D). Participants were recruited in Australia only. Written information concerning the study was distributed as an information statement, and those who chose to participate gave consent.

Eighteen SPs indicated their interest, and eight were able to attend a focus group session. Those who indicated interest in the focus group were also interested in participating in the following survey. Further demographic information was not gathered so as not to limit the desire to participate or the detail of given responses if participants felt pressure to share with others. SPs who were interested in the project but were unable to attend the focus groups were given the opportunity to provide their written feedback based on the focus group protocol. One SP submitted written feedback via email in a Word document. During the recorded sessions, the identity of participants was protected by excluding identifying questions, such as workplace

practices or policies. Further, participants were allocated pseudonyms, which were used during the sessions and afterwards during analysis.

6.3 Data Collection

The data collection was conducted in June 2021. Two focus groups were conducted online via Zoom (version 5.5.0). Before the discussion started, a brief PowerPoint presentation was screen-shared to give participants background information about the previous studies (Phase 1; see Chapter 5) and the objective of the focus group discussion. A discussion guide with questions was developed. It included questions about dementia-related resources that participants used. Furthermore, the survey and interview results from Phase 1, as well as the practical experience of the research team, influenced the questions asked about participants' potential needs and ideas regarding a web-based resource. Overall, there were four categories for the questions: content, purpose, platform, and design. The questions within those categories were only used to prompt an active discussion. At the end, follow-up and additional questions were asked to make sure all participants were heard and their thoughts were verbalised. Table 6.1 displays the guiding questions in each category.

Table 6.1

Guiding Questions

Category	Guiding questions
Purpose	What's the purpose of resources you usually use? What kind of resources do you usually use when you work with people with dementia? Where do you access your resources from? What matters to you when you look for those resources What makes you choose a specific platform/blog/webpage? How do you look them up?
Platform	What platforms do you use when you access these resources? Are there specific platforms/blogs/webpages in particular you are using? Where do you access such resources from?
Content	What content should be included in a web-based resource? What area should be included in particular? Should the resource guide also include the option for networking with other SPs?
Design	How should the perfect resource guide be designed ? Desktop and mobile device version? Drop-down lists? Search function?
Follow up	Is there anything else you would like to add?

The focus groups were conducted by the researcher who acted as a moderator. The first focus group was held on 21 June 2021 with two SPs participating and took 32 minutes. One participant who had wanted to attend did not attend. The second focus group was held on 22 June 2021 with six participating SPs and took 46 minutes. There was one returning participant who participated in the previous conducted interviews (see Chapter 5.5). All other participants in the focus group did not participate in any other phase of the overall study. Overall, participants were actively engaged and there were often spontaneous discussions within the groups. In the second group, one participant did not engage actively or add to the discussions. Statements and discussions were often followed up by another participant adding input or agreeing. The atmosphere was positive and participants were open to sharing their thoughts. The focus group discussion was recorded via the Zoom recording function. The Zoom transcript was used and then checked against the audio recording. The verbatim transcript was checked for identifying information, and any such information was removed from the transcript. Participants were de-identified by replacing their names with the abbreviation SP and a number (SP1 to SP8) to ensure their anonymity. Natural speech was not edited; however, to aid readability, filler words and sounds such as “uh” or “um” were removed from the transcript. Time stamps were added to the transcript as a helpful device to ensure that the audio file corresponded with sections of the transcript. The transcript was sent out to participants as part of the member-checking process, wherein they were given the opportunity to add comments or amend statements.

6.4 Analysis

For the focus group data analysis, a deductive approach was chosen wherein predetermined categories were developed based on the previous data from the survey and interviews (see Chapter 5). The four overall categories (see Table 6.1) covered the potential content of a resource guide, its type of platform, and its purpose and design. A categorisation matrix was created in order to code the data within the predetermined categories (Elo & Kyngäs, 2008). The matrix was used to structure participants’ chosen responses across the categories in tabular format (Drisko & Maschi, 2016).

As qualitative data is subject to the biases of the researcher (Graebner et al., 2012), the data analysis of the content and themes that emerged were discussed among all team members

in regular meetings. Such meetings ensured mutual understanding and interpretation of the generated data.

The two focus group transcripts were prepared for analysis by applying the following procedure (Rabiee, 2004):

1. Excel was used to ensure easy assignment of statements to different participants.
2. Two hard copies of the transcript were made in order to cut off statements and pieces manually and to change them physically towards the categories if needed.
3. Each transcript was organised in a reasonable order (background information of the project that was given as an introduction in the beginning and then the focus group discussion wherein prompting questions were asked and participants discussed these).
4. Each page/paragraph was annotated with the question that was asked by the moderator and discussed by participants.

Such steps enabled familiarisation with the data and were an initial step of the analysis. (Forman & Damschroder, 2007). Additionally, notes were taken during the session to clarify content within transcripts (Bertrand et al., 1992). As the collected data was intended to inform the web-based prototype, the focus was specifically on statements that mentioned materials, ideas regarding design and content, and specific resources in light of the pre-determined categories. Furthermore, there was an option to add categories for undetermined statements.

Participants who were not able to attend in person but still wished to contribute were provided a Word document via email. The questions from Table 6.1 were presented in a two-column table with the questions on the left and a comment field for their notes on the right (see Appendix D). Written feedback received was then copied into an Excel spreadsheet in order to assign the feedback to the predetermined categories.

For each transcript and the written feedback, a separate Excel spreadsheet was used to capture the meaning units. The condensed meanings of such units were then categorised. Table 6.2 shows portions of the focus group discussion and how they were categorised.

Table 6.2*Categorisation of Portions of Focus Group Discussion*

Question	Meaning unit (from quote)	Information	Condensation	Code	Category (pre-determined)
What kind of resources do you usually use when you work with people with dementia?	I use a lot of resources that are recommended by Huntington's Victoria. I work mostly with people with Huntington's disease.	I use a lot of resources that are recommended by Huntington's Victoria	Using resources recommended by Huntington's Victoria	Huntington Victoria	Platform
What content should be included in a web-based resource?	The other thing is, like, if it actually, it's really important that it's clear what is evidence-based and what isn't evidence-based.	It's clear what is evidence-based	Indicate clearly if resources are evidence-based	Mark evidence-based resources	Content
How should it be designed?	[It could have] a component of a blog section or something.	A component of a blog section	Having a blog section	Include blog section	Design
What's the purpose of resources you usually use?	I've got a family member that has dementia and because I'm the speech pathologist in the family, I had to actually do quite a lot of research and look for information.	I had to do quite a lot of research and look for information	Researching information about dementia	Accessing information	Purpose

Following the coding process, codes from all single documents (transcripts and written feedback) were combined in a table with the four main categories. To keep track of the codes and provide a reasonable overview, subcategories within the main categories were created. Table 6.3 shows a portion of different codes that were organised into the categories and subcategories.

Table 6.3*Organisation of Codes Into Categories and Subcategories*

Category	Subcategories	Codes
Content	Dementia: Disease and symptoms	Complexity of dementia Overview of dementia types Overview of dementia stages
	Accessing and providing information	Access information Defining SP role in early stage Providing information to other allied health workers
	Evidence-based practice	Best-practice library Up-to-date information Evidence-based resources
Purpose	Access to information and resources	Individualised resources Information for carers Easy access for NESB
	Family involvement	Working with families of PWD Families most valuable resource Share links directly to families
	Area of speech pathology	Role of SPs in communication Access interdisciplinary knowledge Awareness of SP responsibilities
Platform	Specific platforms	Dementia Australia Huntington Victoria
	Types and characteristics of platforms	Peer-reviewed platforms Specific journal databases Cochrane reviews
	Device type to access platforms	iPad Computer Convenience of smartphone
Design	Visuals on website	Integrating animations Include clips Written pictures
	Characteristics of website	Mobile-friendly website Search function for keywords Fast speed
	Layout	Simple design Save PDFs in one location Adequate formatting on screen

Note. SP = speech pathologist; PWD = people with dementia

6.5 Results

Overall, no more categories were added to the four predetermined categories (see Table 6.3). Across all four categories, seventeen subcategories emerged, which will be discussed in the following subsections. Although participant numbers in each of the two focus groups were different, there were no significant differences in ideas or answers between the two groups. However, content in the second focus group with the higher participant numbers was discussed in more depth.

6.5.1 Content

In this category, participants discussed content they would like to see on a web-based resource. Overall, seven subcategories were determined for the content category (see Table 6.4). Dementia as an umbrella term for different diseases and symptoms was discussed, as participants indicated they would like to have an overview of the diseases and symptoms in order to develop understanding of their professional practice. Educating others and providing information was seen as another important factor that should be included to enable access to information for themselves and others. To support their clinical practice, evidence-based practice was highlighted as another important content category, along with approaches and tools that can be used for their intervention. Further, connecting with other clinicians and other allied health professionals to exchange knowledge was discussed. As another content category, participants indicated they would like to have downloads and links to other pages to inform their practice. The last subcategory was working with families as a central component in the management of dementia.

Table 6.4

Subcategories: Content

Category	Subcategories
Content	Dementia: Diseases and symptoms
	Accessing and providing information
	Evidence-based practice
	Intervention: Approaches and tools
	Networking and interdisciplinarity
	Downloads and links
	Working with families of PWD

Note. PWD = people with dementia.

Participants indicated they would like to see content on the website that is dedicated to the disease and symptoms but also progression of dementia.

I think one of the things is definitely the progression of dementia and to know what that means in terms of their staging ... if it's mild, moderate, severe, and what type of dementia. (SP3)

Additionally, participants indicated they would use the website resource to access information for themselves but also to provide information in terms of educating others.

Something that has information for both families and therapists would be mind-blowing. Like a central place to go for people to access information. (SP5)

In terms of accessing information, the need to find information autonomously was mentioned.

If you're really interested in this area, then here's some resources that you can read more about it. (SP3)

Another subcategory covered evidence-based practice when working with PWD. Participants discussed in the group that they were aiming to provide the best evidence-based practice. Hence, content on the website needs to be evidence-based.

The content has to be evidence-based; we're always looking for the evidence-based practice. (SP1)

Participating SPs elaborated their thoughts on intervention approaches and potential tools they were using for PWD as part of their practice. The tool that was mentioned most was a life-story book or "about me" book with individual photos of the patients.

I like life-story books or things that are relevant to them anyway, so you'd want the family to be taking pictures around their house and their family and making resources based on what they know as well. (SP1)

Participants were agreed that potential approaches and tools could not be generalised as patients have individual needs and interests. The choice of the tools and resources was described as a carefully evaluated process.

According to the patient's background, cultural influences, visual discrimination ... all the factors that we look at, we don't just go to Google and choose the first photo that you look at. We are actually mindfully choosing on a range of different factors, and so I just think it would be difficult, potentially, to come up with a set that's going to then be able to be rolled out across the board. (SP5)

Hence, providing templates as a content category on the website was discussed by participants with mixed feelings, as some agreed that those templates may be too general.

I think it might be difficult having just general templates on it when you're going to have to modify it quite significantly for the person anyway, and then they might not be able to use it in the end, regardless, for whatever reason. (SP4)

Another potential use of the website with its contents was the opportunity to network and exchange with others who work with specific subgroups of PWD. One participant mentioned that professional exchanges with others who work in the same field of interest was currently limited and not fulfilling.

I find it really difficult to find speech pathologists who have an interest in prog neuro [progressive neurodegenerative dementia] or young-onset dementia. I'm on a few different groups and the ECS mailing list through Speech Pathology Australia, and I am on a neuro Facebook page, but it's very inactive. (SP1)

Furthermore, the potential for interdisciplinary networking with other professionals through the website was discussed.

In the rehab setting I've been very fortunate to have access to allied health assistance. A webpage could provide the opportunity to reach out to them. (SP4)

Participants commented that downloads and links would be a useful type of content in order to be redirected to other websites or to download printable information sheets.

I think it'd be great if the website has like printables, like a summary, and then you can print it down [at] the end, that would be really beneficial. (SP3)

Additionally, the redirection to other information points was mentioned, such as videos through YouTube.

There's also so much stuff on YouTube about dementia. (SP3)

Although participants were informed that at this stage the website resource was focusing on SPs only, the inclusion of families was an inseparable part of their practice when working with PWD. Hence, the importance of adding a section for families as well was heavily discussed.

I like the idea of breaking it into two sections, for speech pathologists and for families. Having a section with support for families or some kind of mentoring for speech pathologists. (SP4)

Within this subcategory, SPs indicated that information about communication and swallowing should be added in order to support families of PWD. As one participant suggested, this could also include some guidelines to provide simple information on these topics.

I think it would be really good if we developed guidelines for family members. (SP1)

Additionally, there was overall agreement that the families of PWD were actively involved in different areas of intervention, such as diagnosis and indirect or direct therapy.

My take is that the patient's family are the most valuable resource and I'm going to capture as much information as I need to about the patient in regards to his communication status.

(SP4)

In the next phase of this research, the content subcategories arising from the focus groups will be considered as modular content components for the development of the website prototype. Potentially, they will ensure easy navigation through the website and may comprise further information and details.

6.5.2 Purpose

Questions covered in this category initiated discussions around the purpose of platforms and resources participants used on a regular basis. Such questions were asked in order to inform the content categories discussed above. Four subcategories were identified (see Table 6.5). Participants discussed that they accessed different digital resources with information about the management of dementia. Part of their practice included extensive researching for different levels of information and resources to inform their work. Besides information for themselves, they accessed different platforms to involve families and to provide them with links to websites. This ensured they were able to access information about communication and swallowing by themselves. A further subcategory on the purpose of different resources was advocacy of SPs about their role in the management of dementia to support their professional background. Further, participants again discussed the importance of evidence-based practice, which appeared to be a crucial element in the management of dementia.

Table 6.5*Subcategories: Purpose*

Category	Subcategories
Purpose	Access to information and resources
	Family involvement
	Area of speech pathology
	Evidence-based practice

The first subcategory discussed an aspect of participants' purpose for using resources, which was the access to information and resources. It was communicated by participants that researching for information and resources was an active component of their daily practice to inform their interventions with PWD.

I think just information on what the ... role is and whether that's linking to research or what things we can actually do in the earlier stages in the community. (SP3)

Another participant added that her purpose for accessing information and resources was to gain knowledge and test herself based on the given information.

If there are videos that you're watching with questions that you can be asking yourself to try and answer. Or scenario-based questions trying to apply some of the knowledge that you're learning. (SP4)

Another reason why participants were choosing a specific resource was the desire to involve families. Participants discussed that it was helpful to equip families with links to websites to ensure they could access any information about communication and swallowing by themselves.

Being able to use things that you can then potentially also share the link directly to a family who are going to be more connected and tech savvy and using their own devices as well. (SP5)

A further subcategory on the purpose of chosen resources was their relationship to the area of speech pathology. Participants discussed that they looked up resources that covered their professional background.

I'm really passionate about our role in reablement in early stage to say so, something that absolutely grasps that whole continuum is fantastic. (SP2)

As in the content category already presented, evidence-based practice was mentioned as their purpose when SPs looked for resources for PWD.

For more ... specific stuff for myself it's really going to look at the research and looking at what the research has done, and what people have been doing the research. (SP6)

6.5.3 Platform

In this category, questions aimed to facilitate discussion about explicit platforms the participating SPs were already accessing. Three subcategories were identified (see Table 6.6).

Table 6.6

Subcategories: Platform

Category	Subcategories
Platform	Specific platforms
	Types and characteristics of platforms
	Device type to access platforms

Participants discussed specific platforms they were using to access information, exchange with others, or expand their knowledge about dementia. Platforms ranged from professional and interprofessional websites, interest groups, and blogs, to typical social media platforms (see Table 6.7).

Table 6.7*Platforms Used by Participants*

Specific platform	Type of platform
Dementia Australia https://www.dementia.org.au/	Website
Dementia Australia Facebook page https://www.facebook.com/DementiaAustralia/	Social media
Dementia Training Australia https://dta.com.au/	Online course
Huntington's Victoria https://huntingtonsvic.org.au/	Website
Google Scholar https://scholar.google.com/	Search tool
Speech pathology email chats https://groups.google.com/g/ecs?hl=en	Mailing list
Speech Pathology Australia https://www.speechpathologyaustralia.org.au/	Website
American Speech-Language-Hearing Association (ASHA) https://www.asha.org/	Website
SpeechBite https://speechbite.com/	Website
Aged Care Quality and Safety Commission https://www.agedcarequality.gov.au/	Website
Med Bridge https://www.medbridgeeducation.com/	Website
Med Bridge webinars https://www.medbridgeeducation.com/live-webinars/#upcoming-webinars	Webinar
University of Tasmania MOOC https://www.utas.edu.au/wicking/understanding-dementia	Massive open online course
Jade Cartwright's workshop via Speech Pathology Australia	Online workshop
Victorian Dementia community of practice	Interest group
Swallow Your Pride podcast https://podcast.theresarichard.com/	Podcast
Dysphagia Café https://dyhagiacafe.com/blog-dyhagia/	Blog
Theresa Richards Instagram account https://www.instagram.com/theresarichardSP/?hl=de	Social media
YouTube https://www.youtube.com/	Social media
Twitter https://twitter.com/	Social media
Scope Victoria https://www.scopeaust.org.au/	Website

In terms of types and characteristics of platforms participants were already using, they indicated that content on each platform they were looking at should be “easily searchable” (SP2). But participants also took into account the level of evidence and discussed that they made sure it was a reliable source or “something that’s peer reviewed” (SP5).

Participants were asked how they would usually access websites. They all stated they used either their computer/laptop or their smartphone. One participant indicated that their work setting allowed her to access such platforms via her work computer:

We have offices in a dungeon so we have no mobile phone service and certainly my preference would be using the computers at work to access information within work hours.
(SP4)

Another important point discussed among participants was that sometimes platforms were accessed via a smartphone device and therefore needed to display properly on these devices.

I guess, the main thing is that when you open it on the phone that you don’t have wrapped stuff. (SP2)

The platforms with different links and resources discussed by participants and shown in Table 6.7 provided valuable information which influenced the prototyping of the website enormously in the next phase of this research. These ranged from informal social media accounts to more formal, official websites, for example, the Australian Government Aged Care Quality and Safety Commission website.

6.5.4 Design

The final category covered in the focus group discussions related to the design of the proposed resource. This category asked specific questions about the design for the website development. Three subcategories were identified (see Table 6.8). Discussions around design included ideas around the visuals on the website, specific characteristics of the website, and the overall layout. Participants discussed that different clips with information about dementia would add to the website, as well as some resources with animation. Specific characteristics of the website that came up included the loading speed of content, as well as intuitiveness in presentation. Further, participants indicated that content should be easily searchable. The overall layout should be an adequate size, as well as using bookmarks or markings for interesting content. Participants also suggested the idea of receiving a frequent newsletter, which potentially is also connected to a social media account to disseminate updates.

Table 6.8*Subcategories: Design*

Category	Subcategories
Design	Visuals on website
	Characteristics of website
	Layout

In the first subcategory, participants overall agreed that the website for this project should definitely include visuals. As one participant suggested:

[The website could be] a central place to go for people to access information with little clips. (SP5)

I wouldn't mind seeing some clips, almost from an educational point of view. (SP3)

In terms of visuals, participating SPs discussed that visuals on the website should support simplicity in order to convey information.

It would be great if there were resources available that were easy resources ... with some animation. (SP1)

In terms of the characteristics of the website, participants indicated they would prefer a website rather than an app. However, they suggested that “the speed of it needs to be fast” (SP2) and content needed to be “intuitive” in presentation (SP1). Another participant indicated that website characteristics were not that relevant as:

I think easily searchable things should be included because I think it doesn't matter if you design it whether it's categories, lists, icons. (SP5)

For the layout of the website resource, the content was discussed as needing to be flexibly formatted to fit the screen size, with the option to mark favourite PDFs and printables as well as including bookmarks. Furthermore, participants elaborated that the option to sign up to an email newsletter would be worthwhile adding in order to receive updates.

I quite like to get an email, maybe [a] fortnightly or monthly email, with some bits that are new. (SP6)

Alternatively, the idea was raised to link a social media page to disseminate updates:

... or perhaps this site has a Facebook page or something linked to it, and then you might see things pop up on your feed and be prompted to go onto the site to have a further look. (SP6)

6.6 Summary

This chapter has presented the results of Phase 2 of this research, the ideation phase, which consisted of two focus groups. All participants were actively engaged in the discussions and interacted with each other in a fair manner. The results highlighted what kind of resources and platforms SPs currently used to manage dementia as part of their daily practice. Such platforms included social media, general and professional websites, such as the ASHA website, and podcasts or blogs. However, ensuring evidence-based practice was strongly emphasised during the discussions. In terms of content, participating SPs discussed that dementia as a disease with its stages and symptoms should be a part of a web-based resource. Furthermore, accessing information as a professional and providing information to clients and their families was another matter of importance to participants. The need for networking with others as well as interdisciplinary exchange was another discussed point as part of the content category, and the website resource could act as a connection point for those who work with PWD. To facilitate the SP role, downloadable PDFs or links should be included as well. Participants usually accessed other websites or resources for the purpose of self-education, to gain awareness of the role, or to share knowledge with families of PWD. In terms of the design of the resource guide, participants stated that they wanted an easy-to-access, multimodal information repository with a search function and visuals.

This phase of the research helped to collect ideas and data from an expert panel to inform the development of a web-based resource prototype. The next chapter will describe the steps applied in developing the website.

Chapter 7: Phases 3 and 4: Prototyping and User Feedback

In the previous chapter, focus group data regarding SPs' ideas and opinions were generated across the predetermined themes, covering content, purpose, platform, and design. Within the two focus groups, participants agreed on the preference for a website that is easily accessible and searchable regarding specific terms. As content for the website, subcategories generated for the main page included dementia diseases and symptoms, access and provision of information, evidence-based practice, approaches and tools for intervention, networking and interdisciplinarity, specific downloads and links, and working with families of PWD. Participants expressed the view that the website should be an information repository that supports SPs in their role. This included providing information about dementia types and the range of different symptoms, links to evidence-based practice through research updates and articles, materials used in therapy settings with PWD, and engagement with other clinicians. In this chapter, the gathered information as well as contemporary resources inform the development and prototyping process for a website product to support SPs when working with PWD. Following the prototyping process, user feedback was gathered to evaluate the prototype. The user evaluation process and results are as well outlined in this chapter.

7.1 Development of a Dementia Resource Guide for SPs

7.1.1 Rationale

In evaluating user requirements by gathering SPs' views and perceptions in Chapter 5 and Chapter 6, data revealed that there was not enough information to support their practice when working with PWD. Initially, the scoping review (see Chapter 3) identified multidisciplinary guidelines in order to define the SP role in the management of dementia. Neither these existing guidelines nor information given on the SPA website provided sufficient information on the management of dementia specifically for SPs. Further, survey participants indicated they used different types of information scattered throughout different resources. The SPA website includes a "Resource Guide" page with eight external links: Aged Care, Disability, Language, Literacy, Speech/articulation, Swallowing, and Voice (Speech Pathology Australia, 2019). Going through the links in detail, there is no specific consideration of resources for dementia. Further information on the website includes special interest groups, wherein one group is specifically dedicated to early onset dementia. Useful contacts on the SPA website (SPA, n.d.)

include links to professional organisations overseas, allied health organisations, and an external “Your Health Link” to a website (<https://yourhealthlink.health.nsw.gov.au/>) designed as a centralised gateway to Australian health organisation websites to assist consumers and allied health professionals in searching for information. However, in-depth information about working with PWD and their carers is not given on the SPA website. Consequently, to meet the needs of practising clinicians and support SPs working with PWD in Australia, there is a need for a resource hub.

In the last few decades, SP practice has been influenced by technological advancement, wherein the internet has become an indispensable tool for clinicians as it enables them to access information and resources flexibly from anywhere. Retrieval of online information, such as ebooks, is attractive to consumers as such information has the advantage of being accessible without additional weight and is environmentally friendly (Shaver & Shaver, 2003). Furthermore, technology not only makes information more accessible for clients (McGill & McLeod, 2019) but also enables SP services to be provided as teletherapy for clients and patients, especially in rural areas and geographically isolated regions (Fairweather et al., 2016; Hill & Miller, 2012; Mashima & Doarn, 2008; Mohan et al., 2017; Reynolds et al., 2009).

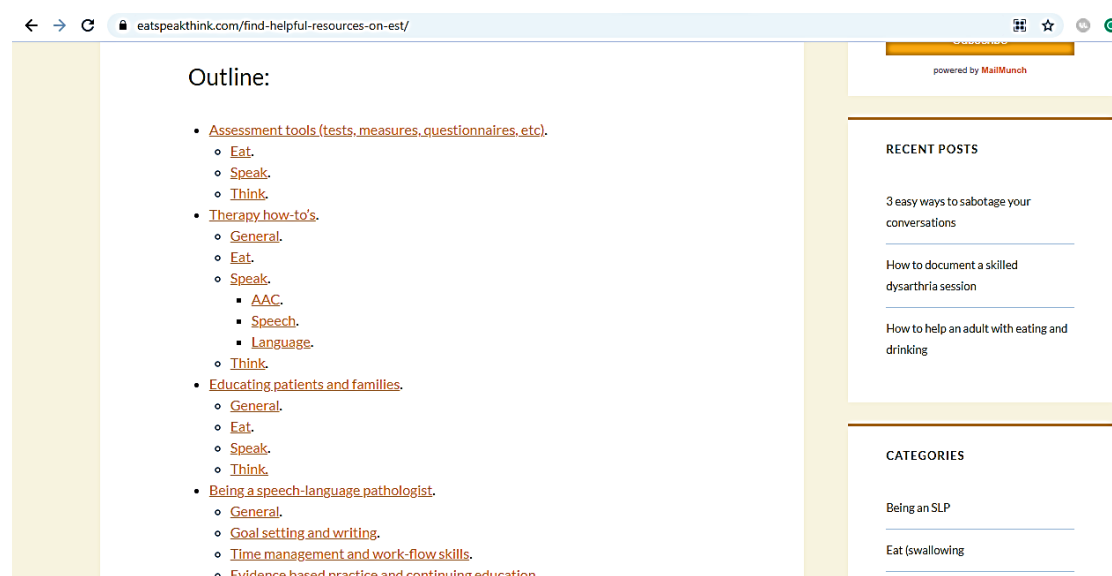
As part of teletherapy, SPs are experienced in using cameras, headphones and microphones, and the internet with different communication technologies (Keck & Doarn, 2014). In the last three years, in response to the global COVID-19 pandemic, the terms “telemedicine” and “e-health” have experienced increased interest as the urgency of integrating technological devices and digital therapy delivery services rose. This experience revealed that used materials and resources need to be easy to prepare and access (Rettinger et al., 2021; Tambyraja et al., 2021). Now that the trend goes more towards online-based practice, therapists and clients need to be able to access their materials online and, if necessary, manipulate them and interact through them (Towey, 2012). This is a chance for advancement of SP practice as digital resources, such as worksheets and therapy materials, can be more easily retrieved, modified, and recombined for individual purposes compared to hard copies (Littlejohn, 2003; Macmillan, 2004).

In recent years, blogs have become more popular as they are an informal way to publish any kind of information so it is accessible to the public (Hsu & Lin, 2008). Based on the variety of existing websites with blogs, their outlines and contents are diverse. They can be formatted as single entries with lists or essays, including announcements or links, and sometimes with an interactive comment function for their readers (Bar-Ilan, 2005). As opportunities for blogging

are limitless, this movement did not skip health-related topics and allied health research. Blog sites have become a common tool to distribute information or to discuss topics for healthcare students or professionals (Maag, 2005). A number of professional blogs written by SP students and clinicians exist, where they share ideas, views, personal stories, materials, and information on specific topics (Kay, 2012). Such blogs can also have a learning function and may be used as a professional development tool, for example, in the area of teaching (Hou et al., 2009; Khan, 2017) or medical education (Sandars, 2006). As there is no specific method for sharing blog posts or information, they add value in different kinds of ways. As shown in Figure 7.1, blogs can include lists of subject-based headings that lead to posts about a specific topic, such as therapy materials, information regarding a disease, or assessment tools.

Figure 7.1

Blog: Eat, Speak, & Think



Note. From *Easily Find Helpful Resources on Eat, Speak, & Think*, by L. A. Young, n.d., *Eat, Speak & Think: A blog for medical speech-language pathologists* (<https://eatspeakthink.com/find-helpful-resources-on-est/>).

Copyright 2018–2022 by L. A. Young. Reprinted with permission.

The ways clinicians access information and resources has changed over the past two decades; thus, there has been a development in web-based resources. In general, websites are complex document types that combine a visual organisation with different communicative purposes and functions simultaneously (Santini, 2007). Today, websites are an indisputable part of the internet and are a major element of our “communicative infrastructure” (Brügger, 2009, p. 115). Therefore, the resource guide as part of this study was designed as a digital, web-based tool.

7.2 Phase 3: Prototyping

For the purpose of the overall study in this thesis, a prototype of the web-based resource was developed. A prototype constitutes a solid basis for identifying difficulties, clarifying problems, and highlighting strengths for the subsequent main development process (Budde et al., 1992). The definition of prototypes is vague as they can vary in quality, ranging from rough drafts to very detailed running systems (Hennipman et al., 2008). The aim of this study was to create a resource that reflected the needs of the SPs as identified in Phases 1 and 2 (see Chapters 5 and 6, respectively), which will then be evaluated by the SPs in Phase 4 to follow. Different methods for prototyping are explained in the literature, such as user interface prototyping, wherein users are already actively involved in the design process (Baumer et al., 1996; Weichbroth & Sikorski, 2015); service prototyping or design thinking, which is a problem-solving process to improve user experience by identifying solutions (Adams & Nash, 2016); and rapid prototyping, a method that is an initial realisation of a conceptual structure of the final product (Jones et al., 1992). For this project, rapid prototyping was chosen as this allowed the researcher to apply, test, and retest different ideas and content in a time-efficient manner. This then enabled preparation of the website for Phase 4 of the project: receiving user feedback. Furthermore, rapid prototyping of a website kept the development process within time and money constraints, as none of the research team had extensive experience in coding or generating a website from scratch. Focusing on the final prototype, design fidelity was considered. “Fidelity describes how easily prototypes can be distinguished from the final product and can be manipulated to emphasize aspects of the design” (M. Walker et al., 2002, p. 661). Hence, the prototype developed was not meant to represent a finished product. Moreover, the focus of the prototype was on content rather than aesthetics. Whereas low-fidelity prototypes are often paper-based (Virzi, 1989), mid- to high-fidelity prototypes present with detailed information and content and allow interaction by the end user, in this case, the SPs participating in Phase 4 of this project (Engelberg & Seffah, 2002). For this project, a mid-fidelity prototype was considered as information that emerged from the previous focus group discussion was considered where possible, and interaction through specific buttons on the prototype website were taken into account. To achieve this, an internet search was conducted, looking up the terms and phrases “creating a website”, “website building”, and “website development”. Reviewing the search results, two commercial sources stood out: TechRadar (2022), an online publication focused on technology, and Website Builder Expert (2022), a website that lists and compares different website building platforms. Reading through the lists,

the following criteria were considered: ease of use, flexible design opportunities and provision of photos, price, and any provided help and support. Making a final decision based on these criteria, Wix (www.wix.com) was chosen as the website builder. Given that the research team were novice creators of websites, this builder included various applications to build a website without any coding experience. It offered a doable and affordable design process, as applications such as a visual editor with different templates, photo galleries, and web-hosting opportunities were included. Other builders were considered as well but did not seem to have such a wide template and gallery offer.

7.2.1 Prototyping Procedure

For the rapid prototyping process, themes and subthemes from the preceding focus groups that involved expressed expectations and values from participating clinicians were the focus, as they provided a guide for organising the content areas within the website (see Table 6.4).

Engelberg and Seffah (2002) introduced a rapid-prototyping framework, which was adapted for this research by considering the four predetermined themes: design, content, platform, and purpose. Given that the original framework was used for website prototypes built from scratch, steps were adapted to fit the chosen website builder and were used as a model throughout the prototyping process:

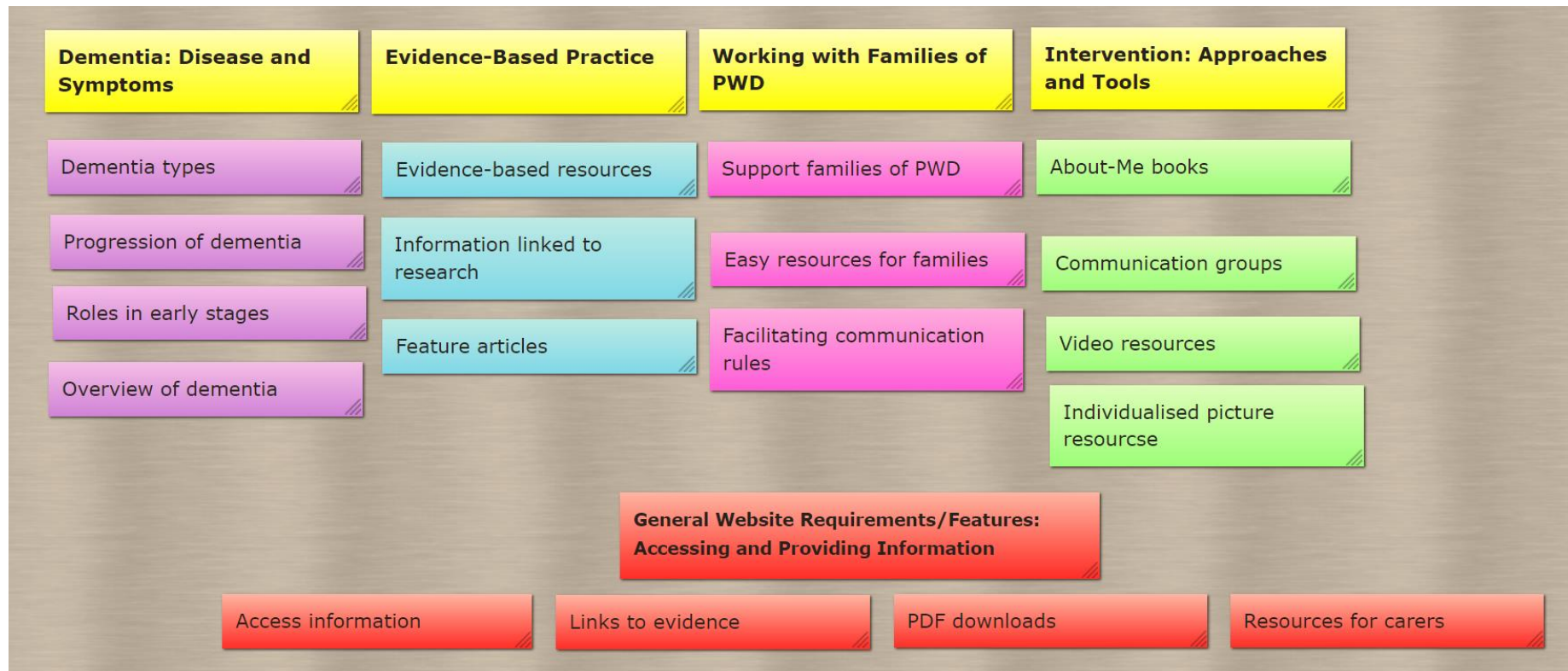
1. Prepare outline of content.
2. Define design pattern and main areas of content.
3. Define screen capabilities and fonts.
4. Define main areas and navigation.
5. Insert different pages, PDFs, and links.
6. Test links and navigation.
7. Detail and refine page contents and links (recurring step).

Step 1: Prepare Outline of Content

In this initial step, an outline of the content areas of the website was created by structuring the ideas generated by the SPs in the previous phase. To do this, patterns and tendencies mentioned in the focus groups and identified with subcategories were evaluated to determine the content categories for the home page. The main categories were visualised on a digital board with different coloured digital post-it notes (see Figure 7.2).

Figure 7.2

Digital Board: Outline of Website Content



Step 2: Define Design Patterns and Main Areas of Content

In defining the design of the website, statements and preferences of participating SPs were taken into account, such as one focus group participant's statement that "easily searchable things should be included because I think it doesn't matter if you design it whether it's categories, lists, icons" (SP5). To define a design pattern for the prototype website, a rough outline of the order of potential main content areas was created, based on content from Figure 7.2. This ensured that the ideas generated from the focus group were included. Once the outline of the website was prepared, a wireframe was created to decide where and how the generated ideas could be placed (see Figure 7.3). A wireframe is a structural plan of a website. It does not include inserting of any concrete design constructs and can be seen as an architectural concept plan for a website as it is helpful to flesh out different functions of the system (Morson, 2014).

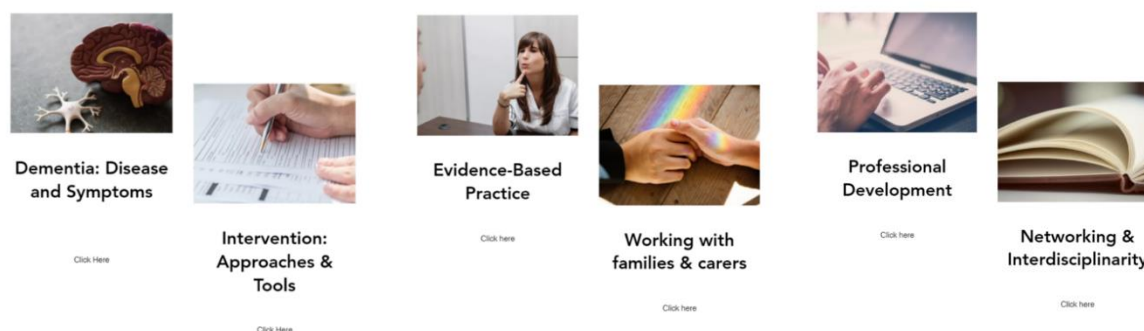
Figure 7.3
Wireframe for Website Prototype



The categories for the home page that were decided on in the previous step were arranged in the following order: (a) Dementia: Disease and Symptoms, (b) Intervention: Approaches and Tools, (c) Evidence-Based Practice, (d) Working With Families and Carers, (e) Professional Development, and (f) Networking & Interdisciplinarity (see Figure 7.4).

Figure 7.4

Order of Content Categories on Home Page on Website



The order was determined based on the frequency of the ideas generated in the focus group discussion. Furthermore, a logo and name for the website was applied at this stage to support a consistent design throughout the website. The website and the project were named Dementia Messages, as this conveys a brief idea of what the project is about and draws people's attention. Additionally, no reference was made to SP in the project title, with the aim of keeping it general to address other potential target groups in the future, such as PWD, their families and carers, and other allied health professionals. The logo was chosen as a “graphic element to support a corporate identity” (Ad'r et al., 2012) in order to convey the main purpose of the website. The logo was chosen from a copyright-free catalogue of pre-made images and illustrations on Wix (www.wix.com). Figure 7.5 shows the chosen logo.

Figure 7.5

Logo: Dementia Messages Website



Step 3: Define Screen Capabilities and Fonts

Most focus group participants indicated they would access the web-based resource guide from a computer; hence, screen responsiveness was not considered in particular. However, the Wix website builder included screen responsiveness for mobile devices automatically. Considering research showing that simple backgrounds and fonts on webpages increase readability and positive attitude among users (Geissler et al., 2006; Miniukovich et al., 2017; Stevenson et al., 2000), screen design was kept simple with a white background and black font.

Step 4: Define Navigation

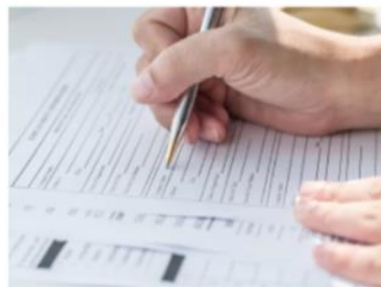
In this step the navigation for the different content areas was prepared to allow users to navigate to different pages within a few clicks. For the prototype website, a maximum of two pages for each category on the home page were decided on in order to make content easy to find and enable easy navigation. Website navigation was achieved by presenting buttons leading to separate internal pages. The navigation buttons were labelled “Click Here” (see Figure 7.6).

Figure 7.6

Navigation Buttons



**Dementia: Disease
and Symptoms**



**Intervention:
Approaches &
Tools**



Additionally, a drop-down navigation menu was placed horizontally near the top of the website, as this function was mentioned by SPs in the focus groups as desirable. Such function allows users to locate content easily by navigating through different websites (see Figure 7.7).

Figure 7.7

Drop-Down Navigation



Step 5: Insert Different Pages, PDFs, and Links

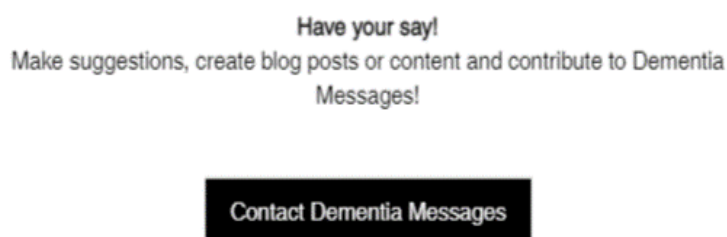
The next step was to create separate pages and links. Those pages included PDF documents and external links, as focus group participants had mentioned the desire for inclusion of links to take them to sources of information. To generate sources for the PDFs and external links, frequently mentioned platforms and external websites (see Table 6.7), such as the Dementia Australia or ASHA websites, were considered.

The category “Dementia: Disease and Symptoms” contains general information about dementia, with statistics and facts and dementia types and symptoms. There are two linked videos in this category, explaining dementia in general and explaining PPA. The PPA video is also presented with a link, leading to further information about this dementia type. Content for the category “Intervention: Approaches and Tools” on the prototype website included nine links to external sites, organised into tools for assessment of cognition and communication, and swallowing and feeding or clinical resources, such as a link to a memory book template. The content page for evidence-based practice included links to databases that could be used to find essential research. Furthermore, key research articles in dementia (identified by high citation rates) were featured on this page, as well as links to organisations with expertise in dementia (e.g., Dementia Australia). To highlight the importance of working with families and carers of PWD, links with information were provided on a separate content page for this category. This

included links to external information such as existing support groups or advice for families and carers. The professional development content page included four links leading to online courses, including MOOCs which convey knowledge about dementia in general. A further four links led to online courses specific to dementia for SPs, including courses from SPA or ASHA. The last content page on the prototype website was for networking and interdisciplinarity. A Facebook page for Dementia Messages was set up, aiming for users to share different updates and news regarding the website resource guide. This was suggested by focus group participants, who indicated they would like to get any updates and news showing up in their personal social media feed. Also, the blog section of the whole website was highlighted on the networking and interdisciplinary page. Both the Facebook page and the blog section were accessible through “Click Here” buttons. The blog section, where it was intended that different posts could be read and commented on by SPs, provides the opportunity for website users to keep up to date with information or to discuss some content around a specific topic. The option to include SPs directly in the project was generated as an idea in the focus groups, so for this purpose a contact button was added to the website (see Figure 7.8).

Figure 7.8

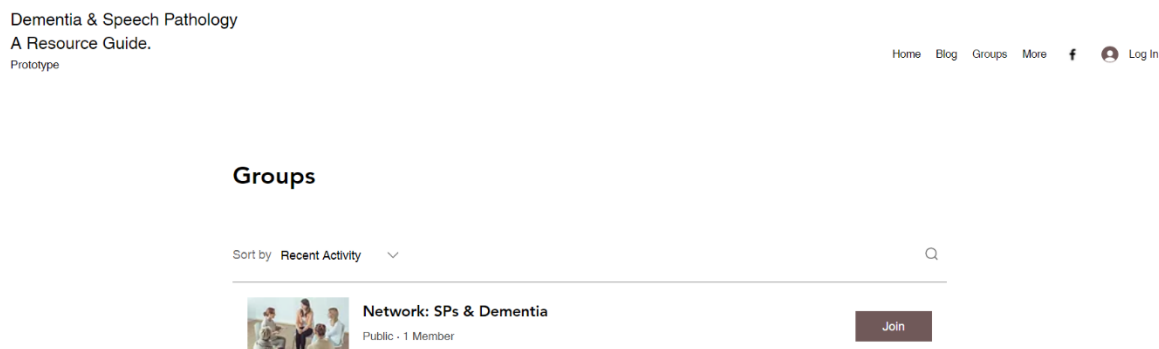
Contact Button



A forum was set up on the networking and interdisciplinary page. It was set up as a members page to facilitate connections between SPs who work with PWD (see Figure 7.9). Individuals who sign up as members will have the opportunity to start a discussion, ask specific questions, and share thoughts with like-minded clinicians. For the prototype, the forum was set as private, and it was not planned to be moderated. However, a forum etiquette with ground rules will be included as a code of conduct once the website is live online. Finally, a forwarding link to an SPA list of interest groups as well as allied health groups was included.

Figure 7.9

Dementia Messages Group Forum



Downloadable PDFs were included on the website as embedded links with credits to the author or website of origin. This meant that the PDFs would be downloadable through the author or website responsible for their creation. Because in the future it is planned to create and upload PDFs created by the Dementia Messages team, this download option was just informal for the prototype phase to test potential resources for the future. The prototype version was not accessible to the public in order to avoid copyright issues.

Step 6: Test Links and Navigation

The prototype with internal and external links was tested eight times by the research team. The final prototype was reviewed, followed by testing all links and navigation throughout. Information provided under the categories were revised. An information video that was connected to an external page did not work properly as the file size data was too big and navigation on the page was interrupted. This was solved after embedding the video directly as an external link on the page.

Step 7: Detail and Refine Page Contents and Links

Finally, minor adjustments were made, including refinement of contents and links. It appeared that two function buttons with the prompt "Click Here" did not work properly as no new page opened. This was resolved by replacing these buttons with new ones. Furthermore, content needed to be adjusted slightly to fit the mobile version and the desktop version equally. As the format was slightly different on the desktop version, content pages were rearranged by placing only two headings next to each other. Overall, four adjustments with minor revisions

of the prototype were performed to ensure easy navigation and before progressing to the next phase of the research.

7.2.2 Summary of Phase 3: Prototype Development

In this phase, steps for creating the prototype of a web-based resource guide were outlined. As explained, prototypes can be very ambiguous in their presentation, ranging from rough drafts to more detailed systems. For the prototype created in this project, a mid-fidelity prototype was chosen (Engelberg & Seffah, 2002). This enabled the inclusion of content discussed by SPs and demonstrated real interaction through specific buttons on the website. As the website building tool, Wix (www.wix.com) was used to ensure prototyping a mid-fidelity website was achievable, as none of the research team had experience in creating a website from scratch. The predetermined themes from the focus group phase influenced the whole prototyping process, covering design, content, platform, and purpose for the potential website resource guide. A further aspect considered that was discussed in the focus groups was the preference for a dynamic website which was easy to navigate. This was addressed by organising content into six areas on the website: (a) Dementia: Disease and Symptoms, (b) Intervention: Approaches & Tools, (c) Evidence-Based Practice, (d) Working with families & carers, (e) Professional Development, and (f) Networking & Interdisciplinarity. Information and helpful resources for clinical practice, such as downloadable PDF templates, were added within the content categories through embedded external links. Ensuring information flow and interaction, a Facebook page and a blog on the website were created. The blog potentially gives end users a platform to share their thoughts on a specific topic in a blog post in the future. Also, as desired by focus group participants, a networking area on the website was created, appearing as a forum.

7.3 Phase 4: User Feedback

After exploring SPs' needs and ideas, the prototype website, Dementia Messages, was developed (<https://echoudery.wixsite.com/dementia>, accessible via password: 2022Dementia). The website prototype includes six categories on the home page, as detailed in Section 7.2.1. Lots of direct links to helpful resources were included, as well as downloadable PDFs, to facilitate the SP's role when working with PWD. Furthermore, a forum for group discussions and interaction was created, as well as a Facebook page and a blog. Issues around administration of the live site are yet to be determined as they were not relevant to the prototyping phase. In this fourth phase of the research, an online survey was created to evaluate the website prototype

from a user's perspective regarding the design, content, purpose, and platform. This section details the recruitment of participants and the survey method and presents the survey results of participants who reviewed the prototype and evaluated it based on criteria relating to design, meaningful content when working with PWD, purpose, and platform. Participants commented on the existing content and rated features that were beneficial for their work as a clinician. Identified strengths and weak points are presented in Section 7.3.3.

7.3.1 Recruitment

As part of the overall recruitment process for this study, participants initially had the opportunity to register for either the focus group, the user-feedback survey, or both. Past research has indicated that 80% of usability problems can be recognised with a sample of only five users (Nielsen, 2000). According to Alroobaea and Mayhew (2014), there is no specific number of participants to find all usability issues, although the 16 ± 4 method can be seen as a useful outline (at least 12 and a maximum of 20 participants). This will ensure that users identify problems unfolding in design, navigation, and the key objects and purposes for which the system is built. Hence, the 16 ± 4 method was used as a framework for the sample size in the current research. Overall, 15 participants registered to participate in evaluating the website prototype and provide feedback via the survey. They all indicated they worked as SPs with PWD, and their expert opinion enabled them to make useful recommendations for improvements. More demographic information is not available as the prototype development was not based on any specific requirements, such as experience or workplace settings. Participants received two links via email: one link to the prototype website and a separate link to the survey in order to provide their feedback (see Appendix F). This procedure ensured that all submitted answers were anonymous. Participants had 2 weeks to review the prototype and submit the survey with their feedback. A reminder was sent out via email after 7 days. From the pre-registered participants, all 15 completed the survey.

7.3.2 Method

Following the prototyping process, usability testing and evaluation was used to examine the functionality of the created prototype and to uncover areas of confusion and expose opportunities to improve the overall user experience (Wichansky, 2000). This step ensured also that needs specific to SPs were met (Bevan, 2009). Considering this project and design constraints, an online questionnaire was used to capture user feedback and measure product

features in an efficient way (Laugwitz et al., 2008). Compared to other methods for gathering user feedback, the choice of method was made based on the option to make it repeatable and transferable to a more advanced context (Bragge et al., 2005). Furthermore, participants were able to access and review the website before or while simultaneously answering survey questions. This allowed flexibility to reach all participants across Australia. With regard to cost effectiveness and data quality, a survey provided sufficient data to revise the website according to received feedback within a short period of time (Newby et al., 2003).

To gather user feedback, the guiding questions for evaluating the prototype were:

1. To what extent is the developed website resource guide helpful?
2. Do included categories/content effectively and efficiently help SPs accomplish the tasks they are using it for?
3. Is the content concise but still useful?
4. Is the resource user-friendly?

Survey

The questionnaire was developed once focus group data analysis was completed, and the prototype of the web-based resource guide was designed. There were three sections comprising 30 questions regarding the four content categories: (a) design (15 questions), (b) content (8 questions), and (c) platform and purpose (7 questions). Keeping within the framework of the predetermined categories used throughout the phases of the project guaranteed the ability to assign data to the associated theme and make revisions accordingly. The questionnaire included both closed questions and open-ended questions (e.g., requiring written responses). The questionnaire was piloted by three academic SPs under survey conditions, wherein validity of each question was scrutinised carefully. This enabled early identification of any occurring problems prior to implementing the survey. After initial feedback and discussions, revisions were made to gather participants' opinions about the website prototype but also allow space for further suggestions by adding an open-ended text field as the final question. The survey questionnaire was designed to be distributed and completed using Google Forms, a survey administration software offered by Google Docs for creating and managing survey questionnaires. The survey questions are included in Appendix F.

Data Analysis

Responses from the questionnaire were downloaded from Google Forms for analysis and transferred into an Excel Spreadsheet. Closed questions included multiple-choice questions and

ranking questions, and responses were analysed using descriptive statistics (frequency distribution). Open-ended responses were allocated to the four predetermined categories (see Chapter 6) manually: design, content, purpose, and platform. Given that questions were already organised into the predetermined categories, a biased analysis was minimised.

7.3.3 Results

Design

The information collected in this section of the questionnaire allowed respondents to link specific design settings of the prototype with its appearance. The first two questions covered information about the device the prototype was accessed from to gain information related to screen size and device type, as many types of web-enabled devices such as smartphones and tablets exist. The majority of participants (73%; $n = 11$) used a laptop or computer, while four participants used a tablet (7%; $n = 1$) or their phone (20%; $n = 3$). Most (87%; $n = 13$) of the users specified that the website did load quickly; however, a few participants (20%; $n = 3$) who used their smartphones indicated that the mobile version of the prototype did not load quickly or work properly. Further information on problems experienced, such as the loading time of the website, was not specified. The next question aimed to identify issues related to different browsers. A web browser is an operating system that allows users to access the internet or a specific website (Taivalsaari et al., 2008) and includes such common systems as Microsoft Edge, Chrome, Safari, Opera, and Firefox (Boda et al., 2011; Gray, 2009; TechAdvisor, 2021). Given that installed operating systems vary across different types of devices, participants were asked if the website prototype was viewable in different browsers to relate potential issues back to those systems. About half the participants (47%; $n = 7$) answered “Yes”, 20% ($n = 3$) answered “No”, and 33% ($n = 5$) viewed the prototype in one browser only.

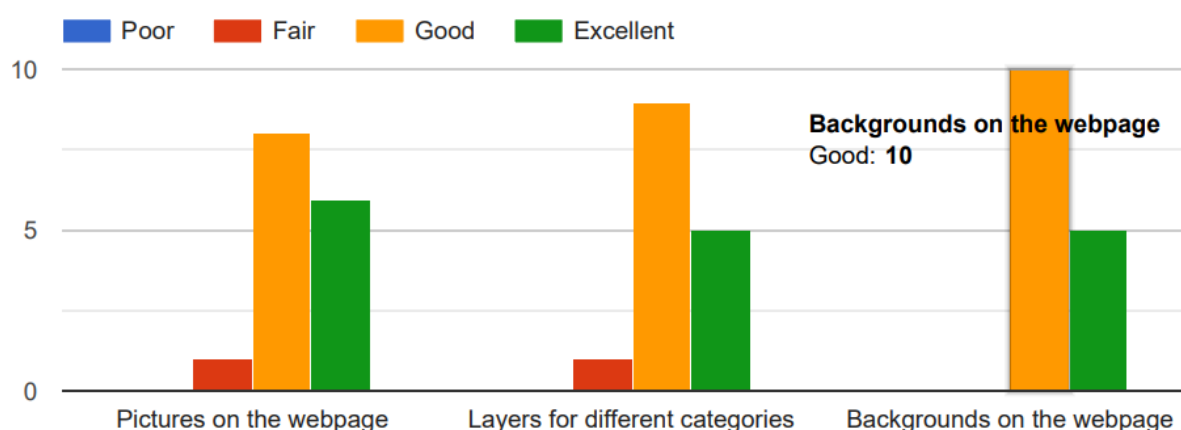
The overall navigation can be a fiddly process as website visitors may have problems seeking and finding information, and link structures may not be presented plainly (Karim et al., 2009). Hence, participants were asked to review the navigation of the prototype. The majority (67%; $n = 10$) specified that the website was easy to navigate, with only one participant (7%) indicating that it was not easy to navigate through the website. Four participants provided specific feedback in terms of navigation, which included the desire for a “search bar” or “search engine”, but also feedback regarding the mobile version, which did not allow proper navigation. Therefore, the next question asked if participants experienced any pop-up windows that appeared on top of the actual page. Eight participants (53%) did not mention any obtrusive pop-up windows, four

participants (27%) were not sure regarding any pop-up windows. Three participants (20%) were not sure about any pop-up windows. One participant commented that some pop-up windows appeared, “but that was on the page you are taken to and out of your control”.

As the website aims to serve as a resource guide, the overall website visit should be as pleasant as possible for end users. Therefore, users were asked to evaluate the overall design. Thirteen participants (87%) indicated that the website was visually appealing and only two participants (13%) were not sure about the visual appeal. To provide more information about the overall appeal, participants were asked to rate the pictures on the website representing different categories, the layers of single pages leading to different categories, and the backgrounds on the webpages. Overall, the majority rated those features as “good”. Figure 7.10 shows more details:

Figure 7.10

Rating of Aspects of the Website Design



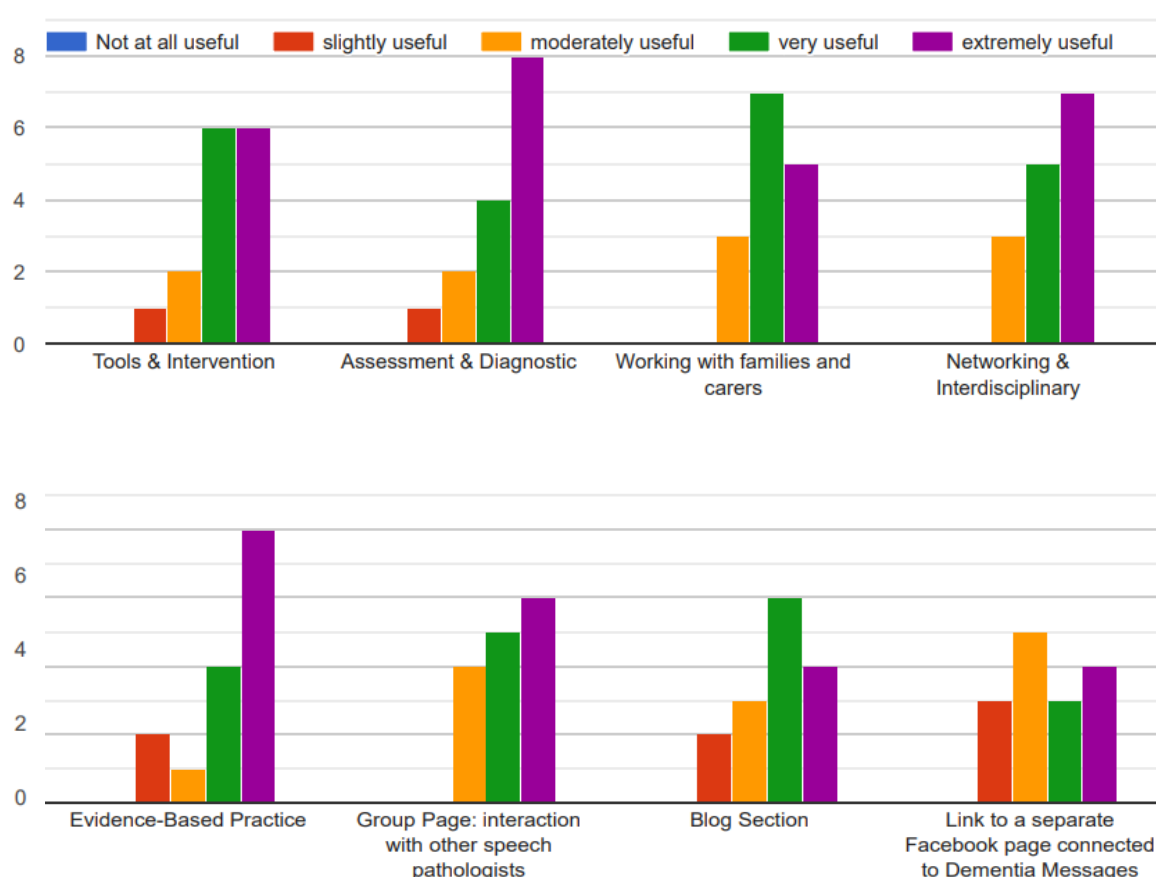
As described in Phase 3, the font was considered while developing the website to increase readability and generate a positive response among users. Consequently, the majority (87%; $n = 13$) rated the font size throughout the website as appropriate, as well as colours and shapes used (93%; $n = 14$). As the website prototype at this stage was designed for SPs only, participants were asked if the website design was confusing or overwhelming from their perspective, for example, due to a lack of signposts. The majority (73%; $n = 11$) said that the website was not confusing or overwhelming, while 27% ($n = 4$) indicated that they were not sure. The majority (93%; $n = 14$) stated the design was consistent throughout the website.

Content

Since the website prototype was planned as a resource guide to convey information that is specific and meaningful to SPs, choice of appropriate content is important. As the content categories were based on focus group ideas and thoughts, participating SPs were asked to rate the different categories. The majority identified the categories “Assessment & Diagnostic”, “Networking & Interdisciplinarity”, and “Evidence-Based Practice” as extremely useful. The separate linked Facebook page for further interaction were rated as not as useful. Figure 7.11 illustrates the usefulness ratings in more detail.

Figure 7.11

Usefulness of Website Content Categories



As the website will be an adaptable and flexible resource which is meant to be modifiable, participants were asked whether more content categories should be added. About half of the participants (53%; $n = 8$) indicated that more content should be added to the website in the future. Seven participants (47%) were not sure if they would like more content. Those who

specified the desire for more content were invited to provide a comment with some further ideas. Five participants provided the ideas shown in Table 7.1.

Table 7.1

Further Website Content Ideas

Content ideas
More therapy-related content
A separate page dedicated to PPA
Exchange of templates and resources
More PDFs and templates
Digital resources (like apps)
More articles and summaries
Printable information sheets
Tutorials (videos)

Note. PPA = primary progressive aphasia.

To check if the provided content with downloadable PDFs worked properly, participants were asked to test the document links on the website. Eight participants (53%) downloaded them and indicated that the PDF downloads worked well. Nine participants (60%) tested the external links on the website, which led smoothly to the intended external websites.

Purpose and Platform

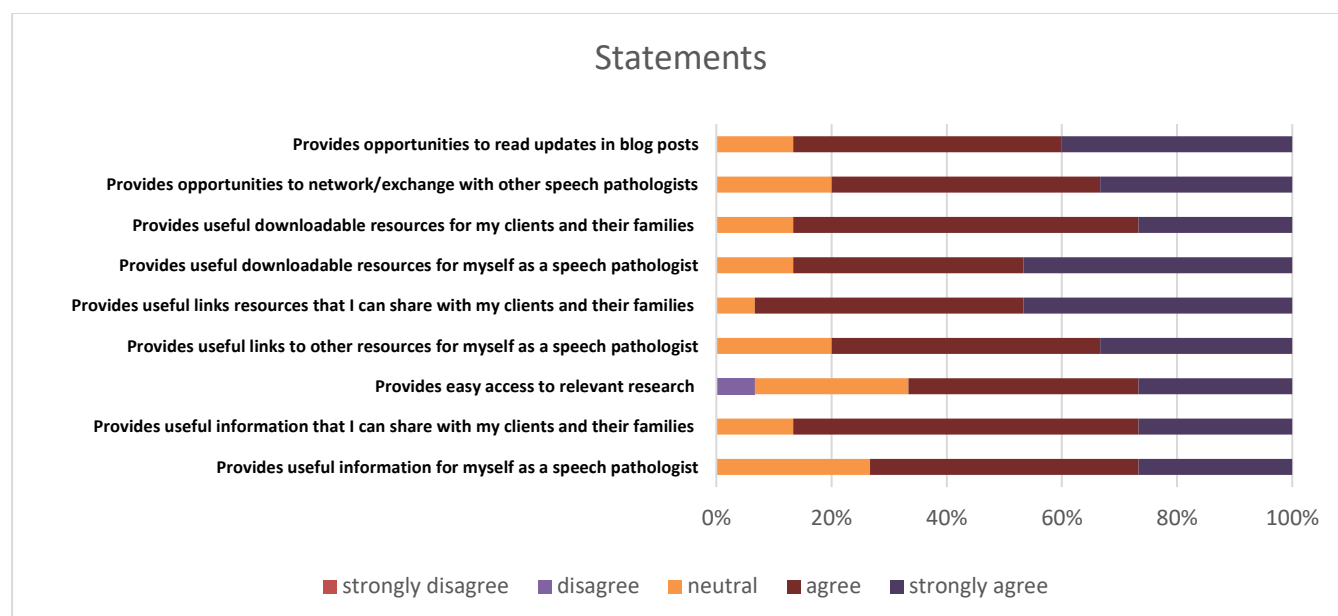
Questions regarding purpose and platform were asked in a combined section of the questionnaire, as they were overlapping and affected each other. Overall, seven questions were asked in this last section, concerning the purpose of the website and the usefulness of it as a platform. As the website prototype is a means of communication, the importance of an obvious and clear site message was a focus. The majority of participants (93%; $n = 14$) said that the purpose and scope of the website was clear as the provided information was concise but precise in order to facilitate the SP role. Furthermore, participating SPs were asked why they would access the website as this feedback would assist with making specific revisions and adjustments if necessary. Thirteen participants (87%) indicated they would like to download resources and access information for their clients and their families and carers. Twelve participants (80%) stated they would like to access information and links to external resources for themselves as professional clinicians. Ten participants (67%) indicated they would use the website to download resources such as PDF documents for themselves. The same number of participants

($n = 10$; 67%) stated that they would visit the website to access research articles. Only nine participants (60%) said they would use the website to network or exchange with other SPs and only eight (53%) indicated they would access the website specifically for reading blog posts.

In the next question, participants were asked to share their level of agreement with nine statements using a 5-point Likert scale ranging from “Strongly Disagree” to “Strongly Agree”. The nine statements were included to decide if the purpose criteria and needs of end users were met. Figure 7.12 shows that the majority of participants agreed or strongly agreed with the statements about the purpose of the website.

Figure 7.12

Statements About Purpose of the Website



In a single-choice question, participants were asked how often they would access the website as a resource guide once it was published. This question was included to take into account frequency for potential updates. One participant (7%) stated they would visit the website once a week, three (20%) would visit it a few times a month, six (40%) would visit it once a month, three (20%) indicated they would access it more infrequently, and two (13%) were not sure how often they would access the website. To keep users engaged with the website, the idea of a newsletter was proposed in the subsequent question. Most participants (60%; $n = 9$) indicated they would sign up for a frequent newsletter, which would include information about new blog posts, ongoing research projects, and new resources on the website. The other participating SPs (40%; $n = 6$) were unsure about receiving newsletters. Asking about the

frequency, participants were invited to indicate how often they would like to receive a newsletter. This question was asked to ensure that users are not overloaded by emails or messages from the website. Seven comments were given; five of these expressed that they would like to receive a newsletter on a monthly basis, while the other respondents indicated once a week or that they did not have any preference. The final question in this section asked whether participants would recommend the website to colleagues, as recommendation among colleagues is a trustworthy form of advertising for new users (Shen, 2014). Almost all participants (93%; $n = 14$) responded that they would recommend it to their colleagues, while one was not sure if they would do so.

7.4 Summary and Conclusion: User Feedback and Prototype Implementation

Overall, the prototype website appeared to be helpful and user friendly, with 67% of participants ($n = 10$) indicating it was easy to navigate and 87% ($n = 13$) indicating it was visually appealing. Pictures, layers, and backgrounds were generally rated as “good”. There were issues with the website being viewed through different devices, as it did not load properly on some mobile devices. Evaluating to what extent the content on the website was useful, participants rated the categories “Assessment & Intervention” and “Evidence-Based Practice” as very useful for providing interventions with PWD. No categories were rated as “not at all useful”, which indicates that the main aim to serve as a useful resource guide was met. More than half the respondents (53%; $n = 8$) indicated they would like to see more content on the website, with suggestions to provide more therapy-related content, information dedicated to PPA, and more articles, templates, and tutorials. External links were tested and nine participants (60%) did not experience any interruptions or difficulties. The majority (93%; $n = 14$) evaluated the overall scope of the website as clear, which suggests that the given information was concise and useful. Twelve participants (80%) said they would purposely use the website as a platform to access information and links to external resources and for their work as an SP, which includes accessing information and resources for themselves, their clients, families, and carers. Most participants stated that they would recommend the website resource guide to their colleagues. Participant responses indicated that a potential area for improvement was providing easy access to relevant research. How frequently, effectively, and efficiently the website resource will be used once it is published should be evaluated over a longer period as this question cannot be answered for the unpublished prototype. Overall, apart from some problems with the mobile version, the desktop version of the website appeared to be user friendly based on respondents’ feedback.

7.4.1 Implementation of the Prototype

Following this performance evaluation and adaptation of the prototype in response to the user feedback, it was ready for Phase 6, implementation. As the website is the subject of this thesis, it is currently password protected while the thesis is under examination. Furthermore, as demonstrated in Figure 4.2 (the user-centred design process according to ISO 9241-210 in Chapter 4), there is potential to consider further iterations of the website resource after further evaluation. Given that it is a digital resource, content needs to be updated constantly to address the requirements of users.

Chapter 8: Discussion and Conclusion

This thesis explored SPs' clinical practice in the management of dementia. An HCD approach was used to gather and understand SPs' perceptions, needs, and concerns when working with PWD. By focusing on real experiences of SPs, a prototype of a web-based resource guide for the management of dementia was developed and feedback was sought about the prototype website. Following the literature and scoping reviews, the primary aim of the research was to determine and address SPs' experiences and perceptions when working with PWD. Overall, there were six phases applied to the HCD approach. In Phase 1 (Chapter 5), a mixed-method study was applied to explore current SP practice for PWD in Australia and identify potential issues when working with these cases. In Phase 2, the ideation phase (Chapter 6), focus groups were conducted to gather SPs' needs, concerns, and ideas to generate a solution to the previously identified issues. In Phase 3 and Phase 4 (Chapter 7), a prototype for a web-based resource guide was developed to respond to SPs' needs, views, and ideas. Following the prototyping, user feedback was collected for the prototype with an online questionnaire. In Phase 5, iteration, user feedback from the online questionnaire was processed and the website was adapted accordingly. Following the iteration, the website was ready for implementation (Phase 6).⁴ This chapter provides an overview and a summary of the relevant literature and the scoping review identified in Chapters 1 to 3. Drawing from these chapters, the applied HCD approach with its phases and the results of the studies will be discussed, and methodological and clinical implications presented. Finally, limitations of the study and potential future directions for research will be discussed.

8.1 Overview and Summary

This thesis contains eight chapters. In Chapter 1, an overview of dementia and background information were provided. As dementia is an umbrella term that covers different dementia types, common underlying syndromes and diseases were discussed. Dementia types include Alzheimer's disease (Alzheimer, 1907), vascular dementia (Akiguchi et al., 1997), Lewy body dementias (Gomperts, 2016), and frontotemporal dementia (Pick, 1892, as cited in Förstl, 2002). Highlighting that dementia is progressive, a decline of cognitive functions (APA,

⁴ To date, the website is password-protected while the thesis is under examination. Additional changes will be considered to update information and resources.

2013) affects an individual's ability to perform daily and independent activities. Arguing that cognitive changes, including MCI (Petersen, 2000, 2016), and lifestyle factors (Livingston et al., 2020) increase dementia risk, prevention of dementia onset became a priority. Chapter 1 highlighted the importance of a holistic preventative approach to the management of dementia, including a healthy lifestyle with physical and mental activity (Gillette-Guyonnet et al., 2009; Kivipelto et al., 2013; Vellas et al., 2014; Yaffe et al., 2019). Considering a comprehensive assessment and diagnosis of dementia, including cognitive tests and laboratory investigations (Feldman et al., 2008), pharmacological and non-pharmacological treatment options for the management of dementia were discussed. To date, available drugs for dementia can only improve or slow down the progression of deterioration in cognitive abilities and symptoms; further progression of the disease or reversion of brain damage cannot be attained with drugs (Cummings et al., 2017). This highlights the need for non-pharmacological treatment options, which aim to minimise symptoms and assist with the maintenance of function and independence (S. Douglas et al., 2004). Non-pharmacological treatment options are applied as individualised treatments (Bessey & Walaszek, 2019) by multidisciplinary teams (Zucchella et al., 2018). Given that symptoms and progression of dementia are highly individual, a person-centred approach is necessary to consider individual needs and preferences for quality of life for as long as possible. By considering domains from the ICF framework (WHO, n.d.), the strengths and needs of PWD can be identified. Consequently, not only do body structure and functioning matter, but also contextual factors such as environment and personal factors need to be considered, as proposed and conceptualised in the ICF framework (Byrne & Orange, 2005).

In Chapter 2, the role of the SP profession in the management of dementia was discussed. Initially, evidence-based practice as a major part of SP services was elaborated, as it considers aspects of client perspectives, clinical expertise, and internal and external evidence (ASHA, n.d.-b). It was highlighted that procedures in clinical practice need to integrate and apply the ICF principles (Howe, 2008) to ensure a person-centred and holistic approach. Focusing more on habilitation rather than restoring function (Wynn & Khayum, 2015), the focus of therapy lies more on individual strengths and personal interests. This requires tailored and multicomponent interventions and strategies (Khayum & Rogalski, 2018; Rogalski & Khayum, 2018). A vast body of literature has documented areas of practice for cognitive-communication and feeding and swallowing. In the last two decades, research interest in clinical practice in dementia has emerged and addressed specifically cognitive-communication disorders (Beber et al., 2015; Croot et al., 2019; Krajenbrink et al., 2018; Taylor et al., 2009; Taylor-Rubin et al.,

2017; Volkmer et al., 2018). A number of authors have investigated and indicated that implementation of different strategies is helpful to conserve healthy cognitive areas, which helps to delay further progression of the disease (Croot, 2018; Croot et al., 2019; Machado et al., 2014; Senaha et al., 2010). Strategies can be delivered as direct or indirect intervention strategies and approaches (Clark, 1995). Direct intervention strategies implement cognitive-linguistic stimulation techniques (Beales et al., 2016; Bourgeois et al., 2015; Egan et al., 2010; Mahendra, 2001; Payne, 2014) and can be implemented using an impairment-based (Des Roches et al., 2015) or functional approach (Warchol, 2006).

Despite the vast amount of literature and evidence to potentially guide SPs' clinical practice, implementation approaches and current practice of Australian SPs remained unexplored. Therefore, a scoping review of recommended practices in the management of dementia was conducted (Chapter 3). As argued in the literature review in Chapter 1, a multidisciplinary approach was highlighted as the best path to address the individual needs of PWD, as each profession adds different aspects of expertise to collaborative and multidisciplinary practice. Within these teams, SPs add to the assessment and diagnosis of dementia and are involved in treatment and care planning. However, their specific role regarding different stages of dementia is imprecise and not well described in the literature. The primary aim was to investigate to what extent the SP role was identified and described in dementia management guidelines, recommendations, and position statements on a professional level and across allied health professions as these professions, along with the medical team, are involved in the care of PWD. Specifically, the review aimed to determine at what stage(s) of the disease SPs were involved in care; the role of SPs in assessment of PWD; the role of SPs in management of communication and language; and the role of SPs in the management of swallowing and feeding difficulties.

Overall, 20 documents met the inclusion criteria for the review and were included. Five of these documents were specifically written for SPs and differed in scope and depth. Other documents from allied health areas included reference to the role of SPs by addressing deterioration of language in the initial stages and malnutrition in the later stages. Given that the scoping review revealed a lack of guidance for SPs in the clinical management of dementia, SPs' current practice in Australia remained unknown.

Based on the literature review and results from the scoping review, this thesis sought to explore Australian SPs' perceptions, needs, potential issues, and solutions through an HCD approach. Overall, there were six phases applied to the approach, consisting of different studies.

In Phase 1, current practice of Australian SPs who worked with PWD was explored. This included identifying settings in which they worked, patterns of referral to determine when they became involved, and types of services they provided. A mixed-method study was conducted and reported in Chapter 5. The study comprised a survey (Stage 1) and interviews (Stage 2). Seventy-one (71) Australian SPs participated in the online survey. The majority worked with PWD in public or private hospitals. Seventy percent (70%) of participating SPs had further training in the management of dementia after graduating, and the majority indicated that there was not enough information to support their work with PWD. Consequently, participants used a variety of information sources, including brochures, blogs, websites, online MOOCs, and research papers. Furthermore, participants reported the use of international guidelines to inform their clinical practice. Interestingly, the majority of participants indicated that most of their initial referrals were for PWD in the late or intermediate stages of dementia. Referrals when clients were in the early stages were rare. Furthermore, the primary reason for referrals was due to swallowing difficulties, and the therapy focus was on swallowing and feeding always or most of the time.

In Stage 2 of Phase 1, 11 SPs participated in semi-structured interviews. Five themes were identified from the data and revealed more in-depth information, adding to the results from the online questionnaire. The five themes were (a) factors affecting SP management in working with PWD; (b) regulatory/time constraints for provision of services for PWD; (c) person-centred practice approach for PWD; (d) education and engagement of carers and families; and (e) challenges of working with the diversity of presentation, severity, and characteristics of dementia. One of the main issues identified from Phase 1 was that SPs experienced difficulty accessing sufficient information for their work with PWD. Consequently, they had to do comprehensive researching to find information and resources to provide adequate services. Subsequently, the idea for a web-based resource guide for Australian SPs evolved and informed Phase 2 of the HCD study design.

In Phase 2 (see Chapter 6), ideas and direct feedback relating to a resource guide were obtained through two focus groups with eight participating SPs in total, and one SP who provided written feedback via email. Predetermined categories were implemented to structure the focus group discussions. The categories informed four areas for the development of the resource guide: purpose, platform, content, and design. SPs reported using a variety of online and social media platforms to obtain information and resources for their practice. Analysis of the focus group discussions highlighted the overwhelming need for a web-based resource that

provided information about the disease, the SP role, and evidence-based practice, as well as providing an opportunity for professional networking and information exchange.

In Chapter 7, Phase 3, a prototype for a website resource was developed from the ideas generated. Content categories included information about the disease and symptoms of dementia, access and provision of information with downloadable PDFs and links, evidence-based practice, approaches and tools for intervention, networking and interdisciplinarity, and working with families of PWD. Following rapid prototyping, the web-based resource guide was then evaluated by end users (SPs) as part of Phase 4 of the HCD approach. Fifteen SPs completed an online survey that included questions related to the design, appropriateness and usefulness of content, purpose, and platform of the resource guide. They commented on the existing content and rated features that were beneficial for their work as a clinician. Overall findings indicated that they perceived the website as helpful, especially the content categories for assessment and diagnostic, and evidence-based practice, which were rated as extremely useful. Furthermore, SPs made suggestions for changes and raised ideas for further improvement.

In Phase 5, revisions to the website based on previously collected feedback were performed. Furthermore, ongoing iteration of the overall design thinking process is a central part of the HCD approach. Given that an HCD approach is dynamic rather than static, further iterations of the website will be undertaken regularly to adjust and update it. As the website is the subject of this thesis, it will not go public until after thesis examination. The website is currently password protected while the thesis is under examination.

8.2 Implications

This thesis has both methodological implications for the HCD approach and clinical implications for the SP profession in the management of dementia.

8.2.1 Methodological Implications of HCD Approach

This study highlights the successful application of an HCD approach to identify and address real-life problems and solve them by integrating end users from conceptualisation through to evaluation. SPs who work with PWD were involved to collect their perceptions, needs, and views. This thesis has acknowledged that an HCD approach fits into the clinical decision-making of SPs, considering clinical expertise, client perspectives, and external and internal evidence (ASHA, n.d.-b; SPA, 2021). As discussed in Chapter 5, findings from Phase

1 of the project revealed that the majority of participants needed further training in the management of dementia after graduating with an SP degree, as dementia was not extensively addressed in the participants' curriculum. The study in this phase also revealed that there was not enough information to support clinicians who work with PWD. Consequently, they had to use a range of sources for information, as information was not in one place. Given that there were no dementia guidelines for SPs in Australia, participants indicated discussing questions about their clients with dementia with more experienced colleagues. These findings are similar to previously conducted studies. In 2009, Taylor and colleagues found that there is a need for more accessible information for clinicians who work with clients with PPA in Australia. In a study conducted in Portugal, Nóbrega and colleagues (2016) found that clinicians had limited clinical practice when working with PWD. In response, they addressed the need for more dementia-specific content in undergraduate and postgraduate curricula, including practical training. Furthermore, Nóbrega and colleagues pointed to the need for broader advocacy of professional roles and activities in this area in the management of dementia.

The results of studies in Phase 1 presented in Chapter 5 identified and highlighted problems that SPs are facing when working with PWD. The recognition of design thinking in the form of an HCD approach is evidenced by supporting literature in allied health areas and education as it maximises study outcomes by meeting consumer group needs. To date, a considerable number of projects for specific SP matters exist. These, for example, include the Developmental Language Disorder project (<https://thedldproject.com/developmental-language-disorder-dld/>) and the Australian Aphasia Rehabilitation Pathway website (www.aphasiapathway.com.au) with best practice statements (Power et al., 2015). Both address an area of practice and aim to improve the overall patient journey and diminish evidence–practice gaps by providing access to best evidence comprised in a user-friendly website. Although content on both websites was informed by experts and research projects, the overall evaluation and usefulness of the websites could be assessed through an HCD approach.

8.2.2 Clinical Implications

Several issues identified in the studies are important for clinical practice in the management of dementia. Given the current lack of SPA guidelines specifically for the management of dementia, results of this thesis imply that there is a need for development of professional guidelines. Such guidelines would inform and define quality services for PWD in all stages and settings on a professional and multidisciplinary level. Another clinical implication

is the need for advocacy for the SP role in the early stages of dementia. Given that dementia rates are rising in Australia rapidly, advocacy for SPs working with PWD should be set out as a priority in order to educate other health professionals about the roles of SPs and what they can contribute to care of PWD and their families.

Need for Development of Guidelines to Support SPs Working With PWD

As highlighted in the scoping review in Chapter 3, there are currently no professional SP clinical guidelines on the management of dementia in Australia. Reviewing the SPA website, SPA refers to clinical practice guidelines for PWD published by the National Health and Medical Research Council in 2016. The guidelines provide guidance for allied health professionals involved in primary care, aged care, and hospital settings and gives recommendations according to evidence on dementia. Grades of recommendations include initial investigation and management of symptoms, wellbeing and education of PWD, medication, and support for carers and families. Although the guidelines provide a sufficient overview, they are only partly suitable to guide SPs in their work with PWD as they are not specific enough to provide recommendations for language and communication, and swallowing and feeding. Therefore, it is timely to introduce professional policies and establish clinical guidelines based on different studies (Clare et al., 2000; Croot et al., 2019; Drulia & Ludlow, 2013; Hopper et al., 2005; Mahendra et al., 2006; Murphy et al., 2017) to facilitate evidence-based practice and decision-making in clinical practice. This will improve overall service delivery for PWD and their families and carers. Given that the SP role was barely considered within multidisciplinary guidelines, professional SP guidelines will define and specify the SP role in the management of dementia, which will help other allied health professionals and authorities to decide on care plans and referrals.

Need for Advocacy for SP Responsibilities in Preliminary and Early Stages of Disease

As part of the SP's role when working with PWD, results from the study in Phase 1 showed that SPs receive initial referrals for PWD in the intermediate or later stages of the dementia disease rather than in the early stages. The main reasons for receiving referrals were for swallowing and feeding in the first instance. However, language can be seen as a first indicator for detecting MCI and early-stage dementia. Given that early detection, timely diagnosis, and prevention of rapid progression are a priority, SPs are responsible as experts for language and communication to be involved early on. In serving the needs of PWD, advocacy

is essential to provide timely access to SP services. A further result identified in Phase 1 was that aspects of cognitive-communication were considered as a low priority by referrers. This is potentially due to lack of awareness about the whole potential of SP services in the management of dementia. Advocacy of SPs role in working with PWD need to occur in order to raise awareness of the service SPs can provide throughout the progression of dementia from early through to late stages. SPA is the body representing SPs in Australia and this advocacy could be driven at the organisational level. This could include the development and distribution of a policy and/or guidelines clarifying the role of SPs in PWD and their families.

As part of current discussions around the quality of aged care services on a national level in Australia, SPA made a submission the Royal Commission into Aged Care Quality and Safety (SPA, 2020c). The submission addressed the needs of Australian stakeholders, including those living with dementia, with regard to improved dementia care. The final report of the Royal Commission into Aged Care Quality and Safety (2021) found that people in aged care have restricted access to services from SPs, and dementia appears to be an underserved area of practice. This relates to the findings in Phase 1, wherein SPs indicated receiving referrals in the intermediate and later stages of dementia. Given that dementia is such a complex disorder not only affecting elderly people, responsibilities in the management of dementia go beyond aged care services. Therefore, the concept of advocacy needs to be broadened to (a) introduce specific policies that improve intervention for PWD; (b) demonstrate the width of available evidence and resources SPs can provide in pre- and early dementia stages; (c) support PWD, carers, and families in a variety of settings; (d) provide efficient SP services in the early management of dementia; and (e) ensure aspects of the ICF framework to ensure a person-centred approach. As a consequence of advocacy, awareness of the SP role when working with dementia cases will increase and will facilitate early involvement and reduce negative consequences on consumer groups, families, and carers (McGill et al., 2020).

8.3 Limitations of the Study

Several limitations were identified in this research. Both studies within the mixed-method study in Phase 1 had limitations. As the online survey was distributed through a variety of channels, such as professional networks, social media, and emails, the population (other than SPs) that potentially could have accessed the survey cannot be described properly. Therefore, a generalised understanding and description of the population cannot be presumed, nor can the extent of bias of participants be known (Andrade, 2020). The small sample size for the semi-

structured interviews is reflective of this research method, however, results as such should be interpreted cautiously. The small sample size is countered to some extent by the range within the sample of participants of settings (e.g., community care, acute, inpatient rehabilitation), different service types, and reported practice. Part of the recruitment process was the distribution via interest groups. Those who were recruited through an online interest group indicated an active interest in maintaining and increasing knowledge of current professional practice. Those motivated to contact the researcher to engage in the research likely had a pre-existing interest in dementia, knowledge about issues, and overall confidence in their ability to discuss their practice. For these reasons, it is possible that participants may not have been representative of the wider SP profession. Issues have also been documented relating to interviewing by videoconferencing rather than face to face (Weller, 2017), and in this study some technical issues were experienced as a participant's microphone was not working. Furthermore, although the majority of participants decided to turn their cameras on, the transferred video was not comparable with engaging in a face-to-face conversation.

Additionally, there were some limitations in the focus groups conducted in Phase 2. Preparation of the focus group guide and moderation were planned and conducted carefully to reduce any bias and limitations; however, there is still the possibility that the opinions of some participants became dominant throughout the discussion and an overall acceptable opinion developed (Smithson, 2000).

Overall, the COVID-19 pandemic affected data collection from the focus groups, as they were held online rather than face to face. This potentially impacted the overall interaction and engagement of participants as ideas may not have been expressed and conveyed (Self, 2021). Due to the technical circumstances of the video call, general speech acts were restricted, such as cooperative overlap of speech and turn-taking. Given that other participants muted their microphones while only one was speaking, there was no scope for approval and consent with regard to statements.

Besides potential restrictions in data collection, there might have been some participant bias in the conducted interviews in Phase 1 and the focus groups in Phase 2, with the possibility that participants perceived the absence of a guiding resource when working with PWD negatively. Even though there have been considerations and precautions to minimise bias (e.g. member checking), it needs to be mentioned that by nature qualitative research design is subjective, with a potential of researcher bias.

In Phase 3, the rapid prototyping process provided only an overview of a potential website, and there is a chance that important content was missing. Given that the prototype was built with a website-building tool, the design, photos, and arrangement of content categories were predetermined by the building-tool provider, Wix (www.wix.com). Even though participants were informed it was a prototype only, the survey conducted in Phase 4 may not have been able to capture comprehensive user feedback to its full potential, as the presented prototype was impacted and biased due to the pre-determined design options. Bespoke design of a website was beyond the scope of this research.

HCD usually incorporates a multidisciplinary expert panel to design a final product, but in this research the focus was solely on SPs' perspectives and views. Although the web-based resource is for the management of dementia, perceptions and views of other important stakeholders, above all PWD, are missing. The inclusion of a multidisciplinary panel in the design project was beyond the scope of this thesis would be a useful stage to incorporate in the future.

Additionally, the web-based resource guide is limited to the Australian context, as gathered data involved Australian SPs. Consequently, information on the website is limited to the Australian cultural and governance context and its healthcare system.

Overall, it is unclear to what extent SPs will adapt the web-based resource guide to their clinical practice in the long term. Given that the development of the website did not consider the variety of clinical settings, service delivery models, or specifically any type of dementia, it is unclear to what extent the resource guide can be applied.

8.4 Future Directions

As highlighted in this thesis, currently there is a lack of advocacy of the SP role in the management of dementia. Given that the SP role is not clearly defined in terms of when SPs should be involved and how, the need for education to raise awareness among allied health professionals, guidelines, and policymakers needs to be further addressed in the future. Additionally, awareness of the SP area of practice in general should be improved to demonstrate the potential of available services.

Furthermore, studies in this thesis demonstrated the application of an HCD process to address and answer a problem. Future research is recommended to explore the web-based

resource guide and its application, including the re-evaluation of the resource guide, the application of the website to other countries, and its application to the SP profession.

As highlighted in the literature review, the individual needs and strengths of PWD should always be a priority, and therefore, the resource guide should be re-evaluated by including other stakeholders. Given that it is a resource for providing services for PWD and their carers and family members, they should be included in the expert panel to create a collective capacity of creative thinking (Lee et al., 2020). As the HCD process is not static, future research should include a variety of stakeholders in all phases of the design thinking process: (a) identification of patterns and requirements, (b) ideation, (c) prototyping, (d) user feedback, (e) iteration, and (f) implementation. Additionally, other allied health professionals should be included in the development. This will ensure that the content of the resource guide considers multidisciplinary and person-centred information.

Once the website is accessible without a password, it needs to be evaluated as to how and to what extent it is integrated into clinical practice. The implementation of the resource guide over a longer period of time will determine potential barriers and facilitators applied to clinical practice, based on a frequent use of the website. This could be done with a larger Delphi study using a multistage questionnaire with experts from different backgrounds (Keeney et al., 2011). Within the procedure of a Delphi study, experiences from different stakeholders can be sought, including PWD, family members, carers and other relevant professions to improve the website and its usability. By implementing rounds of data gathering via questionnaires and analysis, feedback and further ideas can be taken into account before initiating further rounds. As typically for a Delphi study, the same experts are included in all rounds, results of each round are distributed among participants to consider before implementing further rounds. Consequently, revisions of the website can be undertaken between each round to adapt it stepwise to end-users needs.

Following further evaluation, the website as a whole needs to undergo regular monitoring and maintenance. This will ensure that content presented is up to date and external links work properly to engage users (Dobrian, 2013). Therefore, a website administrator is needed who oversees the resource guide, with assigned responsibilities and duties regarding content, links and engagement with users. Considering the current state of the website, this will be done by the student researcher, including maintenance of content, updates and back-ups. With expansion and growth of the website, administration of the website may be outsourced to ensure

a functional website. However, monitoring of content should be undertaken by a SP, to ensure appropriate and accurate information is provided.

As part of the evaluation process of the prototype, SPs provided further content ideas for the web-based resource guide. These included some digital resources and dementia-specific tutorials. In relation to further adjustments, revisions, and expansion of the website, it would be useful to develop further plans for potential tuition videos for SPs. Overall, further adjustments and additions to the website, including tutorials, should be considered and realised in collaboration with professional bodies, including Speech Pathology Australia, Dementia Australia and the Australian Department of Health and Aged Care . Further part of potential collaborations will ensure appropriate distribution and promotion of the website.

8.5 Conclusion

This appears to be the first study to evaluate the current practice of Australian SPs who work with PWD in order to assess their perceptions about working with PWD and their needs to support their work with this caseload. Despite the limitations discussed above, this research can be seen as a first step towards integrating clinicians who work with PWD actively in the process of developing a resource for their practice. The research findings aimed to provide initial insight into the clinical role of Australian SPs working with PWD. It captured and revealed that dementia as an area of SP practice is not considered in curricula at a university level. Professional guidelines specific the SP practice in Australia to provide direction for practice do not exist, and SPs reported that there is insufficient information readily accessible when working with PWD and their carers and families. The current research addressed these issues by developing a web-based resource guide. The resource guide was evaluated by SPs and is the starting point for further investigation, including adding PWD and other stakeholders to the expert team. In summary, presented results, discussion, and recommendations potentially draw other researchers' attention to investigate further and expand on proposed areas. The potential areas for the future will add worthwhile and rewarding resources for SPs, but also PWD and their families and carers.

References

- Abel, S., Schultz, A., Radermacher, I., Willmes, K., & Huber, W. (2005). Decreasing and increasing cues in naming therapy for aphasia. *Aphasiology*, 19(9), 831–848.
- Abrahams, J. P., & Camp, C. J. (1993). Maintenance and generalization of object naming training in anomia associated with degenerative dementia. *Clinical Gerontologist*, 12(3), 57–72.
- Acocella, I. (2012). The *focus groups* in social research: Advantages and disadvantages. *Quality & Quantity*, 46(4), 1125–1136. <https://doi.org/10.1007/s11135-011-9600-4>
- Acosta, I., Borges, G., Aguirre-Hernandez, R., Sosa, A. L., & Prince, M. (2018). Neuropsychiatric symptoms as risk factors of dementia in a Mexican population: A 10/66 Dementia Research Group study. *Alzheimer's & Dementia*, 14(3), 271–279. <https://doi.org/10.1016/j.jalz.2017.08.015>
- Ad'r, G., Ad'r, V., & Pascu, N. E. (2012). Logo design and the corporate identity. *Procedia - Social and Behavioral Sciences*, 51, 650–654. <https://doi.org/10.1016/j.sbspro.2012.08.218>
- Adams, C., & Nash, J. (2016). Exploring design thinking practices in evaluation. *Journal of MultiDisciplinary Evaluation*, 12(26), 12–17.
- Adams, W. C. (2015). Conducting semi-structured interviews. In K. E. Newcomer, H. P. Hatry, & J. S. Wholey (Eds.), *Handbook of practical program evaluation* (4th ed., pp. 492–505). <https://doi.org/10.1002/9781119171386.ch19>
- Agency for Clinical Innovation. (2016). *Better health for people living with dementia: A guide on the role of allied health professionals*. https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0004/310837/Better-health-dementia-allied-health-professionals.pdf
- Akiguchi, I., Tomimoto, H., Suenaga, T., Wakita, H., & Budka, H. (1997). Alterations in glia and axons in the brains of Binswanger's disease patients. *Stroke*, 28(7), 1423–1429. <https://doi.org/10.1161/01.STR.28.7.1423>
- Alm, N., Dye, R., Gowans, G., Campbell, J., Astell, A., & Ellis, M. (2007). A communication support system for older people with dementia. *Computer*, 40(5), 35–41. <https://doi.org/10.1109/MC.2007.153>
- Alroobaea, R., & Mayhew, P. J. (2014). How many participants are really enough for usability studies? *2014 Science and Information Conference*, 2014, pp. 48-56, doi: 10.1109/SAI.2014.6918171.
- Altman, K. W., Richards, A., Goldberg, L., Frucht, S., & McCabe, D. J. (2013). Dysphagia in stroke, neurodegenerative disease, and advanced dementia. *Otolaryngologic Clinics of North America*, 46(6), 1137–1149. <https://doi.org/10.1016/j.otc.2013.08.005>

- Alzheimer, A. (1907). Über eine eigenartige erkrankung der hirnrinde [About a strange disease of the cerebral cortex]. *Allgemeine. Journal of Psychiatry and Forensic Psychiatrie und Psychisch-gerichtliche Medizin*. 64, 146–148.
- Alzheimer Society of Canada. (2014). *7 key elements of person-centred care of people with dementia in long-term care homes*.
https://alzheimer.ca/sites/default/files/documents/PC-PEARLS_Full_Alzheimer-Society-Canada.pdf
- Alzheimer's Association. (2016). 2016 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*, 12(4), 459–509. <https://doi.org/10.1016/j.jalz.2016.03.001>
- Alzheimer's Disease International. (n.d.). *Dementia facts & figures*.
<https://www.alzint.org/about/dementia-facts-figures/>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>
- American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders: DSM-5 text revisions*. <https://psychiatry.org/psychiatrists/practice/dsm>
- American Speech-Language-Hearing Association. (n.d.-a). *Dementia practice portal*.
<https://www.asha.org/Practice-Portal/Clinical-Topics/Dementia/>
- American Speech-Language-Hearing Association. (n.d.-b). *Evidence-based practice*.
<https://www.asha.org/research/ebp/evidence-based-practice-process/>
- American Speech-Language-Hearing Association. (2016). Scope of practice in speech-language pathology. <https://www.asha.org/siteassets/publications/sp2016-00343.pdf>
- Amieva, H., Jacqmin-Gadda, H., Orgogozo, J.-M., Le Carret, N., Helmer, C., Letenneur, L., Barberger-Gateau, P., Fabrigoule, C., & Dartigues, J.-F. (2005). The 9 year cognitive decline before dementia of the Alzheimer type: A prospective population-based study. *Brain*, 128(5), 1093–1101. <https://doi.org/10.1093/brain/awh451>
- Amieva, H., Ouvrard, C., Giulioli, C., Meillon, C., Rullier, L., & Dartigues, J. F. (2015). Self-reported hearing loss, hearing aids, and cognitive decline in elderly adults: A 25-year study. *Journal of the American Geriatrics Society*, 63(10), 2099–2104.
<https://doi.org/10.1111/jgs.13649>
- Andrade, C. (2020). The limitations of online surveys. *Indian Journal of Psychological Medicine*, 42(6), 575–576. <https://doi.org/10.1177/0253717620957496>
- Andrade, C., & Radhakrishnan, R. (2009). The prevention and treatment of cognitive decline and dementia: An overview of recent research on experimental treatments. *Indian Journal of Psychiatry*, 51(1), 12.
- Andrieu, S., Guyonnet, S., Coley, N., Cantet, C., Bonnefoy, M., Bordes, S., Bories, L., Cufi, M.-N., Dantoine, T., Dartigues, J.-F., Desclaux, F., Gabelle, A., Gasnier, Y., Pesce, A., Sudres, K., Touchon, J., Robert, P., Rouaud, O., Legrand, P., ... Vellas, B. (2017). Effect of long-term omega 3 polyunsaturated fatty acid supplementation with or without multidomain intervention on cognitive function in elderly adults with memory

- complaints (MAPT): A randomised, placebo-controlled trial. *The Lancet Neurology*, 16(5), 377–389.
- Ardila, A., Ostrosky-Solis, F., Rosselli, M., & Gómez, C. (2000). Age-related cognitive decline during normal aging: The complex effect of education. *Archives of Clinical Neuropsychology*, 15(6), 495–513.
- Armstrong, L., Borthwick, S. E., Bayles, K. A., & Tomoeda, C. K. (1996). Use of the Arizona battery for communication disorders of dementia in the UK. *International Journal of Language & Communication Disorders*, 31(2), 171–180.
- Arvanitakis, Z., Shah, R. C., & Bennett, D. A. (2019). Diagnosis and management of dementia. *JAMA*, 322(16), 1589–1599.
- Ash, S., McMillan, C., Gross, R. G., Cook, P., Gunawardena, D., Morgan, B., Boller, A., Siderowf, A., & Grossman, M. (2012). Impairments of speech fluency in Lewy body spectrum disorder. *Brain and Language*, 120(3), 290–302.
<https://doi.org/10.1016/j.bandl.2011.09.004>
- Astell, A. J., Ellis, M. P., Bernardi, L., Alm, N., Dye, R., Gowans, G., & Campbell, J. (2010). Using a touch screen computer to support relationships between people with dementia and caregivers. *Interacting with Computers*, 22(4), 267–275.
<https://doi.org/10.1016/j.intcom.2010.03.003>
- Atay, C., Conway, E. R., Angus, D., Wiles, J., Baker, R., & Chenery, H. J. (2015). An automated approach to examining conversational dynamics between people with dementia and their carers. *PLoS One*, 10(12), e0144327.
<https://doi.org/10.1371/journal.pone.0144327>
- Australian Dementia Network. (2021). *Memory and Cognition Clinic guidelines: National service guidelines for specialised dementia and cognitive decline assessment services in Australia*. <https://memoryandcognitionclinic.com.au/wp-content/uploads/2021/11/ADNeT-Memory-and-Cognition-Clinic-Guidelines.pdf>
- Austrom, M. G., Boustani, M., & LaMantia, M. A. (2018). Ongoing medical management to maximize health and well-being for persons living with dementia. *The Gerontologist*, 58(suppl_1), S48–S57. <https://doi.org/10.1093/geront/gnx147>
- Badarunisa, M. B., Sebastian, D., Rangasayee, R. R., & Kala, B. (2015). ICF-based analysis of communication disorders in dementia of Alzheimer's type. *Dementia and Geriatric Cognitive Disorders Extra*, 5(3), 459–469.
- Baker, R., Bell, S., Baker, E., Holloway, J., Pearce, R., Dowling, Z., Thomas, P., Assey, J., & Wareing, L.-A. (2001). A randomized controlled trial of the effects of multi-sensory stimulation (MSS) for people with dementia. *British Journal of Clinical Psychology*, 40(1), 81–96. <https://doi.org/10.1348/014466501163508>
- Baker, R., Holloway, J., Holtkamp, C. C., Larsson, A., Hartman, L. C., Pearce, R., Scherman, B., Johansson, S., Thomas, P. W., Wareing, L.A., & Owens M. (2003). Effects of multi-sensory stimulation for people with dementia. *Journal of Advanced Nursing*, 43(5), 465–477.

- Ball, E. L., Owen-Booth, B., Gray, A., Shenkin, S. D., Hewitt, J., & McCleery, J. (2020). Aromatherapy for dementia. *Cochrane Database of Systematic Reviews*, 8. Article CD003150. <https://doi.org/10.1002/14651858.CD003150.pub3>
- Ballard, K. J., Etter, N. M., Shen, S., Monroe, P., & Tien Tan, C. (2019). Feasibility of automatic speech recognition for providing feedback during tablet-based treatment for apraxia of speech plus aphasia. *American Journal of Speech-Language Pathology*, 28(2S), 818–834.
- Banovic, S., Zunic, L. J., & Sinanovic, O. (2018). Communication difficulties as a result of dementia. *Materia Socio-medica*, 30(3), 221–224. <https://doi.org/10.5455/msm.2018.30.221-224>
- Bar-Ilan, J. (2005). Information hub blogs. *Journal of Information Science*, 31(4), 297–307.
- Barnes, D. E., Yaffe, K., Belfor, N., Jagust, W. J., DeCarli, C., Reed, B. R., & Kramer, J. H. (2009). Computer-based cognitive training for mild cognitive impairment: Results from a pilot randomized, controlled trial. *Alzheimer Disease & Associated Disorders*, 23(3), 205–210. <https://doi.org/10.1097/WAD.0b013e31819c6137>
- Baumer, D., Bischofberger, W., Lichter, H., & Zullighoven, H. (1996). User interface prototyping: Concepts, tools, and experience. In *Proceedings of IEEE 18th International Conference on Software Engineering* (pp. 532–541). <https://doi.org/10.1109/ICSE.1996.493447>
- Bayles, K. A., Kim, E. S., Azuma, T., Chapman, S. B., Cleary, S., Hopper, T., Mahendra, N., McKnight, P., Rackley, A., Tomoeda, C., & Zientz, J. (2005). Developing evidence-based practice guidelines for speech-language pathologists serving individuals with Alzheimer's dementia. *Journal of Medical Speech-Language Pathology*, 13(4), xiii–xxv. <https://asu.pure.elsevier.com/en/publications/developing-evidence-based-practice-guidelines-for-speech-language>
- Bayles, K., McCullough, K., & Tomoeda, C. K. (2020). *Cognitive-communication disorders of MCI and dementia: Definition, assessment, and clinical management*. Plural Publishing.
- Bayles, K. A., & Tomoeda, C. K. (1994). *FLCI: Functional linguistic communication inventory*. Canyonlands Publishing.
- Bayles, K. A., & Tomoeda, C. K. (2013). *Cognitive-communication disorders of dementia: Definition, diagnosis, and treatment*. Plural Publishing.
- Bayles, K. A., Tomoeda, C. K., & Trosset, M. W. (1992). Relation of linguistic communication abilities of Alzheimer's patients to stage of disease. *Brain and Language*, 42(4), 454–472. [https://doi.org/10.1016/0093-934X\(92\)90079-T](https://doi.org/10.1016/0093-934X(92)90079-T)
- Bazzano, A. N., Martin, J., Hicks, E., Faughnan, M., & Murphy, L. (2017). Human-centred design in global health: A scoping review of applications and contexts. *PLoS One*, 12(11), e0186744. <https://doi.org/10.1371/journal.pone.0186744>
- Beales, A., Bates, K., Cartwright, J., & Whitworth, A. (2019). Lost for words: Perspectives and experiences of people with primary progressive aphasia and Alzheimer's disease

- and their families of participation in a lexical retrieval intervention. *International Journal of Speech-Language Pathology*, 21(5), 483–492.
<https://doi.org/10.1080/17549507.2019.1625439>
- Beales, A., Cartwright, J., Whitworth, A., & Panegyres, P. K. (2016). Exploring generalisation processes following lexical retrieval intervention in primary progressive aphasia. *International Journal of Speech-Language Pathology*, 18(3), 299–314.
<https://doi.org/10.3109/17549507.2016.1151936>
- Beber, B. C., Brandão, L., & Chaves, M. L. F. (2015). A warning to the Brazilian speech-language pathology and audiology community about the importance of scientific and clinical activities in primary progressive aphasia. *CODAS*, 27(5), 505–508.
<https://doi.org/10.1590/2317-1782/20152015081>
- Bellchambers, H., & Penning, C. (2007). Person-centered approach to care (PCA): A philosophy of care and management for carers. *Contemporary Nurse*, 26(2), 196–197.
- Beltrami, D., Gagliardi, G., Rossini Favretti, R., Ghidoni, E., Tamburini, F., & Calzà, L. (2018). Speech analysis by natural language processing techniques: A possible tool for very early detection of cognitive decline?. *Frontiers in Aging Neuroscience*, 10.
<https://doi.org/10.3389/fnagi.2018.00369>
- Benigas, J. E., & Bourgeois, M. (2016). Using spaced retrieval with external aids to improve use of compensatory strategies during eating for persons with dementia. *American Journal of Speech-Language Pathology*, 25(3), 321–334.
https://doi.org/10.1044/2015_AJSLP-14-0176
- Bennett, S., Shand, S., & Liddle, J. (2011). Occupational therapy practice in Australia with people with dementia: A profile in need of change. *Australian Occupational Therapy Journal*, 58(3), 155–163.
- Berkman, C., Ahronheim, J. C., & Vitale, C. A. (2019). Speech-language pathologists' views about aspiration risk and comfort feeding in advanced dementia. *American Journal of Hospice and Palliative Medicine®*, 36(11), 993–998.
- Bertrand, J. T., Brown, J. E., & Ward, V. M. (1992). Techniques for analyzing focus group data. *Evaluation Review*, 16(2), 198–209.
- Bessey, L. J., & Walaszek, A. (2019). Management of behavioral and psychological symptoms of dementia. *Current Psychiatry Reports*, 21(8), 66.
<https://doi.org/10.1007/s11920-019-1049-5>
- Beukelman, D. R., Fager, S., Ball, L., & Dietz, A. (2007). AAC for adults with acquired neurological conditions: A review. *Augmentative and Alternative Communication*, 23(3), 230–242. <https://doi.org/10.1080/07434610701553668>
- Bevan, N. (2009). Criteria for selecting methods in user centred design. I-USED,
<https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.165.8942&rep=rep1&type=pdf>
- Bidzan, M., Bidzan, L., & Bidzan-Bluma, I. (2017). Neuropsychiatric symptoms and faster progression of cognitive impairments as predictors of risk of conversion of mild

- cognitive impairment to dementia. *Archives of Medical Science*, 13(5), 1168–1177. <https://doi.org/10.5114/aoms.2017.68943>
- Bird, M., & Kinsella, G. (1996). Long-term cued recall of tasks in senile dementia. *Psychology and Aging*, 11(1), 45.
- Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member checking: A tool to enhance trustworthiness or merely a nod to validation? *Qualitative Health Research*, 26(13), 1802–1811. <https://doi.org/10.1177/1049732316654870>
- Bjork, R. A. (1988). Retrieval practice and the maintenance of knowledge. *Practical Aspects of Memory: Current Research and Issues*, 1, 396–401.
- Boda, K., Földes, Á. M., Gulyás, G. G., & Imre, S. (2011). User tracking on the web via cross-browser fingerprinting. In *Nordic Conference on Secure IT Systems* (pp. 31–46). Springer. https://link.springer.com/chapter/10.1007/978-3-642-29615-4_4
- Botha, H., Duffy, J. R., Whitwell, J. L., Strand, E. A., Machulda, M. M., Schwarz, C. G., Reid, R. I., Spychalla, A. J., Senjem, M., Jones, D. T., Lowe, V., Jack, C. R., & Josephs, K. A. (2015). Classification and clinicoradiologic features of primary progressive aphasia (PPA) and apraxia of speech. *Cortex*, 69, 220–236.
- Bourgeois, M. S. (1990). Enhancing conversation skills in patients with Alzheimer's disease using a prosthetic memory aid. *Journal of Applied Behavior Analysis*, 23(1), 29–42.
- Bourgeois, M. S. (1992). Evaluating memory wallets in conversations with persons with dementia. *Journal of Speech, Language, and Hearing Research*, 35(6), 1344–1357.
- Bourgeois, M. S. (1993). Effects of memory aids on the dyadic conversations of individuals with dementia. *Journal of Applied Behavior Analysis*, 26(1), 77–87.
- Bourgeois, M. S., Brush, J., Elliot, G., & Kelly, A. (2015). Join the revolution: How Montessori for aging and dementia can change long-term care culture. *Seminars in Speech and Language*, 36(3), 209–214. <https://doi.org/10.1055/s-0035-1554802>
- Bourgeois, M. S., Dijkstra, K., Burgio, L. D., & Allen, R. S. (2004). Communication skills training for nursing aides of residents with dementia. *Clinical Gerontologist*, 27(1–2), 119–138. https://doi.org/10.1300/J018v27n01_10
- Bourgeois, M., Fried-Oken, M., & Rowland, C. (2010). AAC strategies and tools for persons with dementia. *The ASHA Leader*, 15(3), 8–11. <https://doi.org/10.1044/leader.FTR1.15032010.8>
- Bourgeois, M. S., & Mason, L. A. (1996). Memory wallet intervention in an adult day-care setting. *Behavioral Interventions*, 11(1), 3–18. [https://doi.org/10.1002/\(SICI\)1099-078X\(199601\)11:1<3::AID-BIN150>3.0.CO;2-0](https://doi.org/10.1002/(SICI)1099-078X(199601)11:1<3::AID-BIN150>3.0.CO;2-0)
- Bowling, A., Rowe, G., Adams, S., Sands, P., Samsi, K., Crane, M., Joly, L., & Manthorpe, J. (2015). Quality of life in dementia: A systematically conducted narrative review of dementia-specific measurement scales. *Aging & Mental Health*, 19(1), 13–31.

- Boy, G. A. (2017). Human-centered design as an integrating discipline. *Journal of Systemics, Cybernetics and Informatics*, 15(1).
- Bragge, J., Merisalo-Rantanen, H., & Hallikainen, P. (2005). Gathering innovative end-user feedback for continuous development of information systems: A repeatable and transferable e-collaboration process. *IEEE Transactions on Professional Communication*, 48(1), 55–67.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Brod, M., Stewart, A. L., Sands, L., & Walton, P. (1999). Conceptualization and measurement of quality of life in dementia: The Dementia Quality of Life instrument (DQoL). *The Gerontologist*, 39(1), 25–36.
- 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(11), 1436–1444.
- Brotherton, A., & Judd, P. (2007). Quality of life in adult enteral tube feeding patients. *Journal of Human Nutrition and Dietetics*, 20(6), 513–522.
- Brügger, N. (2009). Website history and the website as an object of study. *New Media & Society*, 11(1–2), 115–132.
- Brush, J. A., & Camp, C. J. (1998). Using spaced retrieval as an intervention during speech-language therapy. *Clinical Gerontologist*, 19(1), 51–64.
- Brush, J. A., Meehan, R. A., & Calkins, M. P. (2002). Using the environment to improve intake for people with dementia. *Alzheimer's Care Today*, 3(4), 330–338.
- Brush, J. A., Slominski, T., & Boczek, F. (2006). Nutritional and dysphagia services for individuals with Alzheimer's disease. *The ASHA Leader*, 11(7), 8–26.
- Bucks, R. S., Ashworth, D., Wilcock, G., & Siegfried, K. (1996). Assessment of activities of daily living in dementia: Development of the Bristol Activities of Daily Living Scale. *Age and Ageing*, 25(2), 113–120.
- Budde, R., Kautz, K., Kuhlenkamp, K., & Züllighoven, H. (1992). What is prototyping? *Information Technology & People*. 6 (2) 89-95. <https://doi-org.ezproxy.newcastle.edu.au/10.1108/EUM0000000003546>
- Burgio, L. D., Allen-Burge, R., Roth, D. L., Bourgeois, M. S., Dijkstra, K., Gerstle, J., Jackson, E., & Bankester, L. (2001). Come talk with me: Improving communication between nursing assistants and nursing home residents during care routines. *The Gerontologist*, 41(4), 449–460. <https://doi.org/10.1093/geront/41.4.449>
- Burrell, J. R., & Piguet, O. (2015). Lifting the veil: How to use clinical neuropsychology to assess dementia. *Journal of Neurology, Neurosurgery & Psychiatry*, 86(11), 1216–1224. <https://doi.org/10.1136/jnnp-2013-307483>

- Buschke, H., Kuslansky, G., Katz, M., Stewart, W. F., Sliwinski, M. J., Eckholdt, H. M., & Lipton, R. B. (1999). Screening for dementia with the memory impairment screen. *Neurology*, 52(2), 231–231.
- Butler, M., McCreedy, E., Nelson, V. A., Desai, P., Ratner, E., Fink, H. A., Hemmy, L. S., McCarten, R., Barclay, T. R., Brasure, M., Davila, H., & Kane, R. L. (2018). Does cognitive training prevent cognitive decline? A systematic review. *Annals of Internal Medicine*, 168(1), 63–68. <https://doi.org/10.7326/m17-1531>
- Byrne, K., & Orange, J. (2005). Conceptualizing communication enhancement in dementia for family caregivers using the WHO-ICF framework. *Advances in Speech Language Pathology*, 7(4), 187–202.
- Caeyenberghs, K., Clemente, A., Imms, P., Egan, G., Hocking, D. R., Leemans, A., Metzler-Baddeley, C., Jones, D. K., & Wilson, P. H. (2018). Evidence for training-dependent structural neuroplasticity in brain-injured patients: A critical review. *Neurorehabilitation and Neural Repair*, 32(2), 99–114.
- Cahill, S., Macijauskiene, J., Nygård, A.-M., Faulkner, J.-P., & Hagen, I. (2007). Technology in dementia care. *Technology and Disability*, 19(2, 3), 55–60.
- Calzà, L., Gagliardi, G., Rossini Favretti, R., & Tamburini, F. (2021). Linguistic features and automatic classifiers for identifying mild cognitive impairment and dementia. *Computer Speech & Language*, 65, 101113. <https://doi.org/10.1016/j.csl.2020.101113>
- Camp, C., Antenucci, V., Brush, J., & Slominski, T. (2012). Using spaced retrieval to effectively treat dysphagia in clients with dementia. *Perspectives on Swallowing and Swallowing Disorders (Dysphagia)*, 21(3), 96–104.
- Camp, C. J., Foss, J. W., O’Hanlon, A. M., & Stevens, A. B. (1996). Memory interventions for persons with dementia. *Applied Cognitive Psychology*, 10(3), 193–210.
- Caplan, L. R., & Gomes, J. A. (2010). Binswanger disease—an update. *Journal of the Neurological Sciences*, 299(1–2), 9–10.
- Capouch, S. D., Farlow, M. R., & Brosch, J. R. (2018). A review of dementia with Lewy bodies’ impact, diagnostic criteria and treatment. *Neurology and Therapy*, 7(2), 249–263. <https://doi.org/10.1007/s40120-018-0104-1>
- Carós, M., Garolera, M., Radeva, P., & Giro-i-Nieto, X. (2020, June). Automatic reminiscence therapy for dementia. In *Proceedings of the 2020 International Conference on Multimedia Retrieval* (pp. 383–387). <https://doi.org/10.1145/3372278.3391927>
- Cartwright, J., Franklin, D., Forman, D., & Freegard, H. (2015). Promoting collaborative dementia care via online interprofessional education. *Australasian Journal on Ageing*, 34(2), 88–94.
- Cartwright, J., & Oliver, E. (2015). What’s the evidence? Montessori-based interventions for people with dementia in a residential aged-care setting. *Journal of Clinical Practice in Speech-Language Pathology*, 17(2), 94–97.

- Cartwright, J., Roberts, K., Oliver, E., Bennett, M., & Whitworth, A. (2022). Montessori mealtimes for dementia: A pathway to person-centred care. *Dementia*, 21(4), 1098–1119. <https://doi.org/10.1177/14713012211057414>
- Cations, M., Laver, K. E., Crotty, M., & Cameron, I. D. (2017). Rehabilitation in dementia care. *Age and Ageing*, 47(2), 171–174. <https://doi.org/10.1093/ageing/afx173>
- Chaudhury, H., & Cooke, H. (2014). Design matters in dementia care: The role of the physical environment in dementia care settings. *Excellence in Dementia Care*, 2, 144–158.
- Chenery, H. J., Atay, C., Campbell, A., Conway, E., Angus, D., & Wiles, J. (2016). O3-01-02: Using technology to enhance communication between people with dementia and their carers. *Alzheimer's & Dementia*, 12(7S_Part_5), 279–280. <https://doi.org/10.1016/j.jalz.2016.06.507>
- Chern, A., & Golub, J. S. (2019). Age-related hearing loss and dementia. *Alzheimer Disease & Associated Disorders*, 33(3), 285–290. <https://doi.org/10.1097/WAD.0000000000000325>
- Chernoff, R. (2006). Tube feeding patients with dementia. *Nutrition in Clinical Practice*, 21(2), 142–146.
- Cheston, R., & Ivanecka, A. (2017). Individual and group psychotherapy with people diagnosed with dementia: A systematic review of the literature. *International Journal of Geriatric Psychiatry*, 32(1), 3–31.
- Cheston, R., Jones, K., & Gilliard, J. (2003). Group psychotherapy and people with dementia. *Aging & Mental Health*, 7(6), 452–461.
- Chung, J. C. (2004). Activity participation and well-being of people with dementia in long-term-care settings. *OTJR: Occupation, Participation and Health*, 24(1), 22–31. <https://doi.org/10.1177/153944920402400104>
- Clare, L. (2017). Rehabilitation for people living with dementia: A practical framework of positive support. *PLOS Medicine*, 14(3), e1002245. <https://doi.org/10.1371/journal.pmed.1002245>
- Clare, L., Wilson, B. A., Breen, K., & Hodges, J. R. (1999). Errorless learning of face-name associations in early Alzheimer's disease. *Neurocase*, 5(1), 37–46.
- Clare, L., Wilson, B. A., Carter, G., Breen, K., Gosses, A., & Hodges, J. R. (2000). Intervening with everyday memory problems in dementia of Alzheimer type: An errorless learning approach. *Journal of Clinical and Experimental Neuropsychology*, 22(1), 132–146. [https://doi.org/10.1076/1380-3395\(200002\)22:1;1-8;FT132](https://doi.org/10.1076/1380-3395(200002)22:1;1-8;FT132)
- Clare, L., & Woods, R. T. (2004). Cognitive training and cognitive rehabilitation for people with early-stage Alzheimer's disease: A review. *Neuropsychological Rehabilitation*, 14(4), 385–401.

- Clark, L. W. (1995). Interventions for persons with Alzheimer's disease: Strategies for maintaining and enhancing communicative success. *Topics in Language Disorders*, 15(2), 47–65.
- Clemensen, J., Larsen, S. B., Kyng, M., & Kirkevold, M. (2007). Participatory design in health sciences: Using cooperative experimental methods in developing health services and computer technology. *Qualitative Health Research*, 17(1), 122–130.
<https://doi.org/10.1177/1049732306293664>
- Cole, J. H., & Franke, K. (2017). Predicting age using neuroimaging: Innovative brain ageing biomarkers. *Trends in Neurosciences*, 40(12), 681–690.
<https://doi.org/10.1016/j.tins.2017.10.001>
- Cole, J. H., Marioni, R. E., Harris, S. E., & Deary, I. J. (2019). Brain age and other bodily “ages”: Implications for neuropsychiatry. *Molecular psychiatry*, 24(2), 266–281.
- Colucci, E. (2007). “Focus groups can be fun”: The use of activity-oriented questions in focus group discussions. *Qualitative Health Research*, 17(10), 1422–1433.
- Connell, C. M., Janevic, M. R., & Gallant, M. P. (2001). The costs of caring: Impact of dementia on family caregivers. *Journal of Geriatric Psychiatry and Neurology*, 14(4), 179–187.
- Conroy, P., Sage, K., & Lambon Ralph, M. A. (2009). Errorless and errorful therapy for verb and noun naming in aphasia. *Aphasiology*, 23(11), 1311–1337.
<https://doi.org/10.1080/02687030902756439>
- Conway, E., & Chenery, H. (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(7–8), 1145–1155. <https://doi.org/10.1111/jocn.13134>
- Cooke, C. R., & Gould, M. K. (2013). Advancing clinical practice and policy through guidelines. The role of the American Thoracic Society. *American Journal of Respiratory and Critical Care Medicine*, 187(9), 910–914.
<https://doi.org/10.1164/rccm.201301-0009PP>
- Cooper, C., Mukadam, N., Katona, C., Lyketsos, C. G., Ames, D., Rabins, P., Engedal, K., de Mendonça Lima, C., Blazer, D., Teri, L., Brodaty, H., & Livingston, G. (2012). Systematic review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics*, 24(6), 856–870.
<https://doi.org/10.1017/S1041610211002614>
- Cornett, B. S. (2010). Health care reform and speech-language pathology practice. *The ASHA Leader*, 15(9), 14–16.
- Cotelli, M., Manenti, R., & Zanetti, O. (2012). Reminiscence therapy in dementia: A review. *Maturitas*, 72(3), 203–205.
- Cress, C., & King, J. (1999). AAC strategies for people with primary progressive aphasia without dementia: Two case studies. *Augmentative and Alternative Communication*, 15(4), 248–259.

- Creswell, J. W., Klassen, A. C., Plano Clark, V. L., & Smith, K. C., for the Office of Behavioral and Social Sciences Research. (2011). *Best practices for mixed methods research in the health sciences*. National Institutes of Health.
<https://obssr.od.nih.gov/research-resources/mixed-methods-research>
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124–130.
- Croot, K. (2018). Treatment for lexical retrieval impairments in primary progressive aphasia: A research update with implications for clinical practice. *Seminars in Speech and Language*, 39(3), 242–256. <https://doi.org/10.1055/s-0038-1660783>
- Croot, K., Hodges, J. R., Xuereb, J., & Patterson, K. (2000). Phonological and articulatory impairment in Alzheimer's disease: A case series. *Brain and Language*, 75(2), 277–309.
- Croot, K., Raiser, T., Taylor-Rubin, C., Ruggero, L., Ackl, N., Wlasich, E., Danek, A., Scharfenberg, A., Foxe, D., Hodges, J., Piguet, O., Kochan, N. A., & Nickels, L. (2019). Lexical retrieval treatment in primary progressive aphasia: An investigation of treatment duration in a heterogeneous case series. *Cortex*, 115, 133–158.
<https://doi.org/10.1016/j.cortex.2019.01.009>
- Cullen, B., O'Neill, B., Evans, J. J., Coen, R. F., & Lawlor, B. A. (2007). A review of screening tests for cognitive impairment. *Journal of Neurology, Neurosurgery, and Psychiatry*, 78(8), 790–799. <https://doi.org/10.1136/jnnp.2006.095414>
- Cullen, C. (1976). Errorless learning with the retarded. *Nursing Times*, 72(12 suppl.), 45.
- Cummings, J., Lee, G., Mortsdorf, T., Ritter, A., & Zhong, K. (2017). Alzheimer's disease drug development pipeline: 2017. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 3(3), 367–384. <https://doi.org/10.1016/j.trci.2017.05.002>
- Deal, J. A., Betz, J., Yaffe, K., Harris, T., Purchase-Helzner, E., Satterfield, S., Pratt, S., Govil, N., Simonsick, E. M., & Lin, F. R. (2017). Hearing impairment and incident dementia and cognitive decline in older adults: The health ABC study. *Journals of Gerontology Series A: Biomedical Sciences and Medical Sciences*, 72(5), 703–709.
<https://doi.org/10.1093/gerona/glw069>
- Deal, J. A., Sharrett, A. R., Albert, M. S., Coresh, J., Mosley, T. H., Knopman, D., Wruck, L. M., & Lin, F. R. (2015). Hearing impairment and cognitive decline: A pilot study conducted within the atherosclerosis risk in communities neurocognitive study. *American Journal of Epidemiology*, 181(9), 680–690.
- Dearnley, C. (2005). A reflection on the use of semi-structured interviews. *Nurse Researcher*, 13(1), 19–28.
- De Boeck, K., Castellani, C., & Elborn, J. S. (2014). Medical consensus, guidelines, and position papers: A policy for the ECFS. *Journal of Cystic Fibrosis*, 13(5), 495–498.
<https://doi.org/10.1016/j.jcf.2014.06.012>
- Dementia Australia. (n.d.). *Vascular dementia*. <https://www.dementia.org.au/about-dementia/types-of-dementia/vascular-dementia>

- Dementia Australia. (2018a). *Dementia prevalence data 2018–2058*. National Centre for Social and Economic Modelling (NATSEM), University of Canberra.
<https://www.dementia.org.au/information/statistics/prevalence-data>
- Dementia Australia. (2018b). *Let's talk*.
<https://www.dementia.org.au/sites/default/files/resources/2019-Lets-Talk-Booklet.pdf>
- Denning, K. H., Aldridge, Z., Pepper, A., & Hodgkinson, C. (2017). Admiral nursing: Case management for families affected by dementia. *Nursing Standard*, 31(24), 42–50.
<https://doi.org/10.7748/ns.2017.e10600>
- Denning, K. H., Castle, E., Scates, C., & De Vries, K. (2020). Advance care plans in dementia: User-centred design. *BMJ Supportive & Palliative Care*, 10(4), e38.
<https://doi.org/10.1136/bmjspcare-2018-001700>
- Des Roches, C. A., Balachandran, I., Ascenso, E. M., Tripodis, Y., & Kiran, S. (2015). Effectiveness of an impairment-based individualized rehabilitation program using an iPad-based software platform. *Frontiers in Human Neuroscience*, 8, 1015.
<https://doi.org/10.3389/fnhum.2014.01015>
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40(4), 314–321. <https://doi.org/10.1111/j.1365-2929.2006.02418.x>
- Dictionary.com. (n.d.). *Position paper*. Retrieved December 21, 2021, from
<https://www.dictionary.com/browse/position-paper>
- Dobrian, J. (2013). Putting your best face forward: Website maintenance. *Journal of Property Management*, 78(5), 54–58.
- Done, D., & Thomas, J. (2001). Training in communication skills for informal carers of people suffering from dementia: A cluster randomized clinical trial comparing a therapist led workshop and a booklet. *International Journal of Geriatric Psychiatry*, 16(8), 816–821.
- Dooley, S., & Walshe, M. (2019). Assessing cognitive communication skills in dementia: A scoping review. *International Journal of Language & Communication Disorders*, 54(5), 729–741.
- Douglas, J. W., Lawrence, J. C., & Turner, L. W. (2017). Social ecological perspectives of tube-feeding older adults with advanced dementia: A systematic literature review. *Journal of Nutrition in Gerontology and Geriatrics*, 36(1), 1–17.
<https://doi.org/10.1080/21551197.2016.1277174>
- Douglas, N., Brush, J., & Bourgeois, M. (2018). Person-centered, skilled services using a Montessori approach for persons with dementia. *Seminars in Speech and Language*, 39(3), 223–230. <https://doi.org/10.1055/s-0038-1660781>
- Douglas, S., James, I., & Ballard, C. (2004). Non-pharmacological interventions in dementia. *Advances in Psychiatric Treatment*, 10(3), 171–177.
- Downs, M., & Collins, L. (2015). Person-centred communication in dementia care. *Nursing Standard* (2014+), 30(11), 37. doi:<https://doi.org/10.7748/ns.30.11.37.s45>

- Dreier-Wolfgramm, A., Michalowsky, B., Austrom, M. G., van der Marck, M. A., Iliffe, S., Alder, C., Vollmar, H. C., Thyrian, J. R., Wucherer, D., Zwingmann, I., & Hoffmann, W. (2017). Dementia care management in primary care. *Zeitschrift für Gerontologie und Geriatrie*, 50(2), 68–77. <https://doi.org/10.1007/s00391-017-1220-8>
- Drisko, J. W., & Maschi, T. (2016). *Content analysis*. Oxford University Press.
- Drulia, T. C., & Ludlow, C. L. (2013). Relative efficacy of swallowing versus non-swallowing tasks in dysphagia rehabilitation: Current evidence and future directions. *Current Physical Medicine and Rehabilitation Reports*, 1(4), 242–256. <https://doi.org/10.1007/s40141-013-0029-7>
- Duncan, S., Gaughey, J. M., Fallis, R., McAuley, D. F., Walshe, M., & Blackwood, B. (2019). Interventions for oropharyngeal dysphagia in acute and critical care: A protocol for a systematic review and meta-analysis. *Systematic Reviews*, 8(1), 283. <https://doi.org/10.1186/s13643-019-1196-0>
- Dunham, G. (2011). The future at hand: Mobile devices and apps in clinical practice. *The ASHA Leader*, 16(4), 4–4. <https://doi.org/10.1044/leader.FTR6.16042011.4>
- Dykstra, A. D., Hakel, M. E., & Adams, S. G. (2007). Application of the ICF in reduced speech intelligibility in dysarthria. *Seminars in Speech and Language*, 28(4), 301–311. <https://doi.org/10.1055/s-2007-986527>
- Easterling, C. S., & Robbins, E. (2008). Dementia and dysphagia. *Geriatric Nursing*, 29(4), 275–285. <https://doi.org/10.1016/j.gerinurse.2007.10.015>
- 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, Article 906818. <https://doi.org/10.4061/2010/906818>
- 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(3), 345–358. <https://doi.org/10.1017/s1041610212001664>
- Ehrich, K., Freeman, G. K., Richards, S. C., Robinson, I. C., & Shepperd, S. (2002). How to do a scoping exercise: Continuity of care. *Research, Policy and Planning*, 20(1), 25–29.
- Ekberg, O., Hamdy, S., Woisard, V., Wuttge-Hannig, A., & Ortega, P. (2002). Social and psychological burden of dysphagia: Its impact on diagnosis and treatment. *Dysphagia*, 17(2), 139–146.
- Elias, M. F., Beiser, A., Wolf, P. A., Au, R., White, R. F., & D’Agostino, R. B. (2000). The preclinical phase of Alzheimer disease: A 22-year prospective study of the Framingham cohort. *Archives of Neurology*, 57(6), 808–813. <https://doi.org/10.1001/archneur.57.6.808>

- Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, 62(1), 107–115.
- El-Wahsh, S., Monroe, P., Kumfor, F., & Ballard, K. (2021). Communication interventions for people with dementia and their communication partners. *Dementia Rehabilitation*, 35–56. <https://doi.org/10.1016/B978-0-12-818685-5.00003-9>
- Engelberg, D., & Seffah, A. (2002). A framework for rapid mid-fidelity prototyping of web sites. In J. Hammond, T. Gross, & J. Wesson (Eds.), *Usability: IFIP World Computer Congress, TC 13* (Vol. 99, pp. 203–215). The International Federation for Information Processing. Springer. https://doi.org/10.1007/978-0-387-35610-5_14
- Epelbaum, S., Saade, Y. M., Flamand Roze, C., Roze, E., Ferrieux, S., Arbizu, C., Nogues, M., Azuar, C., Dubois, B., Tezenas du Montcel, S., & Teichmann, M. (2021). A reliable and rapid language tool for the diagnosis, classification, and follow-up of primary progressive aphasia variants. *Frontiers in Neurology*, 11(1781). <https://doi.org/10.3389/fneur.2020.571657>
- Etikan, I., Alkassim, R., & Abubakar, S. (2016). Comparison of snowball sampling and sequential sampling technique. *Biometrics and Biostatistics International Journal*, 3(1), 55.
- Fairweather, G. C., Lincoln, M. A., & Ramsden, R. (2016). Speech-language pathology teletherapy in rural and remote educational settings: Decreasing service inequities. *International Journal of Speech-Language Pathology*, 18(6), 592–602.
- Farri, A., Accornero, A., & Burdese, C. (2007). Social importance of dysphagia: Its impact on diagnosis and therapy. *ACTA Otorhinolaryngologica Itálica*, 27(2), 83.
- Feder, G., Eccles, M., Grol, R., Griffiths, C., & Grimshaw, J. (1999). Using clinical guidelines. *BMJ*, 318(7185), 728–730. <https://doi.org/10.1136/bmj.318.7185.728>
- Feldman, H. H., Jacova, C., Robillard, A., Garcia, A., Chow, T., Borrie, M., Schipper, H. M., Blair, M., Kertesz, A., & Chertkow, H. (2008). Diagnosis and treatment of dementia: 2. Diagnosis. *CMAJ*, 178(7), 825–836. <https://doi.org/10.1503/cmaj.070798>
- Field, M. J., & Lohr, K. N. (1990). *Clinical practice guidelines: Directions for a new program*. National Academy Press.
- Fillingham, J. K., Hodgson, C., Sage, K., & Lambon Ralph, M. A. (2003). The application of errorless learning to aphasic disorders: A review of theory and practice. *Neuropsychological Rehabilitation*, 13(3), 337–363. <https://doi.org/10.1080/09602010343000020>
- Finger, E. C. (2016). Frontotemporal dementias. *Continuum*, 22(2 Dementia), 464–489. <https://doi.org/10.1212/CON.0000000000000300>
- Fink, H. A., Linskens, E. J., MacDonald, R., Silverman, P. C., McCarten, J. R., Talley, K. M., Forte, M.L., Desai, P. J., Nelson, V. A., Miller, M.A., Hemmy, L. S., Brasure, M., Taylor, B. C., Ng, W., Ouellette, J. M., Sheets, K.M., Wilt, T. J., & Butler, M. A. (2020). Benefits and harms of prescription drugs and supplements for treatment of

- clinical Alzheimer-type dementia: A systematic review and meta-analysis. *Annals of Internal Medicine*, 172(10), 656–668.
- Finkel, S. (2000). Introduction to behavioural and psychological symptoms of dementia (BPSD). *International Journal of Geriatric Psychiatry*, 15(Suppl.1), S2–S4.
[https://doi.org/10.1002/\(SICI\)1099-1166\(200004\)15:1+<S2::AID-GPS159>3.0.CO;2-3](https://doi.org/10.1002/(SICI)1099-1166(200004)15:1+<S2::AID-GPS159>3.0.CO;2-3)
- Finucane, T. E., Christmas, C., & Leff, B. A. (2007). Tube feeding in dementia: How incentives undermine health care quality and patient safety. *Journal of the American Medical Directors Association*, 8(4), 205–208.
<https://doi.org/10.1016/j.jamda.2007.01.007>
- Finucane, T. E., Christmas, C., & Travis, K. (1999). Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA*, 282(14), 1365–1370.
- Fleming, K. C., & Evans, J. M. (1995). Pharmacologic therapies in dementia. *Mayo Clinic Proceedings*, 70(11), 1116–1123. <https://doi.org/10.4065/70.11.1116>
- Foley, T., Jennings, A., & Swanwick, G. (2019). *Dementia: Diagnosis and management in general practice*. Irish College of General Practitioners Quality and Safety in Practice Committee. http://dementiapathways.ie/_filecache/e74/e54/839-dementia_qrg_15th_april_2019-1.pdf
- 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(3), 189–198. [https://doi.org/10.1016/0022-3956\(75\)90026-6](https://doi.org/10.1016/0022-3956(75)90026-6)
- Forbes, K. E., Venneri, A., & Shanks, M. F. (2002). Distinct patterns of spontaneous speech deterioration: An early predictor of Alzheimer’s disease. *Brain and Cognition*, 48(2–3), 356–361.
- Forman, J., & Damschroder, L. (2007). Qualitative content analysis. In L. Jacoby & L. A. Siminoff (Eds.), *Empirical methods for bioethics: A primer* (Vol. 11, pp. 39–62). Emerald Group Publishing. [https://doi.org/10.1016/S1479-3709\(07\)11003-7](https://doi.org/10.1016/S1479-3709(07)11003-7)
- Forrester, S. N., Gallo, J. J., Smith, G. S., & Leoutsakos, J.-M. S. (2016). Patterns of neuropsychiatric symptoms in mild cognitive impairment and risk of dementia. *The American Journal of Geriatric Psychiatry*, 24(2), 117–125.
<https://doi.org/10.1016/j.jagp.2015.05.007>
- Förstl, H. (2002). Frontallappendegenerationen und verwandte Erkrankungen [Frontal lobe degeneration and similar disease]. In H. Förstl (Ed.), *Frontalhirn* [Frontal lobe] (pp. 111–144). Springer.
- Furlong, L. M., Morris, M. E., Erickson, S., & Serry, T. A. (2016). Quality of mobile phone and tablet mobile apps for speech sound disorders: Protocol for an evidence-based appraisal. *JMIR Research Protocols*, 5(4), e233.
- Furlong, L., Morris, M., Serry, T., & Erickson, S. (2018). Mobile apps for treatment of speech disorders in children: An evidence-based analysis of quality and efficacy. *PLoS One*, 13(8), e0201513.

- Furuta, M., & Yamashita, Y. (2013). Oral health and swallowing problems. *Current Physical Medicine and Rehabilitation Reports*, 1(4), 216–222. <https://doi.org/10.1007/s40141-013-0026-x>
- Furuya, J., Suzuki, H., Tamada, Y., Onodera, S., Nomura, T., Hidaka, R., Minakuchi, S., & Kondo, H. (2020). Food intake and oral health status of inpatients with dysphagia in acute care settings. *Journal of Oral Rehabilitation*, 47(6), 736–742.
- Gabryelewicz, T., Styczynska, M., Luczywek, E., Barczak, A., Pfeffer, A., Androsiuk, W., Chodakowska-Zebrowska, M., Wasiak, B., Peplonska, B., & Barcikowska, M. (2007). The rate of conversion of mild cognitive impairment to dementia: Predictive role of depression. *International Journal of Geriatric Psychiatry*, 22(6), 563–567. <https://doi.org/10.1002/gps.1716>
- Gačnik, M., Starčič, A. I., Zaletelj, J., & Zajc, M. (2018). User-centred app design for speech sound disorders interventions with tablet computers. *Universal Access in the Information Society*, 17(4), 821–832. <https://doi.org/10.1007/s10209-017-0545-9>
- Galvin, J. E., & Sadowsky, C. H. (2012). Practical guidelines for the recognition and diagnosis of dementia. *Journal of the American Board of Family Medicine*, 25(3), 367–382. <https://doi.org/10.3122/jabfm.2012.03.100181>
- Galvin, J. E., Valois, L., & Zweig, Y. (2014). Collaborative transdisciplinary team approach for dementia care. *Neurodegenerative Disease Management*, 4(6), 455–469. <https://doi.org/10.2217/nmt.14.47>
- Gan, J., Liu, S., Chen, Z., Wang, X.-D., & Ji, Y. (2021). Effect of multiple medicines on dementia initial treatment: Experience and thinking. *American Journal of Alzheimer's Disease & Other Dementias*, 36. <https://doi.org/10.1177/15333175211053134>
- Garreta-Domingo, M., Sloep, P. B., & Hernández-Leo, D. (2018). Human-centred design to empower “teachers as designers”. *British Journal of Educational Technology*, 49(6), 1113–1130. <https://doi.org/10.1111/bjet.12682>
- Gauthier, S., Rosa-Neto, P., Morais, J. A., & Webster, C. (2021). *World Alzheimer report 2021: Journey through the diagnosis of dementia*. Alzheimer's Disease International. <https://www.alzint.org/u/World-Alzheimer-Report-2021.pdf>
- Gauthier, S., Reisberg, B., Zaudig, M., Petersen, R. C., Ritchie, K., Broich, K., Belleville, S., Brodaty, H., Bennett, D., Chertkow, H., Cummings, J. L., de Leon, M., Feldman, H., Ganguli, M., Hampel, H., Scheltens, P., Tierney, M. C., Whitehouse, P., & Winblad, B. (2006). Mild cognitive impairment. *The Lancet*, 367(9518), 1262–1270. [https://doi.org/10.1016/S0140-6736\(06\)68542-5](https://doi.org/10.1016/S0140-6736(06)68542-5)
- Geissler, G. L., Zinkhan, G. M., & Watson, R. T. (2006). The influence of home page complexity on consumer attention, attitudes, and purchase intent. *Journal of Advertising*, 35(2), 69–80.
- Giacomin, J. (2014). What is human centred design? *The Design Journal*, 17(4), 606–623. <https://doi.org/10.2752/175630614X14056185480186>

- Giannakopoulos, P., Hof, P. R., Savioz, A., Guimon, J., Antonarakis, S. E., & Bouras, C. (1996). Early-onset dementias: Clinical, neuropathological and genetic characteristics. *Acta Neuropathologica*, 91(5), 451–465.
- Giebel, C. M., Sutcliffe, C., & Challis, D. (2015). Activities of daily living and quality of life across different stages of dementia: A UK study. *Aging & Mental Health*, 19(1), 63–71.
- Gillette-Guyonnet, S., Andrieu, S., Dantoine, T., Dartigues, J.-F., Touchon, J., Vellas, B., & Group, M. S. (2009). Commentary on “A roadmap for the prevention of dementia II. Leon Thal Symposium 2008.” The Multidomain Alzheimer Preventive Trial (MAPT): A new approach to the prevention of Alzheimer’s disease. *Alzheimer’s & Dementia*, 5(2), 114–121.
- Gitlin, L. N., & Corcoran, M. A. (1996). Managing dementia at home: The role of home environmental modifications. *Topics in Geriatric Rehabilitation*, 12(2), 28–39.
- Glisky, E. L. (2011). Method of vanishing cues. In J. S. Kreutzer, J. DeLuca, & B. Caplan (Eds.), *Encyclopedia of clinical neuropsychology* (pp. 1586–1587). Springer.
https://doi.org/10.1007/978-0-387-79948-3_1101
- Gomperts, S. N. (2016). Lewy body dementias: Dementia with Lewy bodies and Parkinson disease dementia. *Continuum*, 22(2 Dementia), 435–463.
<https://doi.org/10.1212/CON.0000000000000309>
- Gorno-Tempini, M. L., Dronkers, N. F., Rankin, K. P., Ogar, J. M., Phengrasamy, L., Rosen, H. J., Johnson, J. K., Weiner, M. W., & Miller, B. L. (2004). Cognition and anatomy in three variants of primary progressive aphasia. *Annals of Neurology*, 55(3), 335–346.
- Gorno-Tempini, M. L., Hillis, A. E., Weintraub, S., Kertesz, A., Mendez, M., Cappa, S. F., Rohrer, J. D., Black, S., Boeve, B. F., Manes, F., Dronkers, N. F., Vandenbегhe, R., Rascovsky, K., Patterson, K., Miller, B. L., Knopman, D. S., Hodges, J. R., Mesulam, M. M., & Grossman, M. (2011). Classification of primary progressive aphasia and its variants. *Neurology*, 76(11), 1006–1014.
- Graebner, M. E., Martin, J. A., & Roundy, P. T. (2012). Qualitative data: Cooking without a recipe. *Strategic Organization*, 10(3), 276–284.
<https://doi.org/10.1177/1476127012452821>
- Graff, M. J., Vernooij-Dassen, M. J., Thijssen, M., Dekker, J., Hoefnagels, W. H., & Rikkert, M. G. O. (2006). Community based occupational therapy for patients with dementia and their care givers: Randomised controlled trial. *BMJ*, 333(7580), 1196.
<https://doi.org/10.1136/bmj.39001.688843.BE>
- Grand, J. H., Caspar, S., & MacDonald, S. W. (2011). Clinical features and multidisciplinary approaches to dementia care. *Journal of Multidisciplinary Healthcare*, 4, 125.
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105–112.

- Gray, J. (2009, September 1). Google Chrome: The making of a cross-platform browser. *Linux Journal*. <https://www.linuxjournal.com/magazine/google-chrome-making-cross-platform-browser>
- Greenbaum, T. L. (1998). *The handbook for focus group research*. Sage.
- Grossman, M., & Ash, S. (2004). Primary progressive aphasia: A review. *Neurocase*, 10(1), 3–18.
- Grossman, M., Mickanin, J., Onishi, K., Hughes, E., D’Esposito, M., Ding, X.-S., Alavi, A., & Reivich, M. (1996). Progressive nonfluent aphasia: Language, cognitive, and PET measures contrasted with probable Alzheimer’s disease. *Journal of Cognitive Neuroscience*, 8(2), 135–154.
- Group Health. (2012). *Dementia and cognitive impairment diagnosis and treatment guideline*. <https://www.universityhealthsystem.com/~media/files/clinicalpathways/dementiacognitive-impairment-guideline-2012.pdf?la=en>
- Guideline Adaptation Committee. (2016). *Clinical practice guidelines and principles of care for people with dementia*. Cognitive Decline Partnership Centre. https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/CDPC-Dementia-Guidelines_WEB.pdf
- Guzman-Parra, J., Barnestein-Fonseca, P., Guerrero-Pertiñez, G., Anderberg, P., Jimenez-Fernandez, L., Valero-Moreno, E., Goodman-Casanova, J. M., Cuesta-Vargas, A., Garolera, M., Quintana, M., Garcia-Betances, R. I., Lemmens, E., Berglund, J. S., & Mayoral-Cleris, F. (2020). Attitudes and use of information and communication technologies in older adults with mild cognitive impairment or early stages of dementia and their caregivers: Cross-sectional study. *Journal of Medical Internet Research*, 22(6), e17253.
- Haberstroh, J., Neumeyer, K., Schmitz, B., & Pantel, J. (2009). Evaluation eines kommunikationstrainings für altenpfleger in der stationären betreuung demenzkranker menschen (tandem im pflegeheim) [Development and evaluation of a training program for nursing home professionals to improve communication in dementia care]. *Zeitschrift für Gerontologie und Geriatrie*, 42(2), 108–116. <https://doi.org/10.1007/s00391-008-0527-x>
- Haglund, L., & Henriksson, C. (2003). Concepts in occupational therapy in relation to the ICF. *Occupational Therapy International*, 10(4), 253–268.
- Hanford, N., & Figueiro, M. (2013). Light therapy and Alzheimer’s disease and related dementia: Past, present, and future. *Journal of Alzheimer’s Disease*, 33(4), 913–922.
- Hanna-Pladdy, B. (2007). Dysexecutive syndromes in neurologic disease. *Journal of Neurologic Physical Therapy*, 31(3).
- Harada, C. N., Natelson Love, M. C., & Triebel, K. (2013). Normal cognitive aging. *Clinics in Geriatric Medicine*, 29(4), 737–752. <https://doi.org/10.1016/j.cger.2013.07.002>

- Harris, J. M., Gall, C., Thompson, J. C., Richardson, A. M., Neary, D., du Plessis, D., Pal, P., Mann, D., Snowden, J. S., & Jones, M. (2013). Classification and pathology of primary progressive aphasia. *Neurology*, 81(21), 1832–1839.
- Harris, J.M., Jones, M. Pathology in Primary Progressive Aphasia Syndromes. *Current Neurology and Neuroscience Reports* 14, 466 (2014). <https://doi-org.ezproxy.newcastle.edu.au/10.1007/s11910-014-0466-4>
- Harte, R. P., Glynn, L. G., Broderick, B. J., Rodriguez-Molinero, A., Baker, P. M. A., McGuiness, B., O’Sullivan, L., Diaz, M., Quinlan, L. R., & ÓLaighin, G. (2014). Human centred design considerations for connected health devices for the older adult. *Journal of Personalized Medicine*, 4(2), 245–281.
- Haslam, C., Moss, Z., & Hodder, K. (2010). Are two methods better than one? Evaluating the effectiveness of combining errorless learning with vanishing cues. *Journal of Clinical and Experimental Neuropsychology*, 32(9), 973–985. <https://doi.org/10.1080/13803391003662686>
- Hawley, M. S., Cunningham, S. P., Green, P. D., Enderby, P., Palmer, R., Sehgal, S., & O’Neill, P. (2012). A voice-input voice-output communication aid for people with severe speech impairment. *IEEE Transactions on Neural Systems and Rehabilitation Engineering*, 21(1), 23–31.
- Hazan, E., Frankenburg, F., Brenkel, M., & Shulman, K. (2018). The test of time: A history of clock drawing. *International Journal of Geriatric Psychiatry*, 33(1), e22–e30.
- Heckathorn, D.D., & Cameron, C.J. (2017). Network Sampling: From Snowball and Multiplicity to Respondent-Driven Sampling. *Review of Sociology*, 43, 101-119.
- Henry, M. L., Hubbard, H. I., Grasso, S. M., Dial, H. R., Beeson, P. M., Miller, B. L., & Gorno-Tempini, M. L. (2019). Treatment for word retrieval in semantic and logopenic variants of primary progressive aphasia: Immediate and long-term outcomes. *Journal of Speech, Language, and Hearing Research*, 62(8), 2723-2749.
- Heerkens, Y., Hendriks, E., & Oostendorp, R. (2006). Assessment instruments and the ICF in rehabilitation and physiotherapy. *Medical Rehabilitation*, 10(3), 1–14.
- Hennipman, E.-J., Oppelaar, E.-J. R., van der Veer, G. C., & Bongers, B. (2008). Rapid and rich prototyping: Proof of concepts for experience. In *Proceedings of the 15th European Conference on Cognitive Ergonomics: The ergonomics of cool interaction* (Article 28, pp. 1–6). <https://doi.org/10.1145/1473018.1473053>
- Hickey, E., & Bourgeois, M. S. (Eds.). (2009). *Dementia: From diagnosis to management – a functional approach*. Psychology Press. <https://doi.org/10.4324/9780203837955>
- Higginbotham, D. J., Shane, H., Russell, S., & Caves, K. (2007). Access to AAC: Present, past, and future. *Augmentative and Alternative Communication*, 23(3), 243–257. <https://doi.org/10.1080/07434610701571058>

- Hill, A. J., & Miller, L. E. (2012). A survey of the clinical use of telehealth in speech-language pathology across Australia. *Journal of Clinical Practice in Speech-Language Pathology*, 14(3), 110–117.
- Hobson, P. (2019). *Enabling people with dementia: Understanding and implementing person-centred care* (3rd ed.). Springer International Publishing. <https://doi.org/10.1007/978-3-030-20479-2>
- Hodges, J. R., Patterson, K., Oxbury, S., & Funnell, E. (1992). Semantic dementia: Progressive fluent aphasia with temporal lobe atrophy. *Brain*, 115(6), 1783–1806.
- Holthe, T., Halvorsrud, L., Karterud, D., Hoel, K.-A., & Lund, A. (2018). Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: A systematic literature review. *Clinical Interventions in Aging*, 13, 863–886. <https://doi.org/10.2147/CIA.S154717>
- Hopper, T. (2001). Indirect interventions to facilitate communication in Alzheimer's disease. *Seminars in Speech and Language*, 22(4), 305–316. <https://doi.org/10.1055/s-2001-17428>
- Hopper, T. (2007). The ICF and dementia. *Seminars in Speech and Language*, 28(4), 273–282. <https://doi.org/10.1055/s-2007-986524>
- 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(1), 126–145. [https://doi.org/10.1044/1058-0360\(2012/11-0137\)](https://doi.org/10.1044/1058-0360(2012/11-0137))
- Hopper, T., Cleary, S., Donnelly, M. J., & Dalton, S. (2007). Service delivery for older Canadians with dementia: A survey of speech-language pathologists. *Canadian Journal of Speech-Language Pathology and Audiology*, 31(3), 114–126.
- Hopper, T., Douglas, N., & Khayum, B. (2015). Direct and indirect interventions for cognitive-communication disorders of dementia. *Perspectives on Neurophysiology & Neurogenic Speech & Language Disorders*, 25(4), 142–157. <https://doi.org/10.1044/nnsld25.4.142>
- Hopper, T., Mahendra, N., Kim, E., Azuma, T., Bayles, K. A., Cleary, S. J., & Tomoeda, C. E. (2005). Evidence-based practice recommendations for working with individuals with dementia: Spaced-retrieval training. *Journal of Medical Speech-Language Pathology*, 13(4), xxvii–xxxiv.
- Hopper, T., Slaughter, S. E., Hodgetts, B., Ostevik, A., & Ickert, C. (2016). Hearing loss and cognitive-communication test performance of long-term care residents with dementia: Effects of amplification. *Journal of Speech, Language, and Hearing Research*, 59(6), 1533–1542. https://doi.org/10.1044/2016_JSLHR-H-15-0135
- Hou, H.-T., Chang, K.-E., & Sung, Y.-T. (2009). Using blogs as a professional development tool for teachers: Analysis of interaction behavioral patterns. *Interactive Learning Environments*, 17(4), 325–340.

- Howard, K., & Rockwood, K. (1995). Quality of life in Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, 6(2), 113–116.
- Howe, T. J. (2008). The ICF contextual factors related to speech-language pathology. *International Journal of Speech-Language Pathology*, 10(1–2), 27–37.
- Hsu, C.-L., & Lin, J. C.-C. (2008). Acceptance of blog usage: The roles of technology acceptance, social influence and knowledge sharing motivation. *Information & Management*, 45(1), 65–74. <https://doi.org/10.1016/j.im.2007.11.001>
- Hughes, J., & Orange, J. (2007). Mapping functional communication measurements for traumatic brain injury to the WHO-ICF. *Canadian Journal of Speech-Language Pathology and Audiology*, 31(3), 135.
- Humbert, I. A., Fitzgerald, M. E., McLaren, D. G., Johnson, S., Porcaro, E., Kosmatka, K., Hind, J., & Robbins, J. (2009). Neurophysiology of swallowing: Effects of age and bolus type. *NeuroImage*, 44(3), 982–991. <https://doi.org/10.1016/j.neuroimage.2008.10.012>
- Hunter, P. V., Hadjistavropoulos, T., Thorpe, L., Lix, L. M., & Malloy, D. C. (2016). The influence of individual and organizational factors on person-centred dementia care. *Aging & Mental Health*, 20(7), 700–708.
- Hurt, C., Bhattacharyya, S., Burns, A., Camus, V., Liperoti, R., Marriott, A., Nobili, F., Robert, P., Tsolaki, M., Vellas, B., Verhey, F., & Byrne E.J. (2008). Patient and caregiver perspectives of quality of life in dementia. *Dementia and Geriatric Cognitive Disorders*, 26(2), 138–146.
- Hussenoeder, F. S., & Riedel-Heller, S. G. (2018). Primary prevention of dementia: From modifiable risk factors to a public brain health agenda? *Social Psychiatry and Psychiatric Epidemiology*, 53(12), 1289–1301. <https://doi.org/10.1007/s00127-018-1598-7>
- Hvidsten, L., Engedal, K., Selbæk, G., Wyller, T. B., Bruvik, F., & Kersten, H. (2018). Quality of life in people with young-onset Alzheimer's dementia and frontotemporal dementia. *Dementia and Geriatric Cognitive Disorders*, 45(1–2), 91–104.
- Idol, L., Nevin, A., & Paolucci-Whitcomb, P. (1994). *Collaborative consultation*. Pro-ed.
- International Organization for Standardization. (1999). *ISO 13407:1999: Human-centred design processes for interactive systems*. <https://www.iso.org/standard/21197.html>
- International Organization for Standardization. (2019). *ISO 9241-210:2019: Ergonomics of human-system interaction — Part 210: Human-centred design for interactive systems*. <https://www.iso.org/standard/77520.html>
- Irish Association of Speech & Language Therapists. (2016). *Speech and language therapy provision for people with dementia. IASLT position statement*. <https://www.iaslt.ie/media/wzshbo2y/iaslt-position-statement-sltserviceprovisiondementia2016.pdf>

- Ivankova, N., & Wingo, N. (2018). Applying mixed methods in action research: Methodological potentials and advantages. *American Behavioral Scientist*, 62(7), 978–997.
- Jacova, C., Kertesz, A., Blair, M., Fisk, J. D., & Feldman, H. H. (2007). Neuropsychological testing and assessment for dementia. *Alzheimer's & Dementia*, 3(4), 299–317.
- Jesus, L. M., Martinez, J., Santos, J., Hall, A., & Joffe, V. (2019). Comparing traditional and tablet-based intervention for children with speech sound disorders: A randomized controlled trial. *Journal of Speech, Language, and Hearing Research*, 62(11), 4045–4061.
- Johnson, P., Rooney, J. J., & Johnson, P. (2000). The synergistic relationship between the nurse practitioner and speech-language pathologist in the treatment of the patient with Alzheimer's dementia and dysphagia. *Perspectives on Swallowing and Swallowing Disorders (Dysphagia)*, 9(1), 4–6.
- Jokel, R., Graham, N. L., Rochon, E., & Leonard, C. (2014). Word retrieval therapies in primary progressive aphasia. *Aphasiology*, 28(8-9), 1038-1068.
- Jolley, D., Benbow, S. M., & Grizzell, M. (2006). Memory clinics. *Postgraduate Medical Journal*, 82(965), 199–206. <https://doi.org/10.1136/pgmj.2005.040592>
- Jones, M. K., Li, Z., & Merrill, M. D. (1992). Rapid prototyping in automated instructional design. *Educational Technology Research and Development*, 40(4), 95–100.
- Jootun, D., & McGhee, G. (2011). Effective communication with people who have dementia. *Nursing Standard*, 25(25), 40–46. <https://doi.org/10.7748/ns2011.02.25.25.40.c8347>
- Jorm, A. F., Masaki, K. H., Petrovitch, H., Ross, G. W., & White, L. R. (2005). Cognitive deficits 3 to 6 years before dementia onset in a population sample: The Honolulu-Asia aging study. *Journal of the American Geriatrics Society*, 53(3), 452–455. <https://doi.org/10.1111/j.1532-5415.2005.53163.x>
- Juárez-Cedillo, T., Gutiérrez-Gutiérrez, L., Sánchez-Hurtado, L. A., Martínez-Rodríguez, N., & Juárez-Cedillo, E. (2020). Randomized controlled trial of multi-component cognitive stimulation therapy (SADEM) in community-dwelling demented adults. *Journal of Alzheimer's Disease*, 78(3), 1033–1045.
- Junaid, O., & Hegde, S. (2007). Supportive psychotherapy in dementia. *Advances in Psychiatric Treatment*, 13(1), 17–23.
- Kales, H. C., Gitlin, L. N., Lyketsos, C. G., & Detroit Expert Panel on the Assessment, and Management of the Neuropsychiatric Symptoms of Dementia. (2014). Management of neuropsychiatric symptoms of dementia in clinical settings: Recommendations from a multidisciplinary expert panel. *Journal of the American Geriatrics Society*, 62(4), 762–769. <https://doi.org/10.1111/jgs.12730>
- Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, 72(12), 2954–2965.

- Karim, J., Antonellis, I., Ganapathi, V., & Garcia-Molina, H. (2009). *A dynamic navigation guide for webpages*. http://ilpubs.stanford.edu:8090/943/3/Navigation_tags_TR.pdf
- Karpicke, J. D., & Bauernschmidt, A. (2011). Spaced retrieval: Absolute spacing enhances learning regardless of relative spacing. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, 37(5), 1250.
- Kay, H. (2012). The best speech-language pathologist blogs from “A to Z”. *Leader Live*. <https://leader.pubs.asha.org/doi/10.1044/the-best-speech-language-pathologist-blogs-from-a-to-z/full/>
- Kearney, P. M., & Pryor, J. (2004). The international classification of functioning, disability and health (ICF) and nursing. *Journal of Advanced Nursing*, 46(2), 162–170.
- Keck, C. S., & Doarn, C. R. (2014). Telehealth technology applications in speech-language pathology. *Telemedicine and e-Health*, 20(7), 653–659. <https://doi.org/10.1089/tmj.2013.0295>
- Keeney, S., Hasson, F., McKenna, H. P., & Wiley, I. (2011). *The Delphi technique in nursing and health research*. Wiley-Blackwell.
- Kelly, C. (2008). Memory clinics. *Psychiatry*, 7(2), 61–63. <https://doi.org/10.1016/j.mppsy.2007.12.001>
- Kemper, S., Kynette, D., Rash, S., O’Brien, K., & Sprott, R. (1989). Life-span changes to adults’ language: Effects of memory and genre. *Applied Psycholinguistics*, 10(1), 49–66.
- Kessels, R. P., & de Haan, E. H. (2003). Implicit learning in memory rehabilitation: A meta-analysis on errorless learning and vanishing cues methods. *Journal of Clinical and Experimental Neuropsychology*, 25(6), 805–814. <https://doi.org/10.1076/jcen.25.6.805.16474>
- Khan, A. (2017). Blog-based professional development of English teachers in Mumbai: The potential of innovative practice under scrutiny. *Australasian Journal of Educational Technology*, 33(4).
- Khayum, B., & Rogalski, E. (2018). Toss the workbooks! Choose treatment strategies for clients with dementia that address their specific life-participation goals. *ASHA Leader*, 23(4), 40–42.
- 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(3), xxiii–xxxiv.
- Kim, J. W., Byun, M. S., Sohn, B. K., Yi, D., Seo, E. H., Choe, Y. M., Kim, S. G., Choi, H. J., Lee, J. H., Chee, I. S., Woo, J. I., & Lee, D. Y. (2017). Clinical dementia rating orientation score as an excellent predictor of the progression to Alzheimer’s disease in mild cognitive impairment. *Psychiatry Investigation*, 14(4), 420–426.

- Kirch, J., & Marquardt, G. (2021). Towards human-centred general hospitals: The potential of dementia-friendly design. *Architectural Science Review*, 1–9.
- Kisling, L. A., & Das, J. M. (2022, May 8). Prevention strategies. In *StatPearls*. StatPearls Publishing. <https://www.ncbi.nlm.nih.gov/books/NBK537222/>
- Kisvetrová, H., Herzig, R., Bretšnajdrová, M., Tomanová, J., Langová, K., & Školoudík, D. (2021). Predictors of quality of life and attitude to ageing in older adults with and without dementia. *Aging & Mental Health*, 25(3), 535–542.
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society*, 12(3), 269–287. <https://doi.org/10.1017/S0144686X0000502X>
- Kitwood, T. M., & Kitwood, T. M. (1997). Dementia reconsidered: The person comes first (Vol. 20, pp. 7-8). Buckingham: Open University press.
- Kivipelto, M., Solomon, A., Ahtiluoto, S., Ngandu, T., Lehtisalo, J., Antikainen, R., Bäckman, L., Hänninen, T., Jula, A., Laatikainen, T., Lindström, J., Mangialasche, F., Nissinen, A., Pajala, S., Peltonen, M., Rauramaa, R., Stigsdotter-Neely, A., Strandberg, T., ... Soininen, H. (2013). The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER): Study design and progress. *Alzheimer's & Dementia*, 9(6), 657–665. <https://doi.org/10.1016/j.jalz.2012.09.012>
- Kleim, J. A., & Jones, T. A. (2008). Principles of experience-dependent neural plasticity: Implications for rehabilitation after brain damage. *Journal of Speech, Language, and Hearing Research*, 51(1), S225–S239. [https://doi.org/10.1044/1092-4388\(2008/018\)](https://doi.org/10.1044/1092-4388(2008/018))
- Klimova, B., Maresova, P., Valis, M., Hort, J., & Kuca, K. (2015). Alzheimer's disease and language impairments: Social intervention and medical treatment. *Clinical Interventions in Aging*, 10, 1401–1407. <https://doi.org/10.2147/CIA.S89714>
- Knopman, D. S., & Petersen, R. C. (2014). Mild cognitive impairment and mild dementia: A clinical perspective. *Mayo Clinic Proceedings*, 89(10), 1452–1459. <https://doi.org/10.1016/j.mayocp.2014.06.019>
- Kolanowski, A., Fortinsky, R. H., Calkins, M., Devanand, D. P., Gould, E., Heller, T., Hodgson, N. A., Kales, H.C., Kaye, J., Lyketsos, C., Resnick, B., Schicker, M., & Zimmerman, S. (2018). Advancing research on care needs and supportive approaches for persons with dementia: Recommendations and rationale. *Journal of the American Medical Directors Association*, 19(12), 1047–1053.
- Kong, W., Jang, H., Carenini, G., & Field, T. (2019). A neural model for predicting dementia from language. *Proceedings of Machine Learning Research*, 106, 270–286. <https://proceedings.mlr.press/v106/kong19a.html>
- Korczyn, A. D., & Davidson, M. (1999). Quality of life in Alzheimer's disease. *European Journal of Neurology*, 6(4), 487–489.
- Krajenbrink, T., Croot, K., Taylor-Rubin, C., & Nickels, L. (2018). Treatment for spoken and written word retrieval in the semantic variant of primary progressive aphasia.

- Neuropsychological Rehabilitation*, 30(5), 915–947.
<https://doi.org/10.1080/09602011.2018.1518780>
- Krueger, R. A., & Casey, M. A. (2002). Designing and conducting focus group interviews. *Citeseer*, 18.
<https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.607.4701&rep=rep1&type=pdf#page=10>
- Kuźma, E., Lourida, I., Moore, S. F., Levine, D. A., Ukoumunne, O. C., & Llewellyn, D. J. (2018). Stroke and dementia risk: A systematic review and meta-analysis. *Alzheimer's & Dementia*, 14(11), 1416–1426.
- Lam, F. M. H., Huang, M.-Z., Liao, L.-R., Chung, R. C. K., Kwok, T. C. Y., & Pang, M. Y. C. (2018). Physical exercise improves strength, balance, mobility, and endurance in people with cognitive impairment and dementia: A systematic review. *Journal of Physiotherapy*, 64(1), 4–15. <https://doi.org/10.1016/j.jphys.2017.12.001>
- Lambon Ralph, M. A., & Fillingham, J. K. (2007). The importance of memory and executive function in aphasia: Evidence from the treatment of anomia using errorless and errorful learning. In A. S. Meyer, L. R. Wheeldon, & A. Krott (Eds.), *Automaticity and control in language processing* (pp. 193–216). Psychology Press.
- Lampit, A., Hallock, H., & Valenzuela, M. (2014). Computerized cognitive training in cognitively healthy older adults: A systematic review and meta-analysis of effect modifiers. *PLOS Medicine*, 11(11), e1001756.
<https://doi.org/10.1371/journal.pmed.1001756>
- Landauer, T. K., & Bjork, R. A. (1978). Optimal rehearsal patterns and name learning *Practical Aspects of Memory*, 625–632. https://bjorklab.psych.ucla.edu/wp-content/uploads/sites/13/2016/07/Landauer_RBjork_1978.pdf
- Lane, C. A., Hardy, J., & Schott, J. M. (2018). Alzheimer's disease. *European Journal of Neurology*, 25(1), 59–70. <https://doi.org/10.1111/ene.13439>
- Lang, I. M. (2009). Brain stem control of the phases of swallowing. *Dysphagia*, 24(3), 333–348. <https://doi.org/10.1007/s00455-009-9211-6>
- Lanzi, A., & Bourgeois, M. S. (2020). Structured external memory aid treatment for mild cognitive impairment. *American Journal of Speech-Language Pathology*, 29, 474–484. https://doi.org/10.1044/2019_AJSLP-CAC48-18-0209
- Lanzi, A., Burshnic, V., & Bourgeois, M. S. (2017). Person-centered memory and communication strategies for adults with dementia. *Topics in Language Disorders*, 37(4), 361–374.
- Lanzi, A., Wallace, S. E., & Bourgeois, M. S. (2018). External memory aid preferences of individuals with mild memory impairments. *Seminars in Speech and Language*, 39(3), 211–222. <https://doi.org/10.1055/s-0038-1660780>
- Larkins, B. (2007). The application of the ICF in cognitive-communication disorders following traumatic brain injury. *Seminars in Speech and Language*, 28(4), 334–342. <https://doi.org/10.1055/s-2007-986530>

- Laugwitz, B., Held, T., & Schrepp, M. (2008). Construction and evaluation of a user experience questionnaire. In A. Holzinger (Ed.), *HCI and usability for education and work: USAB 2008. Lecture notes in computer science* (Vol. 5298, pp. 63–76). Springer. https://doi.org/10.1007/978-3-540-89350-9_6
- Lawlor, B. (2002). Managing behavioural and psychological symptoms in dementia. *The British Journal of Psychiatry*, 181(6), 463–465.
- Lazar, A., Thompson, H., & Demiris, G. (2014). A systematic review of the use of technology for reminiscence therapy. *Health Education & Behavior*, 41(1_suppl), 51S–61S.
- Lee, J. H., Ostwald, M. J., & Gu, N. (2020). *Design thinking: Creativity, collaboration and culture*. Springer International Publishing. <https://doi.org/10.1007/978-3-030-56558-9>
- Leech, N. L., & Onwuegbuzie, A. J. (2009). A typology of mixed methods research designs. *Quality & Quantity*, 43(2), 265–275.
- Leibovici, D., Ritchie, K., Ledesert, B., & Touchon, J. (1996). Does education level determine the course of cognitive decline? *Age and Ageing*, 25(5), 392–397.
- Leng, N. R., Copello, A. G., & Sayegh, A. (1991). Learning after brain injury by the method of vanishing cues: A case study. *Behavioural and Cognitive Psychotherapy*, 19(2), 173–181.
- Leow, L. P., Huckabee, M.-L., Anderson, T., & Beckert, L. (2010). The impact of dysphagia on quality of life in ageing and Parkinson's disease as measured by the Swallowing Quality of Life (SWAL-QOL) questionnaire. *Dysphagia*, 25(3), 216–220. <https://doi.org/10.1007/s00455-009-9245-9>
- Libon, D. J., Price, C. C., Davis Garrett, K., & Giovannetti, T. (2004). From Binswanger's disease to leukoaraiosis: What we have learned about subcortical vascular dementia. *The Clinical Neuropsychologist*, 18(1), 83–100. <https://doi.org/10.1080/13854040490507181>
- Light, J., & Drager, K. (2007). AAC technologies for young children with complex communication needs: State of the science and future research directions. *Augmentative and Alternative Communication*, 23(3), 204–216.
- Lim, M. (2018). Basic oral care for patients with dysphagia: A special needs dentistry perspective. *Journal of Clinical Practice in Speech-Language Pathology*, 20(3), 142–149. <https://www.researchgate.net/publication/330926503>
- Lima-Silva, T. B., Mioshi, E., Bahia, V. S., Cecchini, M. A., Cassimiro, L., Guimarães, H. C., Gambogi, L. B., Caramelli, P., Balthazar, M., Damasceneo, B., Brucki, S., Cruz de Souza, L., Nitrini, R., & Sanches Yassuda, M. (2021). Disease progression in frontotemporal dementia and Alzheimer disease: The contribution of staging scales. *Journal of Geriatric Psychiatry and Neurology*, 34(5), 397–404.
- Lin, F. R., Metter, E. J., O'Brien, R. J., Resnick, S. M., Zonderman, A. B., & Ferrucci, L. (2011). Hearing loss and incident dementia. *Archives of Neurology*, 68(2), 214–220.

- Lin, L. C., Huang, Y. J., Su, S. G., Watson, R., Tsai, B. W. J., & Wu, S. C. (2010). Using spaced retrieval and Montessori-based activities in improving eating ability for residents with dementia. *International Journal of Geriatric Psychiatry*, 25(10), 953–959.
- Littlejohn, A. (2003). *Reusing online resources: A sustainable approach to e-learning*. Psychology Press.
- Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E., Ogunniyi, A., ... Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *The Lancet*, 396(10248), 413–446.
- Livingston, G., Sommerlad, A., Orgeta, V., Costafreda, S. G., Huntley, J., Ames, D., Ballard, C., Banerjee, S., Burns, A., Cohen-Mansfield, J., Cooper, C., Fox, N., Gitlin, L., Howard, R., Kales, H. C., Larson, E., Ritchie, K., Rockwood, K., Sampson, E., ... Mukadam, N. (2017). Dementia prevention, intervention, and care. *The Lancet*, 390(10113), 2673–2734. [https://doi.org/10.1016/S0140-6736\(17\)31363-6](https://doi.org/10.1016/S0140-6736(17)31363-6)
- Logemann, J. A. (1991). Approaches to management of disordered swallowing. *Baillière's Clinical Gastroenterology*, 5(2), 269–280. [https://doi.org/10.1016/0950-3528\(91\)90030-5](https://doi.org/10.1016/0950-3528(91)90030-5)
- Loi, S. M., Goh, A. M., Mocellin, R., Malpas, C. B., Parker, S., Eratne, D., Farrand, S., Kelso, W., Evans, A., Walterfang, M., & Velakoulis, D. (2020). Time to diagnosis in younger-onset dementia and the impact of a specialist diagnostic service. *International Psychogeriatrics*, 34(4), 367–375. <https://doi.org/10.1017/S1041610220001489>
- Lorenz, K., Freddolino, P. P., Comas-Herrera, A., Knapp, M., & Damant, J. (2019). Technology-based tools and services for people with dementia and carers: Mapping technology onto the dementia care pathway. *Dementia*, 18(2), 725–741. <https://doi.org/10.1177/1471301217691617>
- Lynn, J. M. D., Armstrong, E., & Martin, S. (2016). User centred design and validation during the development of domestic brain computer interface applications for people with acquired brain injury and therapists: A multi-stakeholder approach. *Journal of Assistive Technologies*, 10(2), 67–78. <https://doi.org/10.1108/JAT-01-2016-0002>
- Maag, M. (2005). The potential use of “blogs” in nursing education. *CIN: Computers, Informatics, Nursing*, 23(1), 16–24.
- Machado, T. H., Campanha, A. C., Caramelli, P., & Carthery-Goulart, M. T. (2014). Brief intervention for agrammatism in primary progressive nonfluent aphasia: A case report. *Dementia & Neuropsychologia*, 8(3), 291–296.
- Macmillan, D. (2004). Web-based worksheets in the classroom. *Journal of Library & Information Services in Distance Learning*, 1(2), 43–51. https://doi.org/10.1300/J192v01n02_05
- Madhusoodanan, S., & Ting, M. B. (2014). Pharmacological management of behavioral symptoms associated with dementia. *World Journal of Psychiatry*, 4(4), 72–79.

- Maguire, M. (2001). Methods to support human-centred design. *International Journal of Human-Computer Studies*, 55(4), 587–634. <https://doi.org/10.1006/ijhc.2001.0503>
- Mahendra, N. (2001). Direct interventions for improving the performance of individuals with Alzheimer’s disease. *Seminars in Speech and Language*, 22(4), 291–303. <https://doi.org/10.1055/s-2001-17427>
- 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(1), xv–xxv.
- Malone, M. L., & Camp, C. J. (2007). Montessori-based dementia programming®: Providing tools for engagement. *Dementia*, 6(1), 150–157. <https://doi.org/10.1177/1471301207079099>
- Manasco, M. H. (2016). *Introduction to neurogenic communication disorders*. Jones & Bartlett Learning.
- Martinec, R., & Lera, K. (2018). Movement, music and creativity in the elderly with dementia. *Gerontology & Geriatrics Studies*, 4(1), 1–6. <https://doi.org/10.31031/GGS.2018.04.000585>
- Mashima, P. A., & Doarn, C. R. (2008). Overview of telehealth activities in speech-language pathology. *Telemedicine and e-Health*, 14(10), 1101–1117.
- Matsuo, K., & Palmer, J. B. (2008). Anatomy and physiology of feeding and swallowing: Normal and abnormal. *Physical Medicine and Rehabilitation Clinics of North America*, 19(4), 691–707. <https://doi.org/10.1016/j.pmr.2008.06.001>
- Mayo Clinic. (n.d.). *Vascular dementia*. Retrieved June 11, 2022, from <https://www.mayoclinic.org/diseases-conditions/vascular-dementia/symptoms-causes/syc-20378793>
- Mayrhofer, A., Mathie, E., McKeown, J., Bunn, F., & Goodman, C. (2018). Age-appropriate services for people diagnosed with young onset dementia (YOD): A systematic review. *Aging & Mental Health*, 22(8), 933–941. <https://doi.org/10.1080/13607863.2017.1334038>
- McCullough, K. C., Bayles, K. A., & Bouldin, E. D. (2019). Language performance of individuals at risk for mild cognitive impairment. *Journal of Speech, Language, and Hearing Research*, 62(3), 706–722. https://doi.org/10.1044/2018_JSLHR-L-18-0232
- McGill, N., Crowe, K., & Mcleod, S. (2020). “Many wasted months”: Stakeholders’ perspectives about waiting for speech-language pathology services. *International Journal of Speech-Language Pathology*, 22(3), 313–326.
- McGill, N., & McLeod, S. (2019). Aspirations for a website to support families’ active waiting for speech-language pathology. *International Journal of Speech-Language Pathology*, 21(3), 263–274. <https://doi.org/10.1080/17549507.2019.1604802>

- McGinley, E. (2015). Practical nutritional measures in patients with dementia. *Journal of Community Nursing*, 29(6), 36–41.
- McGrath, M., & O’Callaghan, C. (2014). Occupational therapy and dementia care: A survey of practice in the Republic of Ireland. *Australian Occupational Therapy Journal*, 61(2), 92–101. <https://doi.org/10.1111/1440-1630.12081>
- McKeith, I. (2007). Dementia with Lewy bodies. In W. C. Koller & E. Melamed (Eds.), *Handbook of clinical neurology* (Vol. 84, pp. 531–548). Elsevier. [https://doi.org/10.1016/S0072-9752\(07\)84060-7](https://doi.org/10.1016/S0072-9752(07)84060-7)
- McKeith, I., & Cummings, J. (2005). Behavioural changes and psychological symptoms in dementia disorders. *The Lancet Neurology*, 4(11), 735–742. [https://doi.org/10.1016/S1474-4422\(05\)70219-2](https://doi.org/10.1016/S1474-4422(05)70219-2)
- McKittrick, L. A., & Camp, C. J. (1993). Relearning the names of things: The spaced-retrieval intervention implemented by a caregiver. *Clinical Gerontologist: The Journal of Aging and Mental Health*, 14(2), 60–62.
- Medical Advisory Secretariat. (2008). Caregiver- and patient-directed interventions for dementia: An evidence-based analysis. *Ontario Health Technology Assessment Series*, 8(4), 1–98. <https://pubmed.ncbi.nlm.nih.gov/23074509>
- Mehrani, I., Kochan, N. A., Ong, M. Y., Crawford, J. D., Naismith, S. L., & Sachdev, P. S. (2021). Organisational aspects and assessment practices of Australian memory clinics: An Australian Dementia Network (ADNeT) survey. *BMJ Open*, 11(2), e038624. <https://doi.org/10.1136/bmjopen-2020-038624>
- Mehrani, I., & Sachdev, P. S. (2022). The role of memory clinics in the assessment and management of dementia, now and into the future. *Current Opinion in Psychiatry*, 35(2), 118–122.
- Meilán, J. J. G., Martínez-Sánchez, F., Carro, J., López, D. E., Millian-Morell, L., & Arana, J. M. (2014). Speech in Alzheimer’s disease: Can temporal and acoustic parameters discriminate dementia? *Dementia and Geriatric Cognitive Disorders*, 37(5–6), 327–334. <https://doi.org/10.1159/000356726>
- Mendez, M. F., & Cummings, J. L. (2003). *Dementia: A clinical approach*. Butterworth-Heinemann.
- Mendoza Laiz, N., Del Valle Diaz, S., Rioja Collado, N., Gomez-Pilar, J., & Hornero, R. (2018). Potential benefits of a cognitive training program in mild cognitive impairment (MCI). *Restorative Neurology and Neuroscience*, 36(2), 207–213. <https://doi.org/10.3233/RNN-170754>
- Mesulam, M. M. (1982). Slowly progressive aphasia without generalized dementia. *Annals of Neurology*, 11(6), 592–598.
- Mesulam, M.-M. (2001). Primary progressive aphasia. *Annals of Neurology*, 49(4), 425–432. <https://doi.org/10.1002/ana.91>

- Mesulam, M. M., Rogalski, E. J., Wieneke, C., Hurley, R. S., Geula, C., Bigio, E. H., ... & Weintraub, S. (2014). Primary progressive aphasia and the evolving neurology of the language network. *Nature Reviews Neurology*, 10(10), 554-569.
- Meyer, J., Leslie, P., Ciccio, A., & Rodakowski, J. (2021). Whose job is it? Addressing the overlap of speech-language pathologists and occupational therapists when caring for people with dementia. *Perspectives of the ASHA Special Interest Groups*, 6(1), 163–166.
- Middleton, E. L., & Schwartz, M. F. (2012). Errorless learning in cognitive rehabilitation: A critical review. *Neuropsychological Rehabilitation*, 22(2), 138–168.
<https://doi.org/10.1080/09602011.2011.639619>
- Middleton, L. E., & Yaffe, K. (2009). Promising strategies for the prevention of dementia. *Archives of Neurology*, 66(10), 1210–1215. <https://doi.org/10.1001/archneurol.2009.201>
- Miller, P. A., & Butin, D. (2000). The role of occupational therapy in dementia—COPE (caregiver options for practical experiences). *International Journal of Geriatric Psychiatry*, 15(1), 86–89.
- Mimura, M., & Komatsu, S.-I. (2010). Factors of error and effort in memory intervention for patients with Alzheimer's disease and amnesic syndrome. *Psychogeriatrics*, 10(4), 179–186. <https://doi.org/10.1111/j.1479-8301.2010.00339.x>
- Minichiello, V., Sullivan, G., Greenwood, K., & Axford, R. (2004). *Research methods for nursing and health science*. Pearson Education Australia.
- Ministry of Health. (2013). *New Zealand framework for dementia care*.
<https://www.health.govt.nz/system/files/documents/publications/new-zealand-framework-for-dementia-care-nov13.pdf>
- Miniukovich, A., De Angeli, A., Sulpizio, S., & Venuti, P. (2017). Design guidelines for web readability. In *Proceedings of the 2017 Conference on Designing Interactive Systems* (pp. 285–296). <http://eprints.lincoln.ac.uk/id/eprint/30210/1/p285-miniukovich.pdf>
- Mioshi, E., Dawson, K., Mitchell, J., Arnold, R., & Hodges, J. R. (2006). The Addenbrooke's Cognitive Examination Revised (ACE-R): A brief cognitive test battery for dementia screening. *International Journal of Geriatric Psychiatry*, 21(11), 1078–1085.
- Mirnig, A. G., Meschtscherjakov, A., Wurhofer, D., Meneweger, T., & Tscheligi, M. (2015, April). A formal analysis of the ISO 9241-210 definition of user experience. In *Proceedings of the 33rd annual ACM conference extended abstracts on human factors in computing systems* (pp. 437–450). <https://doi.org/10.1145/2702613.2732511>
- Mitchell, G., & Agnelli, J. (2015). Person-centred care for people with dementia: Kitwood reconsidered. *Nursing Standard* (2014+), 30(7), 46.
doi:<https://doi.org/10.7748/ns.30.7.46.s47>
- Mitchell, A. J., & Shiri-Feshki, M. (2009). Rate of progression of mild cognitive impairment to dementia – meta-analysis of 41 robust inception cohort studies. *Acta Psychiatrica Scandinavica*, 119(4), 252–265. <https://doi.org/10.1111/j.1600-0447.2008.01326.x>

- Mitchell, S. L., Kiely, D. K., & Lipsitz, L. A. (1997). The risk factors and impact on survival of feeding tube placement in nursing home residents with severe cognitive impairment. *Archives of Internal Medicine*, 157(3), 327–332.
- Mitchell, S. L., Kiely, D. K., & Lipsitz, L. A. (1998). Does artificial enteral nutrition prolong the survival of institutionalized elders with chewing and swallowing problems? *The Journals of Gerontology: Series A*, 53A(3), M207–M213. <https://doi.org/10.1093/gerona/53a.3.m207>
- Moggridge, B., & Atkinson, B. (2007). *Designing interactions* (Vol. 17). MIT Press.
- Mohan, H. S., Anjum, A., & Rao, P. K. S. (2017). A survey of telepractice in speech-language pathology and audiology in India. *International Journal of Telerehabilitation*, 9(2), 69–80. <https://doi.org/10.5195/ijt.2017.6233>
- Möller, H.-J., & Graeber, M. B. (1998). The case described by Alois Alzheimer in 1911. *European Archives of Psychiatry and Clinical Neuroscience*, 248(3), 111–122.
- Morris, J. C. (1997). Clinical dementia rating: A reliable and valid diagnostic and staging measure for dementia of the Alzheimer type. *International Psychogeriatrics*, 9(S1), 173–176.
- Morson, S. (2014). Using wireframes to design your app. In *Learn design for iOS development* (pp. 69–84). Apress. https://doi.org/10.1007/978-1-4302-6365-4_6
- Mowszowski, L., Batchelor, J., & Naismith, S. L. (2010). Early intervention for cognitive decline: Can cognitive training be used as a selective prevention technique? *International Psychogeriatrics*, 22(4), 537–548.
- Moyle, W., Venturto, L., Griffiths, S., Grimbeek, P., McAllister, M., Oxlade, D., & Murfield, J. (2011). Factors influencing quality of life for people with dementia: A qualitative perspective. *Aging & Mental Health*, 15(8), 970–977.
- Mulhern, B., Rowen, D., Brazier, J., Smith, S., Romeo, R., Tait, R., Watchurst, C., Chua, K.-C., Loftus, V., Young, T., Lamping, D., Knapp, M., Howard, R., & Banerjee, S. (2013). Development of DEMQOL-U and DEMQOL-PROXY-U: Generation of preference-based indices from DEMQOL and DEMQOL-PROXY for use in economic evaluation. *Health Technology Assessment*, 17(5), v–xv. <https://doi.org/10.3310/hta17050>
- Munn, Z., Peters, M. D. J., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, 18(1), 143. <https://doi.org/10.1186/s12874-018-0611-x>
- Muo, R., Schindler, A., Venero, I., Schindler, O., Ferrario, E., & Frisoni, G. B. (2005). Alzheimer's disease-associated disability: An ICF approach. *Disability and Rehabilitation*, 27(23), 1405–1413.
- Murphy, J., & Boa, S. (2012). Using the WHO-ICF with talking mats to enable adults with long-term communication difficulties to participate in goal setting. *Augmentative and Alternative Communication*, 28(1), 52–60.

- Murphy, J. L., Holmes, J., & Brooks, C. (2017). Nutrition and dementia care: Developing an evidence-based model for nutritional care in nursing homes. *BMC Geriatrics*, 17(1), Article 55. <https://doi.org/10.1186/s12877-017-0443-2>
- Nagaendran, K., Chen, L. H., Chong, M. S., Chua, E. V., Goh, C., Kua, J., Lee, T., Shiong, L. W., Marziyana, A. R., Ng, C. C., Ng, L. L., Seow, D. C., Sitoh, Y. Y., Yap, L. K., Yeo, D., & Yeo, Y. W. (2013). Ministry of health clinical practice guidelines: Dementia. *Singapore Medical Journal*, 54(5), 293–299. <https://doi.org/10.11622/smedj.2013112>
- Nasreddine, Z. S., Phillips, N. A., Bédirian, V., Charbonneau, S., Whitehead, V., Collin, I., Cummings, J., & Chertkow, H. (2005). The Montreal Cognitive Assessment, MoCA: A brief screening tool for mild cognitive impairment. *Journal of the American Geriatrics Society*, 53(4), 695–699. <https://doi.org/10.1111/j.1532-5415.2005.53221.x>
- National Health Service England. (2015). *Dementia diagnosis and management. A brief pragmatic resource for general practitioners*. <https://www.england.nhs.uk/wp-content/uploads/2015/01/dementia-diag-mng-ab-pt.pdf>
- National Institute for Health and Care Excellence (NICE). (2018). *Dementia: assessment, management and support for people living with dementia and their carer*. <https://www.nice.org.uk/guidance/ng97/resources/dementia-assessment-management-and-support-for-people-living-with-dementia-and-their-carers-pdf-1837760199109>
- National Institute of Neurological Disorders and Stroke. (2022). *Multi-infarct dementia*. <https://www.ninds.nih.gov/health-information/disorders/multi-infarct-dementia>
- Neophytou, K., Wiley, R. W., Rapp, B., & Tsapkini, K. (2019). The use of spelling for variant classification in primary progressive aphasia: Theoretical and practical implications. *Neuropsychologia*, 133, 107157. <https://doi.org/10.1016/j.neuropsychologia.2019.107157>
- Nettleton, J., & Lesser, R. (1991). Therapy for naming difficulties in aphasia: Application of a cognitive neuropsychological model. *Journal of Neurolinguistics*, 6(2), 139–157. [https://doi.org/10.1016/0911-6044\(91\)90004-3](https://doi.org/10.1016/0911-6044(91)90004-3)
- Newby, R., Watson, J., & Woodliff, D. (2003). SME survey methodology: Response rates, data quality, and cost effectiveness. *Entrepreneurship Theory and Practice*, 28(2), 163–172.
- Ng, N. S. Q., & Ward, S. A. (2018). Diagnosis of dementia in Australia: A narrative review of services and models of care. *Australian Health Review*, 43(4), 415–424.
- Ngo, J., & Holroyd-Leduc, J. M. (2014). Systematic review of recent dementia practice guidelines. *Age and Ageing*, 44(1), 25–33. <https://doi.org/10.1093/ageing/afu143>
- Nguyen, V. T. T., Sallbach, J., dos Santos Guilherme, M., & Endres, K. (2021). Influence of acetylcholine esterase inhibitors and memantine, clinically approved for Alzheimer's dementia treatment, on intestinal properties of the mouse. *International Journal of Molecular Sciences*, 22(3), 1015. <https://www.mdpi.com/1422-0067/22/3/1015>

- Nielsen, J. (2000, March 19). *Why you only need to test with 5 users*. Alertbox. <https://www.nngroup.com/articles/why-you-only-need-to-test-with-5-users/>
- 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(5), 216–221. <https://doi.org/10.1159/000464350>
- Nyumba, T. O., Wilson, K., Derrick, C. J., & Mukherjee, N. (2018). The use of focus group discussion methodology: Insights from two decades of application in conservation. *Methods in Ecology and Evolution*, 9(1), 20–32. <https://doi.org/10.1111/2041-210X.12860>
- O’Brien, J. T., & Thomas, A. (2015). Vascular dementia. *The Lancet*, 386(10004), 1698–1706. [https://doi.org/10.1016/S0140-6736\(15\)00463-8](https://doi.org/10.1016/S0140-6736(15)00463-8)
- Olchik, M. R., Rech, R. S., Jacinto-Scudeiro, L. A., de Mello, A. M., & dos Santos, V. B. (2020). The effects of orofacial thermal-tactile stimulation on elderly long-term-care facility residents with severe dementia: A case series. *Audiology-Communication Research*, 25. <https://doi.org/10.1590/2317-6431-2020-2334>
- Ooms, S., & Ju, Y.-E. (2016). Treatment of sleep disorders in dementia. *Current Treatment Options in Neurology*, 18(9), 1–17.
- O’Philbin, L., Woods, B., Farrell, E. M., Spector, A. E., & Orrell, M. (2018). Reminiscence therapy for dementia: An abridged Cochrane systematic review of the evidence from randomized controlled trials. *Expert Review of Neurotherapeutics*, 18(9), 715–727. <https://doi.org/10.1080/14737175.2018.1509709>
- O’Rourke, D. J., Lobchuk, M. M., Thompson, G. N., & Lengyel, C. (2022). Expanding the conversation: A Person-centred Communication Enhancement Model. *Dementia*, 21(5), 1596-1617.
- Orsulic-Jeras, S., Schneider, N. M., Camp, C. J., Nicholson, P., & Helbig, M. (2001). Montessori-based dementia activities in long-term care. *Activities, Adaptation & Aging*, 25(3–4), 107–120. https://doi.org/10.1300/J016v25n03_08
- Ortega, O., Parra, C., Zarcero, S., Nart, J., Sakwinska, O., & Clavé, P. (2014). Oral health in older patients with oropharyngeal dysphagia. *Age and Ageing*, 43(1), 132–137. <https://doi.org/10.1093/ageing/aft164>
- Page, S., Hope, K., Bee, P., & Burns, A. (2008). Nurses making a diagnosis of dementia—a potential change in practice? *International Journal of Geriatric Psychiatry*, 23(1), 27–33.
- Pagnoni, I., Gobbi, E., Premi, E., Borroni, B., Binetti, G., Cotelli, M. & Manenti, R. (2021). Language training for oral and written naming impairment in primary progressive aphasia: a review. *Translational Neurodegeneration* 10 (1), 1-34. <https://doi.org/10.1186/s40035-021-00248-z>
- Palmer, J. B., Drennan, J. C., & Baba, M. (2000). Evaluation and treatment of swallowing impairments. *American Family Physician*, 61(8), 2453.

- Park, M., Go, Y., & Lee, M. (2020). ICF-based health and social-needs assessment system for person-centered dementia care: Developing topics. *Alzheimer's & Dementia*, 16, e047110.
- Parker, M., & Power, D. (2013). Management of swallowing difficulties in people with advanced dementia. *Nursing Older People*, 25(2).
- Pasquier, F. (1999). Early diagnosis of dementia: Neuropsychology. *Journal of Neurology*, 246(1), 6–15.
- Patra, A., Traut, H. J., Stabile, M., & Middleton, E. L. (2022). Effortful retrieval practice effects in lexical access: A role for semantic competition. *Language, Cognition and Neuroscience*, 1–16. <https://doi.org/10.1080/23273798.2022.2027991>
- Patterson, C., Feightner, J. W., Garcia, A., Hsiung, G.-Y. R., MacKnight, C., & Sadovnick, A. D. (2008). Diagnosis and treatment of dementia: 1. Risk assessment and primary prevention of Alzheimer disease. *CMAJ*, 178(5), 548–556. <https://doi.org/10.1503/cmaj.070796>
- Payne, J. C. (2014). *Adult neurogenic language disorders: Assessment and treatment. A comprehensive ethnobiological approach*. Plural Publishing.
- Peck, A., Cohen, C. E., & Mulvihill, M. N. (1990). Long-term enteral feeding of aged demented nursing home patients. *Journal of the American Geriatrics Society*, 38(11), 1195–1198. <https://doi.org/10.1111/j.1532-5415.1990.tb01498.x>
- Peeters, M. M. M., Harbers, M., & Neerincx, M. A. (2016). Designing a personal music assistant that enhances the social, cognitive, and affective experiences of people with dementia. *Computers in Human Behavior*, 63, 727–737. <https://doi.org/10.1016/j.chb.2016.06.003>
- Petersen, R. C. (2000). Mild cognitive impairment: Transition between aging and Alzheimer's disease. *Neurologia*, 15(3), 93–101. <https://pubmed.ncbi.nlm.nih.gov/10846869/>
- Petersen, R. C. (2003). *Mild cognitive impairment: Aging to Alzheimer's disease*. Oxford University Press.
- Petersen, R. C. (2016). Mild cognitive impairment. *Continuum*, 22(2 Dementia), 404–418. <https://doi.org/10.1212/CON.0000000000000313>
- Petersen, R. C., Smith, G. E., Waring, S. C., Ivnik, R. J., Tangalos, E. G., & Kokmen, E. (1999). Mild cognitive impairment: Clinical characterization and outcome. *Archives of Neurology*, 56(3), 303–308.
- Pham, M. T., Rajić, A., Greig, J. D., Sargeant, J. M., Papadopoulos, A., & McEwen, S. A. (2014). A scoping review of scoping reviews: Advancing the approach and enhancing the consistency. *Research Synthesis Methods*, 5(4), 371–385. <https://doi.org/10.1002/jrsm.1123>
- Pickett, J., Bird, C., Ballard, C., Banerjee, S., Brayne, C., Cowan, K., Clare, L., Comas-Herrera, A., Corner, L., Daley, S., Knapp, M., Lafortune, L., Livingston, G., Manthorpe, J., Marchant, N., Moriarty, J., Louise, R., van Lynden, C., Windle, G., ... Walton, C.

- (2018). A roadmap to advance dementia research in prevention, diagnosis, intervention, and care by 2025. *International Journal of Geriatric Psychiatry*, 33(7), 900–906.
<https://doi.org/10.1002/gps.4868>
- Pilemalm, S., & Timpka, T. (2008). Third generation participatory design in health informatics—Making user participation applicable to large-scale information system projects. *Journal of Biomedical Informatics*, 41(2), 327–339.
<https://doi.org/10.1016/j.jbi.2007.09.004>
- Pitkälä, K., Savikko, N., Poysti, M., Strandberg, T., & Laakkonen, M.-L. (2013). Efficacy of physical exercise intervention on mobility and physical functioning in older people with dementia: A systematic review. *Experimental Gerontology*, 48(1), 85–93.
<https://doi.org/10.1016/j.exger.2012.08.008>
- Plummer-D'Amato, P. (2008). Focus group methodology part 1: Considerations for design. *International Journal of Therapy and Rehabilitation*, 15(2), 69–73.
- Pomeroy, V. M., Warren, C. M., Honeycombe, C., Briggs, R. S., Wilkinson, D. G., Pickering, R. M., & Steiner, A. (1999). Mobility and dementia: Is physiotherapy treatment during respite care effective? *International Journal of Geriatric Psychiatry*, 14(5), 389–397.
- Power, E., Thomas, E., Worrall, L., Rose, M., Togher, L., Nickels, L., Hersh, D., Godecke, E., O'Halloran, R., Lamont, S., O'Connor, C., & Clarke, K. (2015). Development and validation of Australian aphasia rehabilitation best practice statements using the RAND/UCLA appropriateness method. *BMJ Open*, 5(7), e007641.
<https://doi.org/10.1136/bmjopen-2015-007641>
- Prichard, J. C. (1837). *A treatise on insanity and other disorders affecting the mind*. Haswell, Barrington, and Haswell.
- Prior, M. T. (2018). Interviews and focus groups. In A. Phakiti, P. De Costa, L. Plonsky, & S. Starfield (Eds.), *The Palgrave handbook of applied linguistics research methodology* (pp. 225–248). Springer.
- Raatz, M., Ward, E. C., Marshall, J., & Burns, C. L. (2019). Developing the system architecture for conducting synchronous paediatric feeding assessments via telepractice. *Journal of Telemedicine and Telecare*, 25(9), 552–558.
- Rabiee, F. (2004). Focus-group interview and data analysis. *Proceedings of the Nutrition Society*, 63(4), 655–660.
- Rabins, P. V., Mace, N. L., & Lucas, M. J. (1982). The impact of dementia on the family. *JAMA*, 248(3), 333–335.
- Radue, R., Walaszek, A., & Asthana, S. (2019). Neuropsychiatric symptoms in dementia. In S. T. Dekosky & S. Asthana (Eds.), *Handbook of clinical neurology* (Vol. 167, pp. 437–454). Elsevier. <https://doi.org/10.1016/B978-0-12-804766-8.00024-8>
- Ready, R. E., & Ott, B. R. (2003). Quality of life measures for dementia. *Health and Quality of Life Outcomes*, 1(1), 1–9.

- Reams, P., & Twale, D. (2008). The promise of mixed methods: Discovering conflicting realities in the data. *International Journal of Research & Method in Education*, 31(2), 133–142.
- Reisberg, B., Ferris, S. H., de Leon, M. J., & Crook, T. (1982). The global deterioration scale for assessment of primary degenerative dementia. *The American Journal of Psychiatry*, 139(9), 1136–1139. <https://doi.org/10.1176/ajp.139.9.1136>
- Rentz, D. M., Parra Rodriguez, M. A., Amariglio, R., Stern, Y., Sperling, R., & Ferris, S. (2013). Promising developments in neuropsychological approaches for the detection of preclinical Alzheimer's disease: A selective review. *Alzheimer's Research and Therapy*, 5(6), 58. <https://doi.org/10.1186/alzrt222>
- Rettinger, L., Klupper, C., Werner, F., & Putz, P. (2021). Changing attitudes towards teletherapy in Austrian therapists during the COVID-19 pandemic. *Journal of Telemedicine and Telecare*. <https://doi.org/10.1177/1357633X20986038>
- Reynolds, A. L., Vick, J. L., & Haak, N. J. (2009). Telehealth applications in speech-language pathology: A modified narrative review. *Journal of Telemedicine and Telecare*, 15(6), 310–316.
- Richard, E., Van den Heuvel, E., van Charante, E. P. M., Achthoven, L., Vermeulen, M., Bindels, P. J., & Van Gool, W. A. (2009). Prevention of dementia by intensive vascular care (PreDIVA): A cluster-randomized trial in progress. *Alzheimer Disease & Associated Disorders*, 23(3), 198–204.
- Richters, A., Nieuwboer, M. S., Olde Rikkert, M. G., Melis, R. J., Perry, M., & van der Marck, M. A. (2018). Longitudinal multiple case study on effectiveness of network-based dementia care towards more integration, quality of care, and collaboration in primary care. *PLoS One*, 13(6), e0198811.
- Roberts, J. P., Fisher, T. R., Trowbridge, M. J., & Bent, C. (2016). A design thinking framework for healthcare management and innovation. *Healthcare*, 4(1), 11–14. <https://doi.org/10.1016/j.hjdsi.2015.12.002>
- Robillard, J. M., & Sporn, A. B. (2018). Static versus interactive online resources about dementia: A comparison of readability scores. *Gerontechnology*, 17(1), 29–37. <https://doi.org/10.4017/gt.2018.17.1.003.00>
- Robins, B., Ferrari, E., Dautenhahn, K., Kronreif, G., Prazak-Aram, B., Gelderblom, G.-j., Tanja, B., Caprino, F., Laudanna, E., & Marti, P. (2010). Human-centred design methods: Developing scenarios for robot assisted play informed by user panels and field trials. *International Journal of Human-Computer Studies*, 68(12), 873–898. <https://doi.org/10.1016/j.ijhcs.2010.08.001>
- Robinson, L., Tang, E., & Taylor, J.-P. (2015). Dementia: Timely diagnosis and early intervention. *BMJ*, 350. <https://doi.org/10.1136/bmj.h3029>
- Robson, C. (2002). *Real world research: A resource for social scientists and practitioner-researchers* (Vol. 2). Blackwell Oxford.

- Rodda, J., & Carter, J. (2012). Cholinesterase inhibitors and memantine for symptomatic treatment of dementia. *BMJ: British Medical Journal (Clinical Research Edition)*, 344, e2986. <https://doi.org/10.1136/bmj.e2986>
- Roddam, H., & Skeat, J. (Eds.). (2010). *Embedding evidence-based practice in speech and language therapy: International examples*. <https://doi.org/10.1002/9780470686584>
- Rogalski, E. J., & Khayum, B. (2018). A life participation approach to primary progressive aphasia intervention. *Seminars in Speech and Language*, 39(3), 284–296. <https://doi.org/10.1055/s-0038-1660786>
- Rogus-Pulia, N., Malandraki, G. A., Johnson, S., & Robbins, J. (2015). Understanding dysphagia in dementia: The present and the future. *Current Physical Medicine and Rehabilitation Reports*, 3(1), 86–97. <https://doi.org/10.1007/s40141-015-0078-1>
- Rogus-Pulia, N., & Robbins, J. (2013). Approaches to the rehabilitation of dysphagia in acute poststroke patients. *Seminars in Speech and Language*, 34(3), 154–169. <https://doi.org/10.1055/s-0033-1358368>
- Rose, N., Whitworth, A., Smart, S., Oliver, E., & Cartwright, J. (2020). “I remember when ...”: The impact of reminiscence therapy on discourse production in older adults with cognitive impairment. *International Journal of Speech-Language Pathology*, 22(3), 359–371. <https://doi.org/10.1080/17549507.2020.1747542>
- Rossor, M. N., Fox, N. C., Mummery, C. J., Schott, J. M., & Warren, J. D. (2010). The diagnosis of young-onset dementia. *The Lancet Neurology*, 9(8), 793–806. [https://doi.org/10.1016/S1474-4422\(10\)70159-9](https://doi.org/10.1016/S1474-4422(10)70159-9)
- Røsvik, J., Brooker, D., Mjorud, M., & Kirkevold, Ø. (2013). What is person-centred care in dementia? Clinical reviews into practice: the development of the VIPS practice model. *Reviews in clinical gerontology*, 23(2), 155–163.
- Royal College of Nursing. (2019). *Commitment to care of people living with dementia*. <https://www.rcn.org.uk/professional-development/publications/pub-007827>
- The Royal College of Psychiatrists. (2018). *Young-onset dementia in mental health services: Recommendations for service provision*. <https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr217.pdf>
- Royal College of Speech and Language Therapists. (2014a). *Speech and language therapy provision for people with dementia* (RCSLT Position Paper 2014). <https://www.rcslt.org/wp-content/uploads/media/Project/RCSLT/dementia-position-paper-2014.pdf>
- Royal College of Speech and Language Therapists. (2014b). *Standard of proficiency*. Health & Care Professions Council. <https://www.hcpc-uk.org/resources/standards/standards-of-proficiency-speech-and-language-therapists/>
- Royal Commission into Aged Care Quality and Safety. (2021). *Final report: Care, dignity and respect*. <https://agedcare.royalcommission.gov.au/publications/final-report>

- Rozzini, L., Costardi, D., Chilovi, B. V., Franzoni, S., Trabucchi, M., & Padovani, A. (2007). Efficacy of cognitive rehabilitation in patients with mild cognitive impairment treated with cholinesterase inhibitors. *International Journal of Geriatric Psychiatry*, 22(4), 356–360.
- Rubin, J., & Chisnell, D. (2008). *Handbook of usability testing: How to plan, design and conduct effective tests*. John Wiley & Sons.
- Ruksenaite, J., Volkmer, A., Jiang, J., Johnson, J. C., Marshall, C. R., Warren, J. D., & Hardy, C. J. (2021). Primary progressive aphasia: Toward a pathophysiological synthesis. *Current Neurology and Neuroscience Reports*, 21(3), 1–12.
- Sadowsky, C. H., & Galvin, J. E. (2012). Guidelines for the management of cognitive and behavioral problems in dementia. *Journal of the American Board of Family Medicine*, 25(3), 350–366. <https://doi.org/10.3122/jabfm.2012.03.100183>
- Saitoh, E. (2008). Dysphagia rehabilitation. *Rinsho Shinkeigaku = Clinical Neurology*, 48(11), 875–879. <https://doi.org/10.5692/clinicalneurol.48.875>
- Sajjadi, S. A., Patterson, K., Arnold, R. J., Watson, P., & Nestor, P. J. (2012). Primary progressive aphasia: A tale of two syndromes and the rest. *Neurology*, 78(21), 1670–1677.
- Salmon, D. P., & Bondi, M. W. (2009). Neuropsychological assessment of dementia. *Annual Review of Psychology*, 60, 257–282.
- Sandars, J. (2006). Twelve tips for using blogs and wikis in medical education. *Medical Teacher*, 28(8), 680–682.
- Sanderson, H. (2003). Implementing person-centred planning by developing person-centred teams. *Journal of Integrated Care*, 11(3), 18–25. <https://doi.org/10.1108/14769018200300031>
- Sanford, A. M. (2018). Lewy body dementia. *Clinics in Geriatric Medicine*, 34(4), 603–615. <https://doi.org/10.1016/j.cger.2018.06.007>
- Santini, M. (2007). Characterizing genres of web pages: Genre hybridism and individualization. In *2007 40th Annual Hawaii International Conference on System Sciences* (HICSS'07; p. 71). <https://doi.org/10.1109/HICSS.2007.124>
- Savage, S. A., Ballard, K. J., Piguet, O., & Hodges, J. R. (2013). Bringing words back to mind—Improving word production in semantic dementia. *Cortex*, 49(7), 1823–1832.
- Savundranayagam, M. Y., Ryan, E. B., Anas, A. P., & Orange, J. B. (2007). Communication and dementia. *Clinical Gerontologist*, 31(2), 47–63. https://doi.org/10.1300/J018v31n02_04
- Saxton, J., Lopez, O. L., Ratcliff, G., Dulberg, C., Fried, L. P., Carlson, M. C., Newman, A. B., & Kuller, L. (2004). Preclinical Alzheimer disease: Neuropsychological test performance 1.5 to 8 years prior to onset. *Neurology*, 63(12), 2341. <https://doi.org/10.1212/01.WNL.0000147470.58328.50>

- Scales, K., Zimmerman, S., & Miller, S. J. (2018). Evidence-based nonpharmacological practices to address behavioral and psychological symptoms of dementia. *The Gerontologist*, 58(suppl_1), S88–S102. <https://doi.org/10.1093/geront/gnx167>
- Scherer, M. J., Federici, S., Tiberio, L., Pigliautile, M., Corradi, F., & Meloni, F. (2012). ICF core set for matching older adults with dementia and technology. *Ageing International*, 37(4), 414–440.
- Schwab, S. M., & Zeleznik, A. J. (2020). Using the language of the ICF to distinguish physical therapy and occupational therapy services in the acute care setting. *Journal of Acute Care Physical Therapy*, 11(1), 40–43.
- Schwarz, B., Chaudhury, H., & Tofle, R. B. (2004). Effect of design interventions on a dementia care setting. *American Journal of Alzheimer's Disease & Other Dementias*, 19(3), 172–176. <https://doi.org/10.1177/153331750401900304>
- Selai, C., & Trimble, M. (1999). Assessing quality of life in dementia. *Aging & Mental Health*, 3(2), 101–111.
- Self, B. (2021). Conducting interviews during the COVID-19 pandemic and beyond. *Forum: Qualitative Social Research*, 22(3), Article 15. <https://www.qualitative-research.net/index.php/fqs/article/view/3741/4764>
- Senaha, M. L. H., Brucki, S. M. D., & Nitrini, R. (2010). Rehabilitation in semantic dementia: Study of the effectiveness of lexical reacquisition in three patients. *Dementia & Neuropsychologia*, 4(4), 306–312.
- Shaji, K. S., Sivakumar, P. T., Rao, G. P., & Paul, N. (2018). Clinical practice guidelines for management of dementia. *Indian Journal of Psychiatry*, 60(Suppl 3), S312–S328. <https://doi.org/10.4103/0019-5545.224472>
- Sharp, D. (1996). Nuns' stories throw light on ageing and Alzheimer's disease. *The Lancet*, 347(9001), 605.
- Shatenstein, B., & Barberger-Gateau, P. (2015). Prevention of age-related cognitive decline: Which strategies, when, and for whom? *Journal of Alzheimer's Disease*, 48(1), 35–53. <https://doi.org/10.3233/JAD-150256>
- Shaver, D., & Shaver, M. A. (2003). Books and digital technology: A new industry model. *Journal of Media Economics*, 16(2), 71–86. https://doi.org/10.1207/S15327736ME1602_1
- Shen, A. (2014). Recommendations as personalized marketing: Insights from customer experiences. *Journal of Services Marketing*, 28(5), 414–427.
- Simmons-Mackie, N., & Kagan, A. (2007). Application of the ICF in aphasia. *Seminars in Speech and Language*, 28(4), 244–253. <https://doi.org/10.1055/s-2007-986521>
- Slade, K., Plack, C. J., & Nuttall, H. E. (2020). The effects of age-related hearing loss on the brain and cognitive function. *Trends in Neurosciences*, 43(10), 810–821.

- Slevin, T. (2021, March 11). National preventive health strategy: A new era in Australian health is possible. *Intouch Public Health*. <https://intouchpublichealth.net.au/national-preventive-health-strategy-a-new-era-in-australian-health-is-possible/>
- Sloane, P. D. (1998). Advances in the treatment of Alzheimer's disease. *American Family Physician*, 58(7), 1577.
- Smith-Conway, E. R., Baker, R., Angwin, A. J., Pachana, N. A., Copland, D. A., Humphreys, M. S., Gallois, C., Byrne, G. J., & Chenery, H. J. (2012). Education strategies in dementia. *The Australian Nursing Journal*, 19(10), 35.
- Smith, H., Kindell, J., Baldwin, R., Waterman, D., & Makin, A. (2009). Swallowing problems and dementia in acute hospital settings: Practical guidance for the management of dysphagia. *Clinical Medicine*, 9(6), 544.
- Smith, S., Lamping, D., Banerjee, S., Harwood, R., Foley, B., Smith, P., Cook, J. C., Murray, J., Prince, M., Levin, E., Mann, A., & Knapp, M. (2005). Measurement of health-related quality of life for people with dementia: Development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment*, 9(10), iii–iv. <https://doi.org/10.3310/hta9100>
- Smithson, J. (2000). Using and analysing focus groups: Limitations and possibilities. *International Journal of Social Research Methodology*, 3(2), 103–119.
- Snowden, J., Goulding, P. J., & David, N. (1989). Semantic dementia: A form of circumscribed cerebral atrophy. *Behavioural Neurology*, 2, 124043. <https://doi.org/10.1155/1989/124043>
- Snowdon, D. A. (2003). Healthy aging and dementia: Findings from the Nun Study. *Annals of Internal Medicine*, 139(5 Pt 2), 450–454. https://doi.org/10.7326/0003-4819-139-5_Part_2-200309021-00014
- Snowdon, D. A., Greiner, L. H., Mortimer, J. A., Riley, K. P., Greiner, P. A., & Markesbery, W. R. (1997). Brain infarction and the clinical expression of Alzheimer disease: The Nun Study. *JAMA*, 277(10), 813–817.
- Solomon, A., Mangialasche, F., Richard, E., Andrieu, S., Bennett, D. A., Breteler, M., Fratiglioni, L., Hooshmand, B., Khachaturian, A. S., Schneider, L.S., Skoog, I., & Kivipelto, M. (2014). Advances in the prevention of Alzheimer's disease and dementia. *Journal of Internal Medicine*, 275(3), 229–250. <https://doi.org/10.1111/joim.12178>
- Spat, J. (2003). Arnold Pick's concept of dementia. *Cortex*, 39(3), 525–531. [https://doi.org/10.1016/S0010-9452\(08\)70262-4](https://doi.org/10.1016/S0010-9452(08)70262-4)
- Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial. *The British Journal of Psychiatry*, 183(3), 248–254.
- Speech-Language & Audiology Canada. (2010). *Position statement on outcome measures*. https://sac-oac.ca/sites/default/files/resources/outcomes_measures_position_statement_english.pdf

- Speech-Language & Audiology Canada. (2017). *The role of speech-language pathologists and audiologists in dementia care*. https://www.sac-oac.ca/sites/default/files/resources/Dementia_Position-Statement_EN.pdf
- Speech Pathology Australia. (n.d.). *Useful contacts*.
https://www.speechpathologyaustralia.org.au/SPAweb/Resources_For_Speech_Pathologists/Useful_Contacts/SPAweb/Resources_for_Speech_Pathologists/Useful_Contacts/Useful_Contacts.aspx
- Speech Pathology Australia. (2012). *Submission to the House of Representatives Standing Committee on Health and Ageing. An inquiry into dementia early diagnosis and intervention*.
https://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=haa/dementia/subs/sub074%20-%20speech%20pathology%20australia%20-%202002%20may%202012.pdf
- Speech Pathology Australia. (2015). *Position statement: Speech pathologists working with older people*.
https://www.speechpathologyaustralia.org.au/SPAweb/Members/Position_Statements/SPAweb/Members/Position_Statements/Position_Statements.aspx
- Speech Pathology Australia. (2018). *Clinical guideline: Speech pathology in mental health*.
https://www.speechpathologyaustralia.org.au/SPAweb/Members/Clinical_Guidelines/SPAweb/Members/Clinical_Guidelines/Clinical_Guidelines.aspx
- Speech Pathology Australia. (2019). *Resource guide*.
https://www.speechpathologyaustralia.org.au/SPAweb/Resources_For_Speech_Pathologists/Resource_Guide/SPAweb/Members/Resource_Guide/Resource_Guide.aspx
- Speech Pathology Australia. (2020a). *Code of ethics 2020*.
https://www.speechpathologyaustralia.org.au/SPAweb/Members/Ethics/Code_of_Ethics_2020/SPAweb/Members/Ethics/HTML/Code_of_Ethics_2020.aspx
- Speech Pathology Australia. (2020b). *Professional standards for speech pathologists in Australia*.
https://www.speechpathologyaustralia.org.au/SPAweb/Resources_for_Speech_Pathologists/CBOS/Professional_Standards.aspx
- Speech Pathology Australia. (2020c). *Speech Pathology Australia's submission to the Royal Commission into Aged Care Quality and Safety*.
https://agedcare.royalcommission.gov.au/system/files/2020-07/RCD.9999.0324.0001_0.pdf
- Speech Pathology Australia. (2021). *Evidence-based practice for speech pathology in Australia*. https://acdhs.edu.au/wp-content/uploads/2021/07/EBP_speechpathologyinaustralia_16062021-3.pdf
- Speech Pathology Australia (2022). *Speech pathology scope of practice in Australia*.
https://www.speechpathologyaustralia.org.au/SPAweb/About_us/SPA_Documents/SPAweb/About_Us/SPA_Documents/SPA_Documents.aspx

- Sperling, R. A., Aisen, P. S., Beckett, L. A., Bennett, D. A., Craft, S., Fagan, A. M., Iwatsubo, T., Jack, C. R. Jr., Kaye, J., Montine, T. J., Park, D. C., Reiman, E. M., Rowe, C. C., Siemers, E., Stern, Y., Yaffe, K., Carrillo, M. C., Thies, B., Morrison-Bogorad, M., ... Phelps, C. H. (2011). Toward defining the preclinical stages of Alzheimer's disease: Recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's Dementia*, 7(3), 280–292. <https://doi.org/10.1016/j.jalz.2011.03.003>
- Speyer, R. (2011). Behavioural treatment of oropharyngeal dysphagia: Bolus modification and management, sensory and motor behavioural techniques, postural adjustments, and swallow manoeuvres. In O. Ekberg (Ed.), *Dysphagia: Diagnosis and treatment* (pp. 477–491). Springer. https://doi.org/10.1007/174_2011_350
- Speyer, R. (2017). Behavioral treatment of oropharyngeal dysphagia. In O. Ekberg (Ed.), *Dysphagia: Diagnosis and treatment* (2nd ed., pp. 669–686). Springer. https://doi.org/10.1007/174_2017_140
- Speyer, R., Baijens, L., Heijnen, M., & Zwijsenberg, I. (2010). Effects of therapy in oropharyngeal dysphagia by speech and language therapists: A systematic review. *Dysphagia*, 25(1), 40–65.
- Stevenson, J. S., Bruner, G. C., & Kumar, A. (2000). Webpage background and viewer attitudes. *Journal of Advertising Research*, 40(1–2), 29–34.
- Storm, B. C., Bjork, R. A., & Storm, J. C. (2010). Optimizing retrieval as a learning event: When and why expanding retrieval practice enhances long-term retention. *Memory & Cognition*, 38(2), 244–253.
- Strandberg, T. E., Levälähti, E., Ngandu, T., Solomon, A., Kivipelto, M., Kivipelto, M., Ngandu, T., Lehtisalo, J., Laatikainen, T., Soininen, H., Antikainen, R., Jula, A., Tuomilehto, J., Peltonen, M., Levälähti, E., Lindström, J., Rauramaa, R., Pajala, S., Hänninen, T., ... Mangialasche, F. (2017). Health-related quality of life in a multidomain intervention trial to prevent cognitive decline (FINGER). *European Geriatric Medicine*, 8(2), 164–167. <https://doi.org/10.1016/j.eurger.2016.12.005>
- Sura, L., Madhavan, A., Carnaby, G., & Crary, M. A. (2012). Dysphagia in the elderly: Management and nutritional considerations. *Clinical Interventions in Aging*, 7, 287–298. <https://doi.org/10.2147/CIA.S23404>
- Swaffer, K. (2014). Dementia: Stigma, language, and dementia-friendly. *Dementia*, 13(6), 709–716. <https://doi.org/10.1177/1471301214548143>
- Swan, K., Hopper, M., Wenke, R., Jackson, C., Till, T., & Conway, E. (2018). Speech-language pathologist interventions for communication in moderate-severe dementia: A systematic review. *American Journal of Speech-Language Pathology*, 27(2), 836–852. https://doi.org/10.1044/2017_AJSLP-17-0043
- Taivalsaari, A., Mikkonen, T., Ingalls, D., & Palacz, K. (2008). Web browser as an application platform. In *2008 34th Euromicro Conference Software Engineering and Advanced Applications* (pp. 293–302). <https://doi.org/10.1109/SEAA.2008.17>

- Tambyraja, S. R., Farquharson, K., & Coleman, J. (2021). Speech-language teletherapy services for school-aged children in the United States during the COVID-19 pandemic. *Journal of Education for Students Placed at Risk (JESPAR)*, 26(2), 91–111. <https://doi.org/10.1080/10824669.2021.1906249>
- Taylor, C., Kingma, R. M., Croot, K., & Nickels, L. (2009). Speech pathology services for primary progressive aphasia: Exploring an emerging area of practice. *Aphasiology*, 23(2), 161–174.
- Taylor-Goh, S. (2017). *Royal College of Speech & Language Therapists clinical guidelines*. Routledge.
- Taylor-Rubin, C., Croot, K., Power, E., Savage, S. A., Hodges, J. R., & Togher, L. (2017). Communication behaviors associated with successful conversation in semantic variant primary progressive aphasia. *International Psychogeriatrics*, 29(10), 1619–1632. <https://doi.org/10.1017/S1041610217000813>
- TechAdvisor. (2021). *Best web browsers 2021*. <https://www.techadvisor.com/article/728377/best-web-browsers-2021.html>
- TechRadar. (2022). *Best website builder service of 2022*. <https://www.techradar.com/news/the-best-website-builder>
- Teitelman, J., Raber, C., & Watts, J. (2010). The power of the social environment in motivating persons with dementia to engage in occupation: Qualitative findings. *Physical & Occupational Therapy in Geriatrics*, 28(4), 321–333. <https://doi.org/10.3109/02703181.2010.532582>
- Terrace, L. (2003). Development and validation of an international appraisal instrument for assessing the quality of clinical practice guidelines: The AGREE project. *Quality and Safety in Health Care*, 12(1), 18–23. <https://doi.org/10.1136/qhc.12.1.18>
- Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. In C. Willig & W. Rogers (Eds.), *The SAGE Handbook of qualitative research in psychology* (pp. 17–36). SAGE Publications. <https://doi.org/10.4135/9781526405555.n2>
- Thanapornsanguth, S. (2016, October). Using human-centered design and social inventions to find the purposes in making. In *Proceedings of the 6th Annual Conference on Creativity and Fabrication in Education* (pp. 17–25). <https://doi.org/10.1145/3003397.3003400>
- Thiel, L., & Conroy, P. (2014). A comparison of errorless and errorful therapies for dysgraphia after stroke. *Neuropsychological Rehabilitation*, 24(2), 172–201.
- Threats, T. (2007). Access for persons with neurogenic communication disorders: Influences of personal and environmental factors of the ICF. *Aphasiology*, 21(1), 67–80.
- Threats, T. T. (2010). The ICF and speech-language pathology: Aspiring to a fuller realization of ethical and moral issues. *International Journal of Speech-Language Pathology*, 12(2), 87–93.

- Tible, O. P., Riese, F., Savaskan, E., & von Gunten, A. (2017). Best practice in the management of behavioural and psychological symptoms of dementia. *Therapeutic advances in neurological disorders*, 10(8), 297–309.
- Tippett, D. C. (2020). Classification of primary progressive aphasia: Challenges and complexities. *F1000Research*, 9. <https://doi.org/10.12688/f1000research.21184.1>
- Topo, P. (2008). Technology studies to meet the needs of people with dementia and their caregivers: A literature review. *Journal of Applied Gerontology*, 28(1), 5–37. <https://doi.org/10.1177/0733464808324019>
- Tosi, F. (2020). Human-centred design—user experience: Tools and intervention methods. In F. Tosi (Ed.), *Design for ergonomics* (pp. 111–128). Springer International Publishing. https://doi.org/10.1007/978-3-030-33562-5_6
- Towey, M. P. (2012). Speech telepractice: Installing a speech therapy upgrade for the 21st century. *International Journal of Telerehabilitation*, 4(2), 73–78. <https://doi.org/10.5195/IJT.2012.6112>
- Tricco, A. C., Lillie, E., Zarin, W., O’Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M., Garritty, C., ... Straus, S. E. (2018). PRISMA extension for scoping reviews (PRISMA-ScR): Checklist and explanation. *Annals of Internal Medicine*, 169(7), 467–473.
- Tsoukra, P., Velakoulis, D., Wibawa, P., Malpas, C. B., Walterfang, M., Evans, A., Farrand, S., Kelso, W., Eratne, D., & Loi, S. M. (2021). The diagnostic challenge of young-onset dementia syndromes and primary psychiatric diseases: Results from a retrospective 20-year cross-sectional study. *The Journal of Neuropsychiatry and Clinical Neurosciences*, 34(1), 44–52. <https://doi.org/10.1176/appi.neuropsych.20100266>
- The University of Queensland. (n.d.). *Florence project: Make my day go better*. <https://itee.uq.edu.au/florence>
- Vafeas, C., Jacob, E., & Jacob, A. (2020). A younger onset dementia toolkit: Innovative practice. *Dementia*, 19(4), 1299–1307.
- van der Bijl-Brouwer, M., & Dorst, K. (2017). Advancing the strategic impact of human-centred design. *Design Studies*, 53, 1–23. <https://doi.org/10.1016/j.destud.2017.06.003>
- van der Steen, J. T., van Soest-Poortvliet, M. C., Hallie-Heierman, M., Onwuteaka-Philipsen, B. D., Deliëns, L., de Boer, M. E., Van den Block, L., van Uden, N., Hertogh, C. M., & de Vet, H. C. (2014). Factors associated with initiation of advance care planning in dementia: A systematic review. *Journal of Alzheimer’s Disease*, 40(3), 743–757.
- van Hoof, J., Kort, H. S. M., van Waarde, H., & Blom, M. M. (2010). Environmental interventions and the design of homes for older adults with dementia: An overview. *American Journal of Alzheimer’s Disease & Other Dementias*, 25(3), 202–232. <https://doi.org/10.1177/1533317509358885>
- Vellas, B., Carrie, I., Gillette-Guyonnet, S., Touchon, J., Dantoine, T., Dartigues, J. F., Cuffi, M. N., Bordes, S., Gasnier, Y., Robert, P., Bories, L., Rouaud, O., Desclaux, F., Sudres,

- K., Bonnefoy, M., Pesce, A., Dufouil, C., Lehericy, S., Chupin, M., ... Andrieu, S. (2014). MAPT study: A multidomain approach for preventing Alzheimer's disease: Design and baseline data. *The Journal of Prevention of Alzheimer's Disease*, 1(1), 13–22.
- Virzi, R. A. (1989). What can you learn from a low-fidelity prototype? *Proceedings of the Human Factors Society Annual Meeting*, 33(4), 224–228.
<https://doi.org/10.1177/154193128903300405>
- Volkert, D., Chourdakis, M., Faxen-Irving, G., Frühwald, T., Landi, F., Suominen, M. H., Vandewoude, M., Wirth, R., & Schneider, S. M. (2015). ESPEN guidelines on nutrition in dementia. *Clinical Nutrition*, 34(6), 1052–1073.
<https://doi.org/10.1016/j.clnu.2015.09.004>
- Volkmer, A., Spector, A., Beeke, S., & Warren, J. D. (2018). Speech and language therapy for primary progressive aphasia: Referral patterns and barriers to service provision across the UK. *Dementia*, 19(5), 1349–1363. <https://doi.org/10.1177/1471301218797240>
- Volkmer, A., Spector, A., Warren, J. D., & Beeke, S. (2019). Speech and language therapy for primary progressive aphasia across the UK: A survey of current practice. *International journal of language & communication disorders*, 54(6), 914–926.
- Volkmer, A., Rogalski, E., Henry, M., Taylor-Rubin, C., Ruggero, L., Khayum, R., Kindell, J., Gorno-Tempini, M.L., Warren, J. & Rohrer, J. D. (2020). Speech and language therapy approaches to managing primary progressive aphasia. *Practical neurology*, 20(2), 154–161.
- Vollmer Dahlke, D., & Ory, M. G. (2020). Emerging issues of intelligent assistive technology use among people with dementia and their caregivers: A U.S. perspective. *Frontiers in Public Health*, 8. <https://doi.org/10.3389/fpubh.2020.00191>
- Vuorinen, E., Laine, M., & Rinne, J. (2000). Common pattern of language impairment in vascular dementia and in Alzheimer disease. *Alzheimer Disease & Associated Disorders*, 14(2).
- Walker, M., Takayama, L., & Landay, J. A. (2002). High-fidelity or low-fidelity, paper or computer? Choosing attributes when testing web prototypes. *Proceedings of the Human Factors and Ergonomics Society Annual Meeting*, 46, 661–665.
- Walker, Z., Possin, K. L., Boeve, B. F., & Aarsland, D. (2015). Lewy body dementias. *Lancet*, 386(10004), 1683–1697. [https://doi.org/10.1016/S0140-6736\(15\)00462-6](https://doi.org/10.1016/S0140-6736(15)00462-6)
- Wallace, S. J., Worrall, L., Rose, T., & Le Dorze, G. (2017). Using the International Classification of Functioning, Disability, and Health to identify outcome domains for a core outcome set for aphasia: A comparison of stakeholder perspectives. *Disability and Rehabilitation*, 41(5), 564–573. <https://doi.org/10.1080/09638288.2017.1400593>
- Waller, A., Balandin, S. A., O'Mara, D. A., & Judson, A. D. (2005, August). Training AAC users in user-centred design. *Accessible Design in the Digital World Conference 2005*.
<https://doi.org/10.14236/ewic/AD2005.2>

- Warchol, K. (2006). Facilitating functional and quality-of-life potential: Strength-based assessment and treatment for all stages of dementia. *Topics in Geriatric Rehabilitation*, 22(3), 213–227. <https://doi.org/10.1097/00013614-200607000-00004>
- Washington, K. N. (2007). Using the ICF within speech-language pathology: Application to developmental language impairment. *Advances in Speech Language Pathology*, 9(3), 242–255. <https://doi.org/10.1080/14417040701261525>
- Waters, S. O., & Sullivan, P. A. (2012). An approach to guiding and supporting decision-making for individuals with dementia: Feeding, swallowing, and nutrition considerations. *Perspectives on Swallowing and Swallowing Disorders (Dysphagia)*, 21(3), 105–111. <https://doi.org/10.1044/sasd21.3.105>
- Website Builder Expert. (2022). *Best website builder 2022*. <https://www.websitebuilderexpert.com/website-builders/>
- Weichbroth, P., & Sikorski, M. (2015). User interface prototyping: Techniques, methods and tools. *Studia Ekonomiczne*, 234, 184–198.
- Weiner, M. F., Martin-Cook, K., Svetlik, D. A., Saine, K., Foster, B., & Fontaine, C. S. (2000). The quality of life in late-stage dementia (QUALID) scale. *Journal of the American Medical Directors Association*, 1(3), 114–116.
- Weller, S. (2017). Using internet video calls in qualitative (longitudinal) interviews: Some implications for rapport. *International Journal of Social Research Methodology*, 20(6), 613–625.
- Welsh Parliament. (2017). *Inquiry into the Welsh Government's draft national dementia strategy*. <https://business.senedd.wales/ieIssueDetails.aspx?IId=16832&Opt=3>
- Whiting, L. S. (2008). Semi-structured interviews: Guidance for novice researchers. *Nursing Standard*, 22(23), 35.
- Wichansky, A. M. (2000). Usability testing in 2000 and beyond. *Ergonomics*, 43(7), 998–1006.
- Wicklund, M. R., Duffy, J. R., Strand, E. A., Machulda, M. M., Whitwell, J. L., & Josephs, K. A. (2014). Quantitative application of the primary progressive aphasia consensus criteria. *Neurology*, 82(13), 1119–1126. <https://doi.org/10.1212/wnl.0000000000000261>
- Wieseke, A., Bantz, D., Siktberg, L., & Dillard, N. (2008). Assessment and early diagnosis of dysphagia. *Geriatric Nursing*, 29(6), 376–383. <https://doi.org/10.1016/j.gerinurse.2007.12.001>
- Wiles Higdon, C. (2015). Communication sciences and disorders: The future of speech-language pathology and audiology. *Journal of Life Care Planning*, 13(2), 5–26.
- Wilkinson, S. (1998). Focus groups in health research: Exploring the meanings of health and illness. *Journal of Health Psychology*, 3(3), 329–348.
- Wilkinson, S. (2005). Using focus groups: Exploring the meanings of health and illness. In J. Miles & P. Gilbert (Eds.), *A handbook of research methods for clinical and health*

- psychology (pp. 79–94). Oxford Academic.
<https://doi.org/10.1093/med:psych/9780198527565.003.0007>
- Williams, K., Holmes, F., Kemper, S., & Marquis, J. (2003). Written language clues to cognitive changes of aging: An analysis of the letters of King James VI/I. *The Journals of Gerontology: Series B*, 58(1), 42–44. <https://doi.org/10.1093/geronb/58.1.P42>
- Williams, T., II (2020). *The human-centred designer and the cognitive dissonance theory* [Master's thesis, Aalto University]. <http://urn.fi/URN:NBN:fi:aalto-202006143729>
- Wilson, B. A., Baddeley, A., Evans, J., & Shiel, A. (1994). Errorless learning in the rehabilitation of memory impaired people. *Neuropsychological Rehabilitation*, 4(3), 307–326. <https://doi.org/10.1080/09602019408401463>
- Wilson, R. S., Hebert, L. E., Scherr, P. A., Barnes, L. L., Mendes de Leon, C. F., & Evans, D. A. (2009). Educational attainment and cognitive decline in old age. *Neurology*, 72(5), 460–465. <https://doi.org/10.1212/01.wnl.0000341782.71418.6c>
- Winblad, B., Amouyel, P., Andrieu, S., Ballard, C., Brayne, C., Brodaty, H., Cedazo-Minguez, A., Dubois, B., Edvardsson, D., Feldman, H., Fratiglioni, L., Frisoni, G., Gauthier, S., Georges, J., Graff, C., Iqbal, K., Jessen, F., Johansson, G., Jönsson, L., ... Zetterberg, H. (2016). Defeating Alzheimer's disease and other dementias: A priority for European science and society. *Lancet Neurology*, 15(5), 455–532. [https://doi.org/10.1016/s1474-4422\(16\)00062-4](https://doi.org/10.1016/s1474-4422(16)00062-4)
- Wisdom, J., & Creswell, J. W. (2013). *Mixed methods: Integrating quantitative and qualitative data collection and analysis while studying patient-centered medical home models*. Agency for Healthcare Research and Quality.
- Wolfs, C. A., Dirksen, C. D., Severens, J. L., & Verhey, F. R. (2006). The added value of a multidisciplinary approach in diagnosing dementia: A review. *International Journal of Geriatric Psychiatry*, 21(3), 223–232.
- Wong, C. W. (2016). Pharmacotherapy for dementia: A practical approach to the use of cholinesterase inhibitors and memantine. *Drugs & Aging*, 33(7), 451–460. <https://doi.org/10.1007/s40266-016-0372-3>
- World Health Organization. (n.d.). *International classification of functioning, disability and health (ICF)*. <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>
- World Health Organization (2021a, September 2). *Dementia: Key facts*. <https://www.who.int/news-room/fact-sheets/detail/dementia>
- World Health Organization. (2021b, November 10). *Rehabilitation: Key facts*. <https://www.who.int/news-room/fact-sheets/detail/rehabilitation>
- Worrall, L., Sherratt, S., Rogers, P., Howe, T., Hersh, D., Ferguson, A., & Davidson, B. (2011). What people with aphasia want: Their goals according to the ICF. *Aphasiology*, 25(3), 309–322.

- Wright, K. B. (2017). Researching internet-based populations: Advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web survey services. *Journal of Computer-Mediated Communication*, 10(3). <https://doi.org/10.1111/j.1083-6101.2005.tb00259.x>
- Wu, H.-S., Lin, L.-C., Su, S.-C., & Wu, S.-C. (2014). The effects of spaced retrieval combined with errorless learning in institutionalized elders with dementia: Recall performance, cognitive status, and food intake. *Alzheimer Disease & Associated Disorders*, 28(4), 333–339.
- Wynn, R., & Khayum, B. (2015). Developing personally relevant goals for people with moderate to severe dementia. *Seminars in Speech and Language*, 36(3), 199–208. <https://doi.org/10.1055/s-0035-1551837>
- Yaffe, K., Barnes, D. E., Rosenberg, D., Dublin, S., Kaup, A. R., Ludman, E. J., Vittinghoff, E., Peltz, C., Renz, A., Adams, K., & Larson, E. B. (2019). Systematic Multi-Domain Alzheimer's Risk Reduction Trial (SMARRT): Study protocol. *Journal of Alzheimer's Disease*, 70, S207–S220. <https://doi.org/10.3233/JAD-180634>
- Yoon, M. N., & Steele, C. M. (2007). The oral care imperative: The link between oral hygiene and aspiration pneumonia. *Topics in Geriatric Rehabilitation*, 23(3).
- Young, L. A. (n.d.). *Easily find helpful resources on Eat, Speak, & Think*. Eat, Speak, & Think: A blog for medical speech-language pathologists. <https://eatspeakthink.com/find-helpful-resources-on-est/>
- Zahodne, L. B., Glymour, M. M., Sparks, C., Bontempo, D., Dixon, R. A., MacDonald, S. W. S., & Manly, J. J. (2011). Education does not slow cognitive decline with aging: 12-year evidence from the Victoria longitudinal study. *Journal of the International Neuropsychological Society*, 17(6), 1039–1046. <https://doi.org/10.1017/S1355617711001044>
- Zhang, H., Wang, Z., Wang, J., Lyu, X., Wang, X., Liu, Y., Zeng, X., Yuan, H., Wang, H., & Yu, X. (2019). Computerized multi-domain cognitive training reduces brain atrophy in patients with amnesic mild cognitive impairment. *Translational Psychiatry*, 9, 1–10. <https://doi.org/10.1038/s41398-019-0385-x>
- Zucchella, C., Sinforiani, E., Tamburin, S., Federico, A., Mantovani, E., Bernini, S., Casale, R., & Bartolo, M. (2018). The multidisciplinary approach to Alzheimer's disease and dementia. A narrative review of non-pharmacological treatment. *Frontiers in Neurology*, 9(1058). <https://doi.org/10.3389/fneur.2018.01058>

Appendices

Appendix A: Scoping Review Results and Tables

Figure A1

PRISMA Flow Diagram

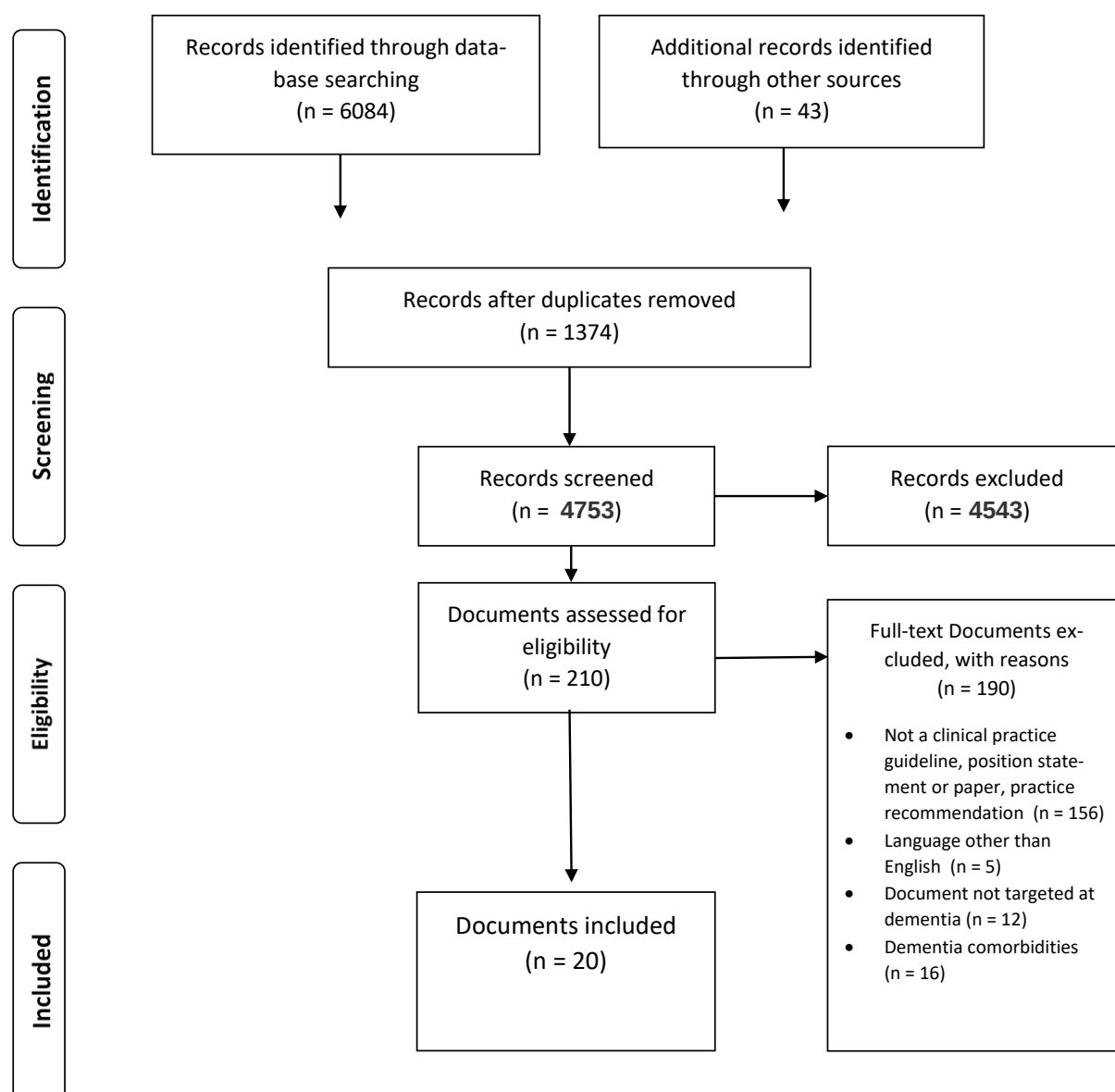


Table A1*Overview of Reviewed Documents*

Author/Editor	Title	Year	Country	Target group	Aims/Content	Document type
Agency for Clinical Innovation	<i>Better health for people living with dementia: A guide on the role of allied health professionals</i>	2016	Australia	Allied health professionals	Collaboration and roles of allied health professionals in providing interventions for PWD	Guideline
Alzheimer Society of Canada	<i>7 key elements of person-centred care of people with dementia in long-term care homes</i>	2014	Canada	Staff working in long-term care homes	Seven key elements to provide person-centred care for PWD	Recommendation
Cognitive Decline Partnership Centre	<i>Clinical practice guidelines and principles of care for people with dementia</i>	2016	Australia	Health and aged care staff	Evidence-based recommendations adapted for Australian context	Guideline
Foley, Jennings, & Swanwick	<i>Dementia: Diagnosis and management in general practice</i>	2019	Ireland	General practitioners	Reference guide with different levels of evidence for the management of dementia	Other: Reference guide
Galvin & Sadowsky	<i>Practical guidelines for the recognition and diagnosis of dementia</i>	2012	United States	Family physicians	Guidance for recognition and diagnosis of dementia	Guideline
Group Health Cooperative	<i>Dementia and cognitive impairment. diagnosis and treatment guideline</i>	2012	United States	Multidisciplinary	Overview of prevention, assessment, diagnosis, treatment, monitoring and referrals along scenarios	Guideline
Irish Association of Speech & Language Therapists	<i>Speech and language therapy provision for people with dementia. IASLT position statement</i>	2016	Ireland	Speech and language therapists	Key roles of SLTs, scope of practice and management of PWD within multidisciplinary team	Position paper
Nagaendran et al.	<i>Ministry of Health. Clinical Practice Guidelines: Dementia</i>	2013	Singapore	Clinicians	Recommendations of pharmacological and non-pharmacological aspects of management for patients ranging from mild cognitive impairment to severe dementia	Guideline
Ministry of Health	<i>New Zealand framework for dementia care</i>	2013	New Zealand	Person with dementia; health and social services	Providing PWD with information and encouraging collaboration between different health and social services	Other: Framework

Author/Editor	Title	Year	Country	Target group	Aims/Content	Document type
National Health Service England	<i>Dementia diagnosis and management. A brief pragmatic resource for general practitioners</i>	2015	UK	General practitioners	Overview of primary care needs of PWD, expert opinion and case scenarios	Other: Practice resource
Royal College of Nursing	<i>Commitment to care of people living with dementia</i>	2019	UK	Health and social care professionals	Five principles to improve care for PWD and their families, based on evidence gathered from people living with dementia, carers and practitioners	Other: Guiding resource
Royal College of Speech & Language Therapists	<i>Speech and language therapy provision for people with dementia: RCSLT position paper</i>	2014	UK	Speech and language therapists	Guidance on the provision of speech and language therapy services and collaboration within a multidisciplinary team	Position paper
Sadowsky & Galvin	<i>Guidelines for the management of cognitive and behavioural problems in dementia</i>	2012	Other: Undisclosed	Family physicians	Review of non-pharmacologic and pharmacologic interventions on the functional abilities	Guideline
Shaji, Sivakumar, Rao, & Paul	<i>Clinical practice guidelines for management of dementia</i>	2018	India	Psychiatrists	Broad framework for assessment, management and follow-up of older PWD	Guideline
Speech-Language and Audiology Canada	<i>The role of speech-language pathologists and audiologists in dementia care</i>	2017	Canada	Speech-language pathologists	Providing an overview of the speech-language pathologist's and audiologist's role in the management of dementia	Position paper
Taylor-Goh	<i>Royal College Of Speech & Language Therapists clinical guidelines</i>	2017	UK	Speech & language therapists	12 clinical guidelines, including disorders of mental health and dementia	Guideline
The National Institute for Health and Care Excellence (NICE)	<i>Dementia: assessment, management and support for people living with dementia and their carer</i>	2018	UK	Healthcare and social care professionals, carers and PWD	Assessment and diagnosis of dementia to provide person-centred care and support	Guideline
The Royal College of Psychiatrists	<i>Young-onset dementia in mental health services. Recommendations for service provision</i>	2018	UK	Psychiatrists	Management of people with young-onset dementia, including assessment services, accessing support and specialised services	Recommendation
Volkert et al.	<i>ESPEN guidelines on nutrition in dementia</i>	2015	Other: Europe	Physicians, nutritionists and dietitians	Evidence-based recommendations for nutritional care of PWD	Guideline

Author/Editor	Title	Year	Country	Target group	Aims/Content	Document type
Waters & Sullivan	<i>An approach to guiding and supporting decision-making for individuals with dementia: Feeding, swallowing, and nutrition considerations</i>	2012	United States	Speech-language pathologists	Evidence-based components of care for decision making in feeding, swallowing and nutrition considerations	Other: Guide for decision making

Note. ESPEN = European Society for Clinical Nutrition and Metabolism; PWD = people with dementia; SP = speech pathologist; SLT = speech and language therapist.

Table A2*SLP Role Within Documents*

Author/Editor	Consideration SLP role	Stages of SLP involvement	SLP role in assessments	SLP services: Communication and language	SLP services: Swallowing and feeding	Other non-pharmacological intervention strategies relevant to SLPs^a	Assessment/diagnostic approach relevant to SLPs^b
Agency for Clinical Innovation, 2016	Yes; cognitive-communication, swallowing/feeding	Early SLP intervention recommended	Communication and swallowing/feeding	Facilitation of communication strategies, memory and communication aids, reminiscence work, promotion of communication-friendly environment, advising about communication modalities	Guidance of texture modification, provision of swallowing strategies, promotion of routines and social aspects, liaison with other healthcare providers	None	Comprehensive communication assessment; deterioration in eating, drinking, and swallowing; identification of abilities and strengths
Alzheimer Society of Canada, 2014	No	Not mentioned	Not mentioned	Not included	Not included	<i>All About Me</i> book	Individualised assessment to meet unique needs
Cognitive Decline Partnership Centre, 2016	Yes; cognitive-communication, swallowing/feeding	Not mentioned	Swallowing/feeding	Not included	Promoting of living well and palliative care; not further specified	Reminiscence therapy; communication training	Clinical cognitive assessment
Foley, Jennings, & Swanwick, 2019	Yes; cognitive-communication, swallowing/feeding	Not mentioned	Communication and swallowing/feeding/drinking	Optimising communication skills of PWD and communication partners	Maintain oral intake for as long as possible; management of feeding, eating, drinking, and swallowing	None	Cognitive assessment and assessment of carers' needs; specialist input/memory clinics
Galvin & Sadowsky, 2012	No	Not mentioned	Not mentioned	Not included	Not included	None	Referral to specialist services for standardised cognitive assessments
Group Health Cooperative, 2012	Yes; cognitive-communication	Early referral to SLP recommended	Evaluation and monitoring of cognitive-communication	Not included	Not included	None	Assessment of cognitive function and functional status

Author/Editor	Consideration SLP role	Stages of SLP involvement	SLP role in assessments	SLP services: Communication and language	SLP services: Swallowing and feeding	Other non-pharmacological intervention strategies relevant to SLPs^a	Assessment/diagnostic approach relevant to SLPs^b
Nagaendran et al., 2013	No	Not mentioned	Not mentioned	Not included	Not included	Environmental design; reminiscence therapy; cognitive stimulation	Comprehensive evaluation, considering cognitive domains such as aphasia, apraxia and/or executive dysfunctioning
Ministry of Health, New Zealand, 2013	Yes; not further specified	Not mentioned	Assessment and monitoring of nutrition and communication	Access to SLP services to develop appropriate communication and behaviour strategies	Not included	Links to resources, including dementia-friendly environment, nutritional activity; importance of adapted communication techniques; interdisciplinary care planning	Interdisciplinary assessment; clinical cognitive assessment
National Health Services England, 2015	No	Not mentioned	Not mentioned	Not included	Not included	Provision of further services to improve quality of life; not further specified	Assessment of cognitive function
Royal College of Nursing, 2019	No	Not mentioned	Not mentioned	Not included	Not included	Not included	Swallow or speech and language assessment; screening of cognitive abilities; assessment of person and carers needs
Sadowsky & Galvin, 2012	No	Not mentioned	Not mentioned	Not included	Not included	Reminiscence therapy; elimination of sources of conflict and frustration	Evaluation of cognition, function and behaviour
Shaji et al., 2018	Yes; cognitive-communication	Not mentioned	Not mentioned	Not included	Not included	Interventions to improve cognitive function, promotion of activities of daily living, participation, and social interaction; provision of caregiver support	Assessment of cognitive changes and functions

Author/Editor	Consideration SLP role	Stages of SLP involvement	SLP role in assessments	SLP services: Communication and language	SLP services: Swallowing and feeding	Other non-pharmacological intervention strategies relevant to SLPs ^a	Assessment/diagnostic approach relevant to SLPs ^b
The National Institute for Health and Care Excellence (NICE), 2018	Yes; eating and drinking	Not mentioned	Not mentioned	Not included	If safe food intake is not given	Cognitive stimulation therapy; group reminiscence therapy; communication training	History of cognitive and behavioural symptoms; performance of cognitive testing
The Royal College of Psychiatrists, 2019	Yes; cognitive-communication, swallowing/feeding	Not mentioned	Access to SLP services included; not further specified	Access to SLP services included; not further specified	Not included	None	Referral to specialist for further assessment
Volkert et al., 2015	No	Not mentioned	Not mentioned	Not included	Not included	Text modifications; behavioural and communication strategies	Evaluation of nutritional status; assessment of dietary intake and eating problems

Note. PWD = people with dementia; SLP = speech-language pathologist.

^a Relevant to cognitive communication, language, social and environmental interaction, swallowing, and feeding. ^b Assessment of cognitive function, behaviour, and domains; assessment of communication and language, and swallowing and feeding function.

Appendix B:

Phase 1 – Stage 1: Survey Material

Phase 1 – Stage 1: Ethics Approval

HUMAN RESEARCH ETHICS COMMITTEE

Notification of Expedited Approval

To Chief Investigator or Project Supervisor:	Doctor Liz Spencer
Cc Co-investigators / Research Students:	Mrs Elisa Choudery Associate Professor Sally Hewat
Re Protocol:	Working with people with dementia and their carers: Speech-language pathologists' experiences and perceptions
Date:	14-May-2019
Reference No:	H-2019-0073
Date of Initial Approval:	14-May-2019

Thank you for your **Response to Conditional Approval (minor amendments)** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under **Expedited** review by the Ethics Administrator.

We are pleased to advise that the decision on your submission is **Approved** effective **14-May-2019**.

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Approval will remain valid subject to the submission, and satisfactory assessment, of annual progress reports. *If the approval of an External HREC has been "noted" the approval period is as determined by that HREC.*

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request. Your approval number is H-2019-0073.

If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants. You may then proceed with the research.

Conditions of Approval

This approval has been granted subject to you complying with the requirements for *Monitoring of Progress, Reporting of Adverse Events, and Variations to the Approved Protocol* as detailed below.

PLEASE NOTE:

In the case where the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University's HREC.

• *Monitoring of Progress*

Phase 1 – Stage 1: Survey Recruitment Flyer

Elisa Choudery - School of Humanities and Social Sciences
Faculty of Education and Arts
The University of Newcastle
Callaghan NSW 2830
Elisa.choudery@uon.edu.au

Working with people with dementia and their carers

– Speech and Language Pathologists’ experiences and perceptions

We are seeking **Australian Speech-Language pathologists** who work with adults (over 18 years) who have dementia in any clinical setting.

You are invited to complete a short survey investigating the clinical practice of Speech-Language Pathologists with adults with dementia and their carers. The results will lead to further in-depth research of clinical practices with key stakeholder groups.

Please note, clinicians who DO NOT work with people with dementia or DO NOT work in Australia, you are not eligible to complete the survey.

The survey should take about 15 minutes to complete.

Survey URL <http://limesurvey.newcastle.edu.au/index.php/286799?lang=en>

Twitter: @EChoudery

Thank you!

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval number H-2019-0073. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research & Innovation Services, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email Human-Ethics@newcastle.edu.au.

**RESEARCH
STUDY**

www.newcastle.edu.au

Phase 1 – Stage 1: Recruitment/Survey Distribution

Dear _____

I am seeking to distribute an online survey to your Speech-Language Pathologist members, investigating experiences and perceptions of working with people with dementia and their carers. This research has been approved by the University of Newcastle Human Research Ethics Committee (Approval No. H-2019-0073). I have attached a copy of the survey questions and Participant Information Statement to be reviewed for your approval. Your members will be able to access each of these documents electronically using the link in the information below.

The survey contains 27 questions and will take about 10 minutes to complete. Below is the recruitment information to be used in advertising this research to you members when posting to online pages or in emails.

Below is the recruitment information to be used in advertising this research to your members when posting to online pages or in emails.

Survey link: <http://limesurvey.newcastle.edu.au/index.php/286799?lang=en>

If more information is required regarding this research project, please contact me via email at Elisa.Choudery@uon.edu.au

Thank you very much for your time and cooperation.

Participant Information Statement



Dr Elizabeth Spencer
School of Humanities and Social Sciences
Faculty of Education and Arts
The University of Newcastle, Callaghan NSW 2308
Ph: (612) 4921 5161
Elizabeth.Spencer@newcastle.edu.au

Information Statement for the Research Project:

Working with people with dementia and their carers – Speech and Language Pathologists' experiences and perceptions

Document 09/04/2019

You are invited to participate in the research project identified above which is being conducted by Elisa Choudery (student researcher), Dr Elizabeth Spencer (primary supervisor), and Associate Professor Hewat (co-supervisor) from the School of Humanities and Social Science, The University of Newcastle, Australia. The research forms part of Elisa Choudery's studies at the University of Newcastle. You may have received this invitation through Speech Pathology Australia, through your membership to an open speech pathology special interest group, or from a colleague that thought you may have been interested in this survey.

Why is the research being done?

The purpose of the research is to investigate the current practices of speech pathologists working with people with dementia. The findings of this research will be used to guide further investigation to implement and improve speech pathology services in dementia care, and assess the need for professional guidelines, education and training to support speech pathologists to implement dementia related services.

Who can participate in the research?

You are invited to participate in this research if you are an Australian speech pathologist who is working with people with dementia, in any clinical setting. If you are

not working with people who suffer dementia or if you work not as a speech pathologist in Australia, then unfortunately you are not eligible to participate.

What would you be asked to do?

If you agree to participate, you will be asked to complete an online survey (using the attached link). You will have until the 12/06/19 to complete the survey. After this time, it will be closed to participation. You will be asked to complete 25 questions, covering five domains: I. Demographic information II. Education and further Training III. Referrals IV. Diagnostic and Intervention V. Service provision. The survey includes questions that will require you to select answers from a list of options, a likert scale and some short answer questions. You will not be asked to provide any identifying information. The survey should take about 15 minutes to complete. You may also wish to pass this information statement on to any colleagues who may be interested using the web link provided. Should you choose to do this, please ensure your colleague is aware that the researcher is responsible for this survey, and that you are only passing on the information. At the end of the survey, you will be asked if you wish to be included on a database of contacts who would like be sent information about future research conducted by the researchers and/or participate or assist with recruitment amongst your network. If you are interested in finding out more about future research, please click on the provided link which will lead you to a separate web page. If you agree to have your details added to the database, you need to provide your name and your email address. Please note, your consent for the database registration is completely voluntary and you may refuse to consent to that. Furthermore, you have the option to be removed from that database at any time.

What choice do you have?

Participation in this research is entirely your choice. As the survey is completely anonymous, your decision to participate will be private and will not affect any personal or professional relationships. Please note that due to the anonymous nature of the survey, you will not be able to withdraw your responses after the survey has been submitted. If you do decide to participate, you may withdraw from the project at any time prior to submitting your completed survey. Any incomplete surveys will not be included In the research. You MUST press SUBMIT for responses to be included in this research.

At the end of the survey, you will also be asked if you would like be sent information about future research conducted by the researchers and/or participate or assist with recruitment amongst your network. The consent is entirely your choice and you have the option to refuse your prior consent at any time without any disadvantages or consequences. If you are interested, you have to click on a separate link which will be linked to an additional page where you can provide your contact details (name and email) to be listed on a secure database. This will ensure that there is no connection between the anonymous questionnaire and your personal details.

How much time will it take?

The questionnaires take about 15 minutes to complete.

What are the risks and benefits of participating?

While there may be no direct benefit to you should you choose to participate in this research, you will have the opportunity to share your views on working with people with dementia, reflect on your personal experience and views, and in the future, help improve the service offered by speech pathologists to their clients with dementia. Though it is unlikely, reflection on your clinical practice may cause some anxiety. Should this occur you may decide to exit the survey at any time.

How will your privacy be protected?

Information that you provide while completing this survey will be anonymous. Anonymous responses will be guaranteed by excluding all identifying respondent information. At the end of the survey, you will be asked if you would like to be sent more information about further research. If so, you will be asked to provide any identifying information. This information will not be linked to the information you will provide in the survey and will be asked via a separate weblink. Both surveys will be administered through the online survey management site "LimeSurvey". This online survey tool is designed to allow anonymous data collection. For more information, please read the LimeSurvey privacy policy:

<https://www.limesurvey.org/policies/privacypolicy>

Anonymous survey responses will be exported to an Excel file and stored in a password-protected file on the student researcher's password-locked computer in the Student Investigator's office. Only the researchers involved in this study will have access to this file. Once the study is completed, the file will be stored on a secure, password protected electronic storage system provided by the University. The data will be stored for a minimum of 5 years after project completion, as per University research policy.

If you register your interest in being contacted about further research in this area, your name and contact details will be stored separate and will be accessible by the chief investigators and the student researcher for a period of four years. It will then be disposed of securely by permanent erasure of the electronic document.

How will the information collected be used?

The collected data will contribute towards Elisa Choudery's research and will be presented in academic publications and conferences. Non-identifiable data may also be shared with other parties to encourage scientific scrutiny and to contribute to further research and public knowledge, or as required by law. Individual participants cannot be identified in any reports arising from the project due to the anonymous nature of responses, although individual anonymous responses may be quoted. A summary of

research outcomes will be available in late June and can be accessed by emailing Elisa Choudery (see email below).

What do you need to do to participate?

If you would like to participate, please complete and submit the anonymous questionnaire. Please read this Information Statement and be sure you understand its contents before you consent to participate. You will need to indicate your consent at the end of this document by answering the 'consent to participate' question. Should you consent, you will be redirected to the survey questions.

If you register your interest in being contacted about further research, you will be contacted via email in the future with further information.

If there is anything you do not understand, or you have questions, please contact the Project Supervisor, Elizabeth Spencer (see email below).

Further information

If you would like further information please contact Project Supervisor: Dr Elizabeth Spencer at Elizabeth.Spencer@newcastle.edu.au; or Student researcher: Elisa Choudery at Elisa.Choudery@uon.edu.au. PLEASE NOTE: If you received this survey information from a colleague, DO NOT contact that colleague with questions or concerns regarding this research. Please contact the researcher or the University of Newcastle Human Research Ethics Committee using the details provided in this information statement.

Thank you for considering this invitation.

Dr Elizabeth Spencer

Dr Sally Hewat

Elisa Choudery

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval number H-2019-0073. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Services, NIER Precinct, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email Human-Ethics@newcastle.edu.au.

Phase 1 – Stage 1: Survey Questions

Working with people with dementia and their carers – Speech and Language Pathologists' experiences and perceptions

Note: These questions were uploaded on LimeSurvey for completion by participants

I. Demographic information

1. What is your current employment status?

- ☐ Full time
- ☐ Part time
- ☐ Casual
- ☐ Fixed term contract(s)
- ☐ Other (please specify)_____

2. How many years (full time equivalent) have you been working as a speech pathologist?

- ☐ Less than 1 year
- ☐ 1–5 years
- ☐ 6–10 years
- ☐ 11–15 years
- ☐ More than 15 years

3. Which settings do you work in? (tick all that apply)

- ☐ Private practice
- ☐ Public hospital
- ☐ Private hospital
- ☐ Inpatient Rehabilitation
- ☐ Outpatient Rehabilitation
- ☐ Community Health
- ☐ Disability Service
- ☐ Residential Aged Care
- ☐ University Clinic
- ☐ Community Health Care centre
- ☐ Other:_____

4. How large is the speech pathology team you work with?

- ☐ I am a sole practitioner
- ☐ Small team (less than 5 people)
- ☐ Large team (more than 5 people)

5. In which state do you work?

- ☐ New South Wales
- ☐ Victoria
- ☐ Queensland
- ☐ Western Australia
- ☐ South Australia
- ☐ Tasmania
- ☐ Northern Territory
- ☐ ACT

II. Education and further training

6. Have you ever had additional training or professional development in the field of dementia after completing your Speech Pathology degree?

- ☐ Yes
- ☐ No (skip to question 11)

7. What kind of training have you undertaken? (Tick all that apply)

- ☐ Postgraduate studies
- ☐ Seminar
- ☐ Conference
- ☐ Congress
- ☐ Workshop
- ☐ Other: _____

8. Was the training specific to speech pathology?

- ☐ Yes
- ☐ No, just general information about dementia
- ☐ No, specific to another area of dementia management (e.g. palliative care/providing carer education). Please specify:

9. Which types of dementia were covered in your training? (Tick all that apply)

- ☐ Overview of dementia only
- ☐ Alzheimer's disease
- ☐ Vascular dementia
- ☐ Dementia with Lewy bodies
- ☐ Frontotemporal dementia (primary progressive aphasia)

10. Did you get much practical knowledge out of the training?

- ☐ Yes
- ☐ No
- ☐ Not sure

III. Referrals

11. How do you usually receive referrals? (tick all that apply)

- ☐ General Practitioner
- ☐ Neurologist
- ☐ Neuropsychologist
- ☐ Dementia care advocacy groups
- ☐ Nursing staff
- ☐ Other allied health professional
- ☐ self-referral
- ☐ family referral
- ☐ I am not sure

12. Have the referral numbers of people with dementia in your workplace or practice changed over the last 3- 5 years? Please indicate your own experience on the scale below.

Decreased _____ Unchanged _____ Increased

☐ N/A

Comment: _____

13. When you receive a referral to assess a person with dementia or suspected dementia, what information do you typically receive from the referring agent?

(Tick all that apply)

- ☐ Full medical report (e.g. mental and physical state)
- ☐ MRI or imaging information or report on imaging

- ☐ Aged care assessment
- ☐ Cognitive screening and assessment
- ☐ Other (e.g. no information at all): _____
- ☐ Comment: _____

14. In which stage of disease do you see individuals with dementia?

Early stage (symptoms can be unnoticed, they look like the normal aging process)

Never - Rarely - Sometimes - Most of the time - Always

☐ N/A

Comment:

Intermediate stage (clear and specific symptoms, difficulty to perform daily activities independently)

Never – Rarely - Sometimes - Most of the time - Always

☐ N/A

Comment:

Late stage (dependency and inactivity, severe memory loss and clear physical deterioration)

Never – Rarely - Sometimes - Most of the time - Always

☐ N/A

Comment:

15. What are the main reasons identified for the referrals to Speech and Language Pathology? (Tick all that apply)

- ☐ Language disorders
- ☐ Speech disorders
- ☐ Reduced intelligibility
- ☐ Swallowing difficulties
- ☐ Voice disorders
- ☐ Difficulty in the breathing control
- ☐ Cognitive issues identified by the individual with dementia (e.g. memory difficulties, word finding difficulties)
- ☐ Problems identified by the carers or family members
- ☐ Other: _____
- ☐ N/A

IV. Diagnostic and intervention

16. What is your role when assessing adults with dementia? (Tick all that apply)

- ☐ Assessment to contribute to the early dementia diagnosis (asked by a different health professional)
- ☐ Assessment of cognitive-communication abilities
- ☐ Language assessment
- ☐ Speech assessment
- ☐ Swallowing and feeding assessment
- ☐ Voice assessment
- ☐ Communication skills intervention
- ☐ Language intervention
- ☐ Speech intervention
- ☐ Intervention for feeding and swallowing process
- ☐ Voice intervention
- ☐ Counselling to the individual with dementia or for carers and family members
- ☐ Support of other health professionals
- ☐ Education on Speech Pathology and dementia
- ☐ I am not sure
- ☐ Other (Please comment): _____

17. How many clients do you assess and/or treat with dementia on average per calendar year approximately?

- ☐ Less than 5
- ☐ 5–10
- ☐ 10–15
- ☐ More than 15
- ☐ N/A
- ☐ Not sure

18. Please indicate the focus of your therapy:

Swallowing and feeding assessment

Never – Rarely - Sometimes - Most of the time - Always

☐ N/A

Comment:

Swallowing and feeding intervention

Never – Rarely – Sometimes - Most of the time -Always

☐ N/A

Comment:

Communication assessment

Never – Rarely – Sometimes - Most of the time - Always

☐ N/A

Comment:

Communication intervention

Never - Rarely – Sometimes - Most of the time - Always

☐ N/A

Comment:

19. Would you describe your approach to goal setting as (tick all that apply):

☐ Traditional (minimize difficulties and improve the affected abilities)

☐ Functional (minimize individual's limitation in daily activities)

☐ Social (minimize barriers in the individual's participation in the community)

☐ N/A

☐ Not sure

20. Which type of intervention do you provide most frequently?

☐ Direct Intervention (with the person with dementia)

☐ Indirect Intervention (with the carers, other health professional and family members)

☐ Group intervention for people with dementia

☐ Group intervention for people with dementia and their carer(s)

☐ N/A

☐ Not sure

21. How would you rate your confidence level in working with people with dementia?

☐ poor

☐ fair

☐ good

☐ very good

☐ excellent

V. Service provision

22. Do you provide services to people with dementia as part of a team?

- ☐ Yes, in a multidisciplinary team/transdisciplinary team
- ☐ Yes, in a Speech pathology team
- ☐ Yes, with medical team guidance
- ☐ No, sole practitioner only

23. If you provide services to people with dementia as part of a team, who else is typically involved in that team? (Tick all that apply)

- ☐ Carer
- ☐ Nurses
- ☐ Case Manager
- ☐ Social Worker
- ☐ Physiotherapists
- ☐ Occupational Therapists
- ☐ Diversional and Recreation Therapists
- ☐ Dietitian
- ☐ Physician
- ☐ Psychologist
- ☐ Medical specialist (Neurologist, Geriatrician)
- ☐ Other: _____

24. What other services do you provide for people with dementia?

Case management

Never – Rarely – Sometimes - Most of the time - Always

Education (training for students, families and other health professionals)

Never – Rarely – Sometimes - Most of the time - Always

Advocacy (regarding the needs and rights of the individual with dementia)

Never – Rarely – Sometimes - Most of the time - Always

Research

Never – Rarely – Sometimes - Most of the time – Always

25. Is information available to support speech pathologists in working with people with dementia and their carer?

☐ Yes

☐ No

☐ Unsure

26. If yes, what kind of information do you use? Please describe.

27. Is there anything you would like to add?

Thank you for participating.

This research forms part of a larger body of research being undertaken by Elisa Choudery, student researcher at the University of Newcastle. Based on the results of this survey we will be developing further studies investigating stakeholders' views and perceptions of working with people with dementia and their needs. Therefore we are seeking to establish a database of contacts if you would like be sent information about future research conducted by the researchers and/or participate or assist with recruitment amongst your network. If you are interested in participating in receiving information about future research, please click on the following link which will ask you for your name and email address for future contact. Please note, there won't be any connections to your given answers in the survey as your personal details submitted via the link below will stored separately from the anonymous survey responses.

[LINK]

Phase 1 – Stage 1: Database Registration

o I would like having consent my name and email address to a database for further research and be sent information about future studies. I am aware that the database will retain my identifying information for 5 years and will be disposed of securely by permanent erasure of the electronic document.

o You can elect to refuse to be in the database at any time by emailing the Chief investigator at any time: Dr Elizabeth Spencer Elizabeth.Spencer@newcastle.edu.au

Name: _____

Email: _____

o Please note that consenting to be on the database does not imply consent to future research. For participation in any future research conducted by the investigators, detailed and informed consent about the research project will be provided and sought.

Thank you for providing your details.

Appendix C:

Phase 1 – Stage 2: Interview Material

Phase 1 – Stage 2: Ethics Approval

HUMAN RESEARCH ETHICS COMMITTEE



Notification of Expedited Approval

To Chief Investigator or Project Supervisor:	Doctor Liz Spencer
Cc Co-investigators / Research Students:	Mrs Elisa Choudery Associate Professor Sally Hewat
Re Protocol:	Exploring Speech Pathologists' experiences of working with people with dementia
Date:	18-Dec-2019
Reference No:	H-2019-0389

Thank you for your **Response to Conditional Approval (minor amendments)** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under **Expedited** review by the Ethics Administrator.

We are pleased to advise that the decision on your submission is **Approved** effective **18-Dec-2019**.

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Approval will remain valid subject to the submission, and satisfactory assessment, of annual progress reports. *If the approval of an External HREC has been "noted" the approval period is as determined by that HREC.*

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request. Your approval number is **H-2019-0389**.

If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants. You may then proceed with the research.

Feedback to researchers:

Withdrawal from the study and withdrawal of data

This was a matter raised in the previous correspondence and has not been addressed.

Please add a statement regarding the withdrawal of data on the information statement. Please consider that 2 weeks after data collection may not be feasible for those wishing to review the transcripts (as cited in the consent form).

The revised document must be submitted prior to commencing project

Conditions of Approval

This approval has been granted subject to you complying with the requirements for *Monitoring of Progress, Reporting of Adverse Events, and Variations to the Approved Protocol as detailed below*.

Phase 1 – Stage 2: Research Flyer

Elisa Choudery
School of Humanities and Social Sciences
Faculty of Education and Arts
The University of Newcastle
Callaghan NSW 2830 Elisa.choudery@uon.edu.au



Exploring Speech Pathologists' experiences of working with people with dementia

We are seeking **Speech-Language pathologists** in any clinical setting in Australia who work with adults who have dementia (12 months' work experience needed within the last 3 years).

Participants will be asked to share their experiences in an **interview** (held online via "zoom") to help us to investigate the clinical practice of SpeechLanguage Pathologists with adults with dementia and their carers. The results will lead to further in-depth knowledge of areas of need and resources for speech pathologists working in this changing area of practice.

Interested?

Please contact Elisa Choudery via Email:
Elisa.choudery@uon.edu.au

Thank you!

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval number **H2019-0389** Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research & Innovation Services, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email HumanEthics@newcastle.edu.au.

RESEARCH STUDY

www.newcastle.edu.au

Phase 1 – Stage 2: Email Invitation

Dear colleague,

We are looking for speech pathologists who work with people with dementia to participate in semi-structured interviews (held via “zoom”) to increase our understanding of Speech Pathologists’ experience when working with people with dementia.

This research has been approved by the University of Newcastle Human Research Ethics Committee (Approval No. H-2019-0389).

If you would like to participate, we will provide the participant information statement and consent form. The signed consent form can be returned via email or post to the student researcher. You will then be contacted via email to arrange a time to participate in the interview of a time that’s convenient to you. If you would like more information regarding this research project, please contact me via email at Elisa.Choudery@uon.edu.au

Please feel free to share this invitation to participate in the research within your network as we are seeking to interview 12 participants.

Thank you.

Kind regards,

Elisa Choudery

Participant Information Statement



Dr Elizabeth Spencer
School of Humanities and Social Sciences
Faculty of Education and Arts
The University of Newcastle, Callaghan NSW 2308
Ph: (612) 4921 5161
Liz.Spencer@newcastle.edu.au

Information Statement for the Research Project: Exploring Speech Pathologists' experiences of working with people with dementia

Document 20/01/20

You are invited to participate in the research project identified above which is being conducted by Elisa Choudery (student researcher), Dr Elizabeth Spencer (primary supervisor), and Associate Professor Hewat (co-supervisor) from the School of Humanities and Social Science, The University of Newcastle, Australia. The research forms part of Elisa Choudery's PhD at the University of Newcastle. You may have received this invitation via email, through your membership to an open speech pathology special interest group, or from a colleague that thought you may have been interested in participating in this study.

Why is the research being done?

The purpose of the research is to investigate the current practices of speech pathologists working with people with dementia. The findings of this research will be used to guide further investigation to implement and improve speech pathology services in dementia care, and assess the need for professional guidelines, education and training to support speech pathologists to implement dementia related services.

Who can participate in the research?

You are invited to participate in this research if you are a speech pathologist who has at least 12 months experience (within the last 3 years) in working with people with dementia in any clinical setting. If you are not working with people who have dementia or if you work not as a speech pathologist in Australia, then unfortunately you are not eligible to participate.

What would you be asked to do?

If you are interested in participating in this study, you will need to return the signed consent form via email to the student researcher. Following receiving your informed consent, you will be invited. If you agree to participate, you will be asked to participate in an interview for approximately 1 hour and asked questions about your experiences and perceptions in working

with people with dementia. Interviews will be held and recorded via “zoom”, an online communication tool. You will need a computer (Windows or Mac) or a mobile device (Android or IOS) with speakers and a microphone. If you decide to participate, you will access “zoom” via an invitation link provided previously in an email by the researcher. During the interview process, you will be asked to NOT identify yourself by name during the recording, nor provide any names or other private details of the clients or colleagues discussed in the interview.

You may also wish to pass this information statement on to any colleagues who may be interested in being interviewed. Should you choose to do this, please ensure your colleague is aware that the researcher is responsible for this research, and that you are only passing on the information.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you.

If you decide to participate, you can review the interview up to 2 weeks after completing the interview and withdraw from the project up to four weeks without disadvantages and consequences and do not have to give any reason for withdrawing.

How much time will it take?

The interview will take up to 1 hour.

What are the risks and benefits of participating?

While there may be no direct benefit to you should you choose to participate in this research, you will have the opportunity to share your views on working with people with dementia, reflect on your personal experience and views, and in the future, help improve the service offered by speech pathologists to their clients with dementia. Though it is unlikely, reflection on your clinical practice may cause some anxiety. Should this occur you may decide to stop the interview at any time. If you require additional support, please contact the following services: lifeline.com or call 13 11 14

How will your privacy be protected?

Data will be retained securely for a minimum period of 7 years from completion of the research and managed/stored in accordance with the University’s Research Data and Materials Management Guideline (see <https://policies.newcastle.edu.au/document/view-current.php?id=72>) or any successor Guideline, and applicable University of Newcastle policy provisions (as amended from time to time).

You will be allocated a code and a pseudonym and any identifying information disclosed during the interview process will be edited and deleted by the researcher/s accordingly during the transcription process.

Furthermore, you will have the opportunity to consent to having your individual transcription emailed to you by the student investigator for the ‘member checking’ process where you can read over, amend, or delete any sections of your own transcript.

How will the information collected be used?

The results will be reported in the PhD candidate’s thesis. The results of this research project will also be reported in a relevant peer-reviewed journal and will be submitted for presentation at national and international conferences of speech pathologists and dementia.

You have the opportunity to indicate whether you would like to receive a copy of the summary of results of this research following peer review (peer review publication, thesis or presentation).

Non-identifiable data may also be shared with other parties to encourage scientific scrutiny and to contribute to further research and public knowledge, or as required by law. Individual participants cannot be identified in any reports arising from the project due to the anonymous nature of responses, although individual anonymous responses may be quoted. A summary of research outcomes will be available in late June 2020 and can be accessed by emailing Elisa Choudery (see email below).

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, contact the researcher.

You will need to indicate your consent at the end of this document by reading and answering the 'consent to participate' questions. Should you consent, the student researcher will contact you.

If there is anything you do not understand, or you have questions, please contact the Project Supervisor, Elizabeth Spencer or the student researcher, Elisa Choudery.

Further information

If you would like further information please contact Project Supervisor: Dr Elizabeth Spencer at Liz.Spencer@newcastle.edu.au; or Student researcher: Elisa Choudery at Elisa.Choudery@uon.edu.au. PLEASE NOTE: If you received this information from a colleague, DO NOT contact that colleague with questions or concerns regarding this research. Please contact the researcher or the University of Newcastle Human Research Ethics Committee using the details provided in this information statement.

Thank you for considering this invitation.

Dr Elizabeth Spencer

Associate Professor Sally Hewat

Elisa Choudery

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. H-2019-0389.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research & Innovation Services, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email Human-Ethics@newcastle.edu.au.



Dr Elizabeth Spencer
School of Humanities and Social Sciences
Faculty of Education and Arts
The University of Newcastle, Callaghan NSW 2308
Ph: (612) 4921 5161
Liz.Spencer@newcastle.edu.au

Consent Form for the interview:

Exploring Speech Pathologists' experiences of working with people with dementia (Approval No. H-2019-0389)

Elisa Choudery, Associate Professor Sally Hewat and Dr Elizabeth Spencer

Date: 20/01/2020

I agree to participate in the above research project and give my consent freely. I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained.

I understand I can withdraw from the project up to two weeks after completing the interview and do not have to give any reason for withdrawing.

I consent to: being contacted to participate and arrange a time and participating in a one-on-one interview with the student researcher via "zoom", a secure telecommunication method (which will be audio recorded), and have some discussions relating to my experiences in working with people with dementia and their carers.

I agree that I will not identify myself by name during this recording, nor provide any names or other private details of the clients or colleagues discussed in this interview.

I am aware that if any identifying information is disclosed during the interview process, the researcher/s will edit and delete this accordingly during the transcription process I agree to being quoted or paraphrased (select all that apply):

- ☐ I understand that my interview will be transcribed verbatim and I consent to being quoted or paraphrased
- ☐ I understand that my interview will be transcribed verbatim and I do not consent to be quoted or paraphrased
- ☐ After completion of the interview, my audio sample will be transcribed by the student investigator. I consent to having my transcription emailed to me by the Student Investigator for the 'member

checking' process where I can read over, amend, or delete any sections of my own transcript as I see fit

☐ I do not consent to the process of 'member checking' as described above. I understand that my personal information will remain confidential to the researchers and that no data will be stored with any identifying information. I have had the opportunity to have questions answered to my satisfaction.

Please read through the above information and retain a copy of the consent form. Your consent to participate in this study will be audio recorded at the beginning of the interview.

Please sign and email back to Student Investigator (elisa.choudery@uon.edu.au) if you wish to participate in this research project. If you wish to return this consent form via post, please refer to the address above.

Print Name: _____

Email: _____

Signature: _____ **Date:** _____

If you do not wish to participate in this research project, please discard the email request and this consent template.

☐ I am interested in receiving a summary of results of the study following completion of the analysis.

Please email to this address: _____

Phase 1 – Stage 2: Interview Guide

1. Tell me about your experience working with people with dementia and their carers.

Probes (if required)

- Overall, what do you see as the benefits of working with this clinical population? And what are the challenges?
 - In what Stage of the disease do you get referrals?
 - What is usually the main focus of the intervention? Is it rather dysphagia than communication?
 - Do you work as part of a multidisciplinary team? Do you think that's effective or would you like the relationship with other allied health professionals?
 - Clinicians experience, training etc.
-

2. What do you think is important to providing effective service when working with people with dementia and their carers? Why do you think these aspects are important?

Probes (if required)

- Referrals
 - Assessment
 - Efficient treatment
 - Service delivery methods
 - Any other observations?
 - Working with other health professionals
-

3. How do you identify your typical aims/goals for intervention?

Probes (if required)

- Client/Care giver desires
 - Environmental requirements
 - Compliance
 - Guidelines
-

4. What are some of the challenges you see in providing services for people with dementia?

Probes (if required)

- How do these challenges arise and in what contexts?
 - Why do you think they happen/occur?
 - What do you think could prevent these challenges?
 - Communication
 - Therapy
 - Resources
-

5. *What resources do you use when you work with people with dementia and their carers?*

Probes (if required)

- Why do you use this resources?
 - How do you access them?
 - Do you feel such resources are helpful? Why?
 - Guidelines
 - Literature/Books
 - Expert opinion
-

6. *In an ideal world, what do you think our role in working with people with dementia would look like? Why do you think this?*

Probes (If required):

- Interdisciplinary support
 - Early assessment and intervention
 - Guidance through policies and guidelines
 - More resources
-

7. *Is there anything else you would like to add?*

Appendix D:

Phase 2 – Focus Group Material

Phase 2 – Ethics Approval

HUMAN RESEARCH ETHICS COMMITTEE



Notification of Expedited Approval

To Chief Investigator or Project Supervisor:	Doctor Liz Spencer
Cc Co-investigators / Research Students:	Mrs Elisa Choudery Associate Professor Sally Hewat
Re Protocol:	Development of a web-based resource for SLP working with people with dementia
Date:	26-May-2021
Reference No:	H-2021-0145

Thank you for your **Response to Conditional Approval (minor amendments)** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under **Negligible Risk Research Expedited** review by the Ethics Administrator.

We are pleased to advise that the decision on your submission is **Approved** effective **26-May-2021**.

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the National Statement on Ethical Conduct in Human Research, 2007, and the requirements within this University relating to human research.

Approval will remain valid subject to the submission, and satisfactory assessment, of annual progress reports. *If the approval of an External HREC has been "noted" the approval period is as determined by that HREC.*

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request. Your approval number is **H-2021-0145**.

If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants You may then proceed with the research.

Conditions of Approval

This approval has been granted subject to you complying with the requirements for *Monitoring of Progress*, *Reporting of Adverse Events*, and *Variations to the Approved Protocol* as detailed below.

PLEASE NOTE:

In the case where the HREC has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that

Phase 2 – Ideation: Focus Group

Dr Elizabeth Spencer

Head of Speech Pathology

College of Human and Social Futures

The University of Newcastle, Callaghan NSW 2308

Ph: (612) 4921 5161 Liz.Spencer@newcastle.edu.au



Development of a resource guide for speech pathologists working with people with dementia

We are seeking **Speech Pathologists** in any clinical setting in Australia who work with adults who have dementia (any level of experience).

Participants will be asked to share their ideas and thoughts as part of a **focus group discussion and/or in a brief online questionnaire** in order to design and evaluate a prototype resource. Focus group participants will receive a \$20 eGift card for their time and contribution.

Interested?

Please contact Elisa Choudery via Email:
Elisa.choudery@uon.edu.au

Thank you!

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval number **H2021-0145**. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research & Innovation Services, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 49216333, email HumanEthics@newcastle.edu.au.

**RESEARCH
STUDY**

www.newcastle.edu.au

Phase 2 – Ideation: Email Invitation

Dear Colleague,

We are recruiting speech pathologists who work with people with dementia in any setting and any level of experience, who are interested in participating in a study (ethics approval number H-2021-0145).

As part of the overall research project, we are seeking to design a web-based resource specifically for speech pathologists who work with people with dementia.

There are **2 phases** in this project:

Initially, we would like to hold a focus group in June 2021 to discuss your thoughts and ideas to further develop a prototype of the resource guide. After that, you will then have the opportunity to give specific feedback on the designed prototype on a brief online survey.

You can decide to participate in both phases of the project or only in one.

The focus group will be held online via zoom, participants will be reimbursed with a \$20 gift card.

Please read through the attached participant information statement with more details about the project. To register your interest and consenting in the project, please click on the following link:

<https://forms.gle/zBz11rNV5snMg5K59>

Please feel free to share this invitation to participate in the research within your network or within your special interest group.

If you have any further questions, feel free to contact me (Elisa.Choudery@uon.edu.au).

Thank you.

Kind regards,

Elisa Choudery

Phase 2 – Ideation: Information Statement and Consent Form

Participant Information Statement Dr Elizabeth Spencer Head of Speech Pathology College of Human and Social Futures The University of Newcastle, Callaghan NSW 2308 Ph: (612) 4921 5161 Liz.Spencer@newcastle.edu.au 

Information Statement for the Research Project:

Development of a web-based resource for speech pathologists working with people with dementia

Dated: 27/05/2021

You are invited to participate in the research project identified above which is being conducted by Elisa Choudery (student researcher), Dr Elizabeth Spencer (primary supervisor), and Associate Professor Hewat (co-supervisor) from the School of Humanities and Social Science,

The University of Newcastle, Australia. The research forms part of Elisa Choudery's PhD at the University of Newcastle. You may have received this invitation via email, through your membership to an open speech pathology special interest group, or from a colleague that thought you may have been interested in participating in this study.

Why is the research being done?

The purpose of the research is to develop a clinically useful web resource for speech pathologists working with people with dementia. The findings of this research will be used to develop a prototype resource in order to support speech pathologists to implement evidence based dementia related services.

Who can participate in the research?

You are invited to participate in this research if you are a speech pathologist working with people with dementia in any clinical setting (any level of experience). If you are not working with people who have dementia or if you are not working in Australia, then unfortunately you are not eligible to participate.

What would you be asked to do?

If you are interested in participating in this study, you will need to submit your consent through the provided link at the end of this document. Following receiving your informed consent, the student researcher will contact you. There are **two phases** in this project and if you agree to participate, you will be asked to participate in **1)** an online focus group discussion (up to 60 minutes) and asked to discuss your ideas and thoughts regarding a prototype for a web-based resource. In Phase **2)**, you will be asked to answer a brief survey once the prototype has been reviewed (8 weeks after the focus group discussion). You can decide if you would like to participate in only one phase or in both. The focus group will be audio and video recorded, and you will be asked to NOT identify yourself by name during the recording, nor provide any names or other private details of the clients or colleagues discussed in the focus group. It will be your choice if you would like to transmit your video via webcam and you can choose to switch that function off. The online survey will be anonymous and once you submitted your answers you are not able to withdraw.

In case you are unable to participate in the focus group, you will be given the opportunity to share your thoughts and views briefly as written feedback.

For participating in the focus group, you will need a computer (Windows or Mac) or a mobile device (Android or IOS) with speakers and a microphone. If you decide to participate, you will access “zoom” via an invitation link for the focus group provided previously in an email by the researcher. For the online survey, the link will be provided via email.

You may also wish to pass this information statement on to any colleagues who may be interested in being involved. Should you choose to do this, please ensure your colleague is aware that the researcher is responsible for this research, and that you are only passing on the information.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you.

If you decide to participate in the focus group discussion (phase 1), you will be able to read the verbatim transcription up to 2 weeks after completing the focus group and withdraw from the project up to four weeks. There won't be any disadvantages and consequences and do not have to give any reason for withdrawing.

How much time will it take?

The focus group discussion will take up to 60 minutes.

The prototype review and the brief survey will take around 45-60 minutes.

What are the risks and benefits of participating?

While there may be no direct benefit to you should you choose to participate in this research, you will have the opportunity to share your views, ideas and thoughts in order to develop a resource prototype of a website. Though it is unlikely, reflection on your clinical practice may cause some anxiety. Should this occur you may decide to stop participating at any time. If you require additional support, please contact the following services: lifeline.com or call 13 11 14

How will your privacy be protected?

Data will be retained securely for a minimum period of 7 years from completion of the research and managed/stored in accordance with the University's Research Data and Materials Management Guideline (see <https://policies.newcastle.edu.au/document/view-current.php?id=72>) or any successor Guideline, and applicable University of Newcastle policy provisions (as amended from time to time).

Focus Group:

You will be allocated a code and a pseudonym and any identifying information disclosed during the focus group project will be edited and deleted by the researcher/s during the transcription process. It is not mandatory to turn your camera on during the focus group and it is entirely your choice if you would like to share yourself via video.

Furthermore, you will have the opportunity to read the transcript as part of the 'member checking' process where you can read over, amend, or delete any sections of your own transcript.

The focus group will be conducted via zoom, a cloud-based video conferencing tool to conduct live chats and record video and audio. Sessions can be viewed later by the assigned host (student researcher). For more information regarding privacy policy see <https://zoom.us/privacy>.

Survey:

Survey responses will be collected via google forms, a survey administration software offered by Google. Your answers will be anonymous and your ID address will not be tracked. Submitted answers will be stored on google drive on the password protected account of the student researcher. For more information regarding the privacy policy see <https://policies.google.com/privacy>.

How will the information collected be used?

The main use of information will be to inform the creation of the webpage. Furthermore, results will be reported in the PhD candidate's thesis. The results of this research project may also be reported in a relevant peer-reviewed journal and will be submitted for presentation at national and international conferences of speech pathologists and dementia.

You have the opportunity to indicate whether you would like to receive a copy of the summary of results of this research following peer review (peer review publication, thesis or presentation). Non-identifiable data may also be shared with other parties to encourage scientific scrutiny and to contribute to further research and public knowledge, or as required by law. Individual participants cannot be identified in any reports arising from the project due to the anonymous nature of responses, although individual anonymous responses may be quoted. A summary of research outcomes will be available in late 2021 and can be accessed by emailing Elisa Choudery (see email below).

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents before you consent to participate.

You will also be asked to indicate your availability if you decide for the focus group. If there is anything you do not understand, or you have questions, please contact the Project Supervisor, Elizabeth Spencer or the student researcher, Elisa Choudery.

If you decide to participate, you can indicate your consent through the provided link:

<https://forms.gle/zBz11rNV5snMg5K59>

Further information

If you would like further information please contact Project Supervisor: Dr Elizabeth Spencer at Liz.Spencer@newcastle.edu.au;
or Student researcher: Elisa Choudery at Elisa.Choudery@uon.edu.au.

PLEASE NOTE: If you received this information from a colleague, DO NOT contact that colleague with questions or concerns regarding this research. Please contact the researcher or the University of Newcastle Human Research Ethics Committee using the details provided in this information statement.

Thank you for considering this invitation.

Dr Elizabeth Spencer

Associate Professor Sally Hewat

Elisa Choudery

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. **H-2021-0145**. Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research & Innovation Services, The University of Newcastle,
University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email Human-Ethics@newcastle.edu.au.

Informed Consent: Focus Group & Survey

27/05/2021

Project:

Development of a web-based resource for speech pathologists working with people with dementia
--

- ☐ I agree to participate in the above research project and give my consent freely.
- ☐ I understand that the project will be conducted in **two phases** as described in the Information statement, a copy of which I have retained.
- ☐ I understand that I can choose to participate in both phases or only in one.
- ☐ I understand I can withdraw from the project up to two weeks after completing the focus group and do not have to give any reason for withdrawing.
- ☐ I consent to: being contacted to participate in a focus group discussion via “zoom”, a secure telecommunication method (which will be recorded), and have some discussions relating to my thoughts and ideas regarding a resource guide for speech pathologists.
- ☐ I consent to: being contacted to answer questions about the web-based resource in a brief survey (anonymous)
- ☐ I agree that I will not identify myself by name during the recording, nor provide any names or other private details of the clients or colleagues discussed in the focus group
- ☐ I am aware that if any identifying information is disclosed during the interview process, the researcher/s will edit and delete this accordingly during the transcription process

I agree to being quoted or paraphrased (select all that apply):

- ☐ I understand that my interview will be transcribed verbatim and I consent to being quoted or paraphrased
- ☐ I understand that my interview will be transcribed verbatim and I do not consent to be quoted or paraphrased

After completion of the interview, my audio sample will be transcribed by the student investigator.

- ☐ I consent to having my transcription emailed to me by the Student Investigator for the ‘member checking’ process where I can read over, amend, or delete any sections of my own transcript as I see fit
- ☐ I understand that my personal information will remain confidential to the researchers and that no data will be stored with any identifying information.

Gift cards: Focus Group

In recognition of contribution and time, you will be provided with a \$20 Coles or Woolworths eGift card for contributing to the **focus group**. Gift cards will be sent out electronically via email. For electronically provided gift cards, an email delivery receipt will be kept. Please note, all gift cards will have **specific conditions** set out by the provider, and you are responsible for ensuring these conditions are met. The gift card is to be used by the recipient and is not able to be exchanged for cash or sold. The researcher team takes no responsibility for lost, stolen or expired gift cards once provided to recipients.

Informed Consent: Focus Group & Survey

☐ I acknowledge that I have read and understood the above procedure

Name: _____

Email: _____

Please indicate your availability for a focus group discussion.

Date 1: 21/06/2021	6 PM AEST
Date 2: 22/06/2021	6 PM AEST
Date 3: 23/06/2021	6 PM AEST

I am interested in giving my written feedback to questions in case I am unable to take part in the focus group discussion

☐ Yes

☐ No

☐ I am aware that providing my written feedback will exclude me from receiving a gift card

☐ I am aware that focus group participants will be chosen based on their availability and by submitting this consent form I am aware that I will not automatically be a participant

☐ I would like to receive a summary of the research findings via my email account

Thank you for your submission. The researcher team will contact you soon.

Phase 2 – Ideation: Focus Group Discussion Protocol

Development of a web-based resource for Speech Pathologists working with people with dementia

12/05/2021

Introduction & Power Point Presentation

Purpose

What would you like to see on a resource guide for working with people with dementia?

What's the purpose of resources you usually use?

Can you tell us what kind of resources you usually use when you work with people with dementia? Where do you access your resources from?

(Prompts: Online, Books...) What matters to you when you look for those resources? How do you look them up?

(Prompts: Google, specific webpages)

Platform

What platforms do you use when you access these resources?

Are there specific platforms/blogs/webpages/resources in particular you are using?

What makes you choose a specific platform/blog/webpage?

Where do you access such resources from? (Prompts: Computer, Laptop, Tablet, Phone)

How should the perfect resource guide be designed? (Prompts: Blog, Webpage, App) Where would you access it from?

Content

What content should be included in a resource guide?

What area should be included in particular? (Prompts: Links, PDF downloads)

Should the resource guide also include the option for networking with other SPs?

Design

How should it be designed?

Desktop and mobile device version? Drop down lists? Search function?

Is there anything else you would like to add?

Phase 2 – Ideation: Written Feedback Form

Written Feedback

for participants unable attending the focus group

Project: Development of a web-based resource for speech pathologists working with people with dementia

This study is part of an overall research project where we initially explored experience and perceptions of SPs working with people with dementia through a survey and interviews. The majority of participants highlighted **the need for more specific resources**. The purpose of this focus group is to explore ideas, views and thoughts on helpful resources and how they should be presented best in order to support SPs working with people with dementia. We will then create a webpage that collects resources, research articles, important links to guidelines, professional development etc. At this stage, we focus on SPs only. This webpage will be a prototype and will be further improved over time.

Feel free to provide your written feedback/ideas below. Questions are not mandatory.

What would you like to see on a web-based resource for dementia?
What's the purpose of resources you usually use?
Can you tell us what kind of resources you usually use when you work with people with dementia?

Where do you access your resources from? (e.g. Online, Books...)

What matters to you when you look for those resources?

How do you look them up? (Google, specific webpages)

What platforms do you use when you access these resources?

Are there specific platforms/blogs/webpages in particular you are using?

What makes you choose a specific platform/blog/webpage?

Where do you access such resources from? (e.g. computer, laptop, tablet, phone)

How should the perfect resource guide be designed? (Blog, Webpage, App etc.)

Where would you access it from?

What content should be included in a web-based resource?

What area should be included in particular? (e.g. links, PDF downloads)

Should the resource guide also include the option for networking with other SPs?

How should it be designed?

Desktop and mobile device version? Drop down lists? Search function?

Is there anything else you would like to add?

Thank you!

Appendix E:

Phase 4 – User Feedback

Phase 4 – User Feedback: Email Invitation

Dear _____

You are receiving this email as part of the research project (Ethics approval number: H-2021-0145). We appreciate your willingness to participate.

Thanks again to those who contributed to our focus group discussion. We gained a lot of insight and based on your feedback and ideas, we were able to create a **first prototype** of a web-based resource guide for speech pathologists who work with people with dementia.

Part of the focus group discussion and analysis were the following categories: Content, Platform, Purpose, and Design.

Those main categories were adapted as areas on the webpage, including different links and downloadable resources. Feel free to test as many options as you like. You can access the webpage with your computer, smartphone or tablet in order to test its proper function.

Based on your ideas, we've also included a link to a Facebook and Twitter page with the opportunity to network with others, as well as a search function in order to find specific resources.

You can access the prototype via this link:

[LINK]

Please keep in mind that in order to complete the prototype, it is necessary to include people with dementia, their families and other allied health professionals. At this stage, we focus on the speech pathologists rolesub- only.

Once you have reviewed and tested the prototype, you can then evaluate the webpage via an online questionnaire: [LINK]

Thanks again! I sincerely appreciate your expertise and enthusiasm and I'm looking forward to receive your feedback.

Kind regards,

Elisa

Phase 4 – User Feedback: Survey Questions/Prototype Evaluation

I. Webpage Design

This section covers questions about the webpage design.

1) What device did you use to access the webpage? (Tick all that apply)

Smartphone
Tablet
Computer/Laptop

2) Was the webpage compatible with your device?

Yes
No
Not sure

Comment

3) Did the webpage load quickly?

Yes
No

4) Was the webpage viewable in different browsers?

Yes
No
N/A - Only accessed from one browser

5) Was the webpage easy to navigate?

Yes
No
Not sure

Comment

6) Did you find any spelling, grammar or punctuation mistakes on the webpage?

Yes

No

Not sure

Comment

7) Did any obtrusive pop-up windows appear?

Yes

No

Not sure

Comment

8) Did the balance of text & images suit your preferences?

Yes

No

Not sure

Comment

9) Was the design consistent throughout the webpage?

Yes

No

Not sure

Comment

10) Does the webpage design allow for easy navigation?

Yes

No

Not sure

Comment

--

11) Is the whole webpage visually appealing?

Yes

No

Not sure

Comment

--

12) How would you rate the following aspects of the webpage?

	Poor	Fair	Good	Excellent
Pictures on the webpage				
Layers for different categories				
Backgrounds on the webpage				

13) Is the font for each category on the webpage appropriate and readable?

Yes

No

Not sure

Comment

--

14) From a speech pathologists' perspective: Is the webpage design overwhelming or confusing?

**Note: At this stage the webpage is targeted at SPs only (not people with dementia/carers or families)*

Yes

No

Not sure

Comment

15) Is the use of colour and shapes on the webpage appropriate?

Yes

No

Not sure

Comment

16) Overall, is there consistency of the webpage design?

Yes

No

Not sure

Comment

II. Content

This section covers questions about the content on the webpage.

17) Please rate the following categories in terms of their usefulness for your clinical practice as a speech pathologists.

	Not at all useful	slightly useful	moderately useful	very useful	extremely useful
Tools & Intervention					
Assessment and Diagnosis					
Working with families and carers					
Networking & Interdisciplinary					
Evidence-Based Practice					
Group Page for interaction with other SPs					
Blog Section					
Link to a separate Facebook page connected to the webpage					

18) Do you think there are categories on the webpage that are NOT necessary?

Comment

19) Do you think more categories should be added to the webpage?

Yes

No

Unsure

20) If you answered YES to the question above: Do you have any recommendations for categories that should be added additionally to the webpage?

Comment

21) Did you download any of the accessible PDF documents?

Yes

No

Not sure

22) If yes, did it work properly?

Yes

No

Not sure

Comment

23) Did you click on any links provided on the webpage?

Yes

No

Not sure

24) If you answered YES to the question above: Did the link(s) you clicked on the webpage work properly?

Yes

No

Not sure

Comment

25) What content needs to be added to the categories in the future?

II. Platform & Purpose

This section asks questions about the platform and purpose of the webpage in general.

26) Based on the main site on the webpage, is the purpose and scope of the site clear?

Yes

No

Not sure

Comment

27) Once the webpage is published, why would you access it? (Tick all that apply)

Accessing information for myself

Accessing information for my clients, their families and carers

Accessing research articles

Accessing links to other resources for myself

Accessing links to other resources for my clients, their families and carers

Downloading resources for myself

Downloading resources for my clients, their families and carers

Networking/Exchange with other speech pathologists

Reading Blog posts

Other:

--

28) Please rate your agreement for the following statements:

Strongly
Disagree

Disagree

Neutral

Agree

Strongly
Agree

Provides useful
information for
myself as a speech
pathologist

Provides useful
information that I can
share with my clients
and their families

Provides easy access
to relevant research

Provides useful links
to other resources for
myself as a speech
pathologist

Provides useful links
to other resources
that I can share with
my clients and their
families

Provides useful
downloadable
resources for myself
as a speech
pathologist

Provides useful
downloadable
resources for my
clients and their
families

Provides
opportunities to
network/exchange
with other speech
pathologists

Provides
opportunities to read
updates in blog posts

29) How often would you use the webpage as a resource guide once it's public?

Once a month

A few times a month

Once a week

A few times of the week

Infrequent Use

Unsure

30) Would you sign up for a newsletter once the webpage is public?

Yes

No

Unsure

31) If you answered YES to the question above: How often would you like to receive a newsletter?

32) Would you recommend the webpage to any of your colleagues?

Yes

No

Unsure

33) Do you have further suggestions, feedback or comments?

Appendix F: Webpage Prototype

Phase 3 – Prototype Screenshots

<https://echoudery.wixsite.com/dementia>

Password: 2022Dementia

Dementia & Speech Pathology
A Resource Guide.
Prototype

Home Blog Groups More   Log In

Dementia Messages

A Resource Guide for Speech Pathologists *Prototype 1.0*

This page is a resource guide for speech pathologists who work with people with dementia and their families and carers. It is dedicated to promoting information, links and resources in order to address the needs of individuals with dementia in light of a person-centred approach.



Dementia: Disease and Symptoms

[Click Here](#)



Intervention: Approaches & Tools

[Click Here](#)



Evidence-Based Practice

[Click here](#)



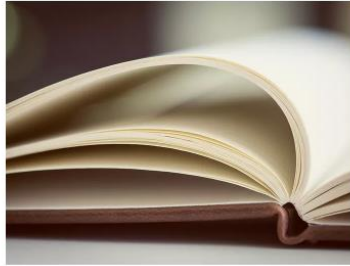
Working with families & carers

[Click here](#)



Professional Development

[Click here](#)

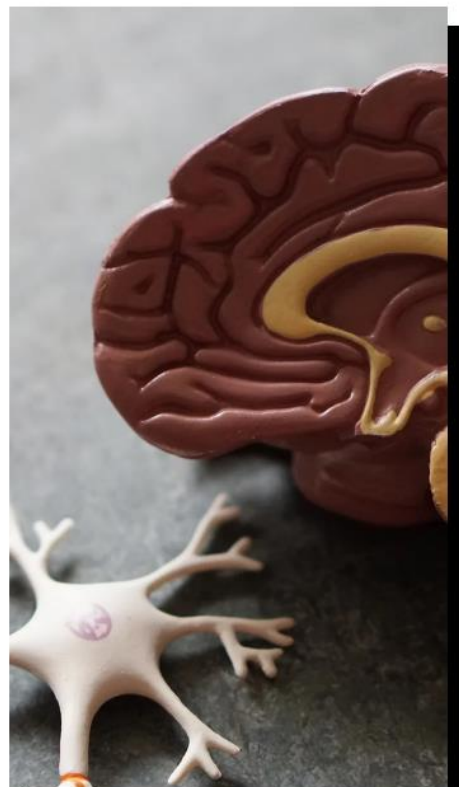


Networking & Interdisciplinarity

[Click here](#)

Dementia: Disease and Symptoms

Dementia is a general term for loss of memory, language, problem-solving and other thinking abilities that are severe enough to interfere with daily life. Click on the video below for general information.



Dementia Facts

Dementia Statistics

Around 50 million people worldwide have dementia with nearly 10 million new cases yearly. Dementia is the second leading cause of death of Australia [1][2].

[Read More](#)

Dementia affects Communication

Language and communication difficulties are a common sign among patients with dementia. Communication problems are a result of nerve cell breakdown. Dementia patients had poorer scores in areas such as comprehension and verbal expression, repetition, reading, and writing. [3]

[Read More](#)

Dementia affects Swallowing

People with dementia can develop problems with eating, drinking and their ability to swallow (Dysphagia) at any stage of their illness.

[Read More](#)

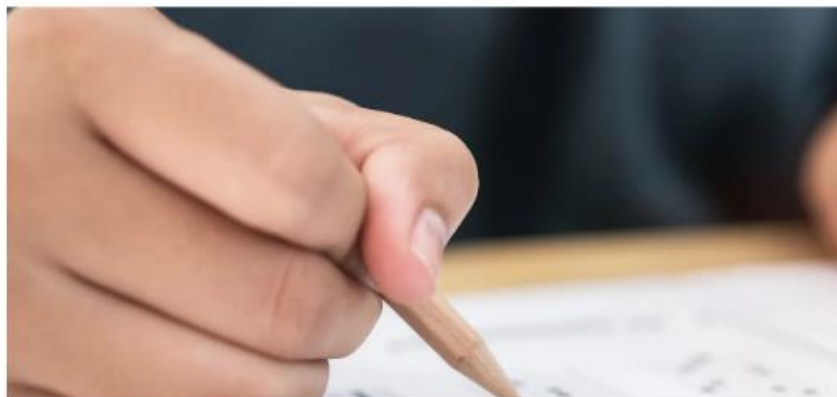
Speech Pathology & Dementia

Speech pathologists play a major role in the management of dementia. Their services include screening, assessment, diagnosis, and treatment of persons with dementia. Part of their practice is involving family members, carers, and collaboration with other allied health professionals. [4]

[Read More](#)

Intervention: Approaches & Tools

Find some helpful links and downloads on this page.



Assessment: Cognition & Communication

Find some cognitive assessment tools via this link.

<https://eatspeakthink.com/online-assessment-cognition/>

<https://www.sydney.edu.au/brain-mind/resources-for-clinicians/dementia-test.html>

Subscribe to Updates



Assessment: Swallowing

Find some swallowing assessment tools via this link:
<https://eatspeakthink.com/9-free-swallow-assessment-tools/>

Subscribe to Updates



Helpful Apps

Find some apps via these links:

<https://afscenter.org/dementia-phone-apps/>

<https://seniordirectory.com/articles/info/9-great-apps-for-people-with-dementia-or-alzheimers>

New: Ask Annie App!

Read more about the Ask Annie App

Find inspiration on these pages...



Dementia Montessori Activities

<https://www.qualityaging.com.au/dementia-montessori-activities/>



Memory and Orientation Books

<https://speechymusings.com/2013/09/24/memory-and-orientation-books/>



Dementia Activities

<https://keepingbusy.com/learning-center/downloadable-dementia-activities/>



Diet Plan

<https://www.countrywidehealthcare.co.uk/blog/post/creating-diet-plan-dementia-residents/>

We're working to launch materials as part of the dementia messages project to support you when working with people with dementia. In the meantime we found some great resources for you to download.

[Click here](#)

Downloads & Links

Find some helpful resources on [this page](#)



Files

Available for Download

List of therapy ideas
(Author: ozarkspeechpathologist)

[Download](#)

Dementia Cue Cards
(Author: goldencarers)

[Download](#)

Life Story Book Template
(Author: Alzheimer's WA)

[Download](#)

Communication and Mealtime Guide
(Author: NHS Dumfries & Galloway)

[Download](#)

The Dementia Guide
(Author: Dementia Australia)

[Download](#)

Communication Help Sheet
(Author: Dementia Australia)

[Download](#)

SP Sample Documentation Guide
(Author: Swallowing and Neurological Rehabilitation LLC)

[Download](#)

Evidence-Based Practice

Integrate your clinical expertise, available evidence and individual patient and caregiver needs as part of your practice. Navigating dementia diagnosis can be overwhelming. We've compiled a list of links and key organisations and journal articles to help build your understanding of dementia. Check out the links below.



Helpful databases:

SpeechBite - Speech Pathology Database

<https://speechbite.com/>

ASHA - Dementia Evidence Map

<https://www2.asha.org/EvidenceMapLanding.aspx?id=8589936399&recentarticles=false&year=undefined&tab=all>

Texas Speech-Language Hearing Association: Evidence Based Resources

https://www.txsha.org/evidence_based_practice

Trip evidence database

<https://www.tripdatabase.com/>

Cochrane Reviews

<https://www-cochranelibrary-com.ezproxy.newcastle.edu.au/>

Dementia Key Articles

Speech-Language Pathologist Interventions for Communication in Moderate-Severe Dementia: A Systematic Review

Swan, K., Hopper, M., Wenke, R., Jackson, C., Tili, T., & Conway, E. (2018).

[Read Article](#)

"I remember when...": The impact of reminiscence therapy on discourse production in older adults with cognitive impairment.

Rose, N., Whitworth, A., Smart, S., Oliver, E., & Cartwright, J. (2020).

[Read Article](#)

Lost for words: Perspectives and experiences of people with primary progressive aphasia and Alzheimer's disease and their families of participation in a lexical retrieval intervention.

Beales, A., Bates, K., Cartwright, J., & Whitworth, A. (2019)

[Read Article](#)

Speech and language therapy approaches to managing primary progressive aphasia.

Volkmer, A., Rogalski, E., Henry, M., Taylor-Rubin, C., Ruggero, L., Khayum, R., ... & Rohrer, J. D. (2020)

[Read Article](#)

Effects of functional communication interventions for people with primary progressive aphasia and their caregivers: a systematic review.

Volkmer, A., Spector, A., Meitani, V., Warren, J. D., & Beeke, S. (2020)

[Read Article](#)

A comparison of training strategies to enhance use of external aids by persons with dementia.

Bourgeois, M. S., Camp, C., Rose, M., White, B., Malone, M., Carr, J., & Rovine, M. (2003)

[Read Article](#)

Organisations with expertise in dementia



Dementia Australia

[Visit page](#)



Speech Pathology Australia

[Visit page](#)



Dementia Alliance International

[Visit page](#)

Working with families & carers

Speech Pathologists recognise the important role of family members of a person with dementia in all aspects of their service. Family members should be included in assessment and treatment, as they can be valuable key decision makers. The resources and links below are specifically for families of people with dementia.



Information about dementia for family members

Dementia Australia

<https://www.dementia.org.au/information/about-you/i-am-a-carer-family-member-or-friend>

Impact on families and social life

Alzheimer's Society

<https://alzheimer.ca/en/help-support/i-have-friend-or-family-member-who-lives-dementia/understanding-how-your-relationship>

Caring for someone with dementia

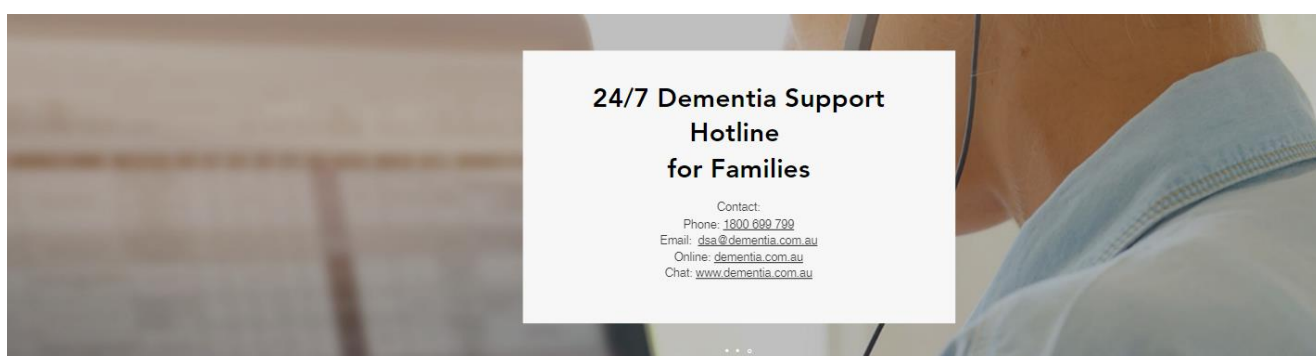
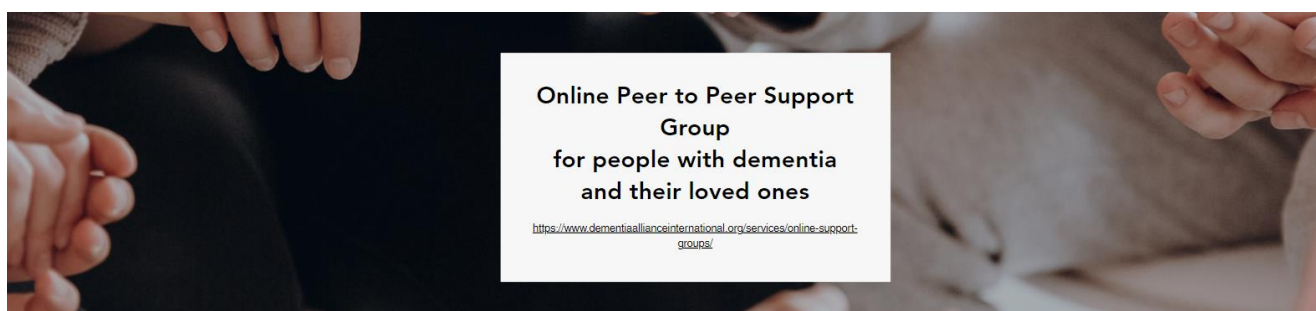
HelpGuide

<https://www.helpguide.org/articles/alzheimers-dementia-aging/tips-for-alzheimers-caregivers.htm#>

Dementia Advice for Families

Better Health Victoria

<https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/dementia-advice-for-families>



MOOCs, workshops and webinars

Find general and professional resources on this site



I Care: Educating Professional And Family Care Partners Of People With Dementia

Online, ASHA accredited
<https://www.northernspeech.com/skilled-nursing-and-toolkit-care-educating-professional-and-family-care-partners-of-people-with-dementia/>

Speech Pathology Courses

A Functional Approach For Achieving Meaningful Goals With Persons With Dementia

Online, ASHA accredited

[Click Here](#)

Creative Connections In Dementia Care: Engaging Activities To Enhance Communication For People With Dementia

Online, ASHA accredited

[Click Here](#)

Navigating Neurocognitive Disorders In Dementia: What The Speech Pathologist Needs To Know About Evidence-Based Practice And Patient- Centered Care

Online, ASHA accredited

[Click Here](#)

Dementia Diaries: Understanding the Types of Dementia

Online Course (Series) via speechpathology.com

[Click Here](#)



Networking & Interdisciplinarity

Are you interested in networking with other speech pathologists or allied health professionals who work with people with dementia?

- Join our **Dementia Messages group on Facebook** and connect with other speech pathologists who work with people with dementia
- **Have you seen our blog section?** Comment and discuss your thoughts on our first blog entry with other speech pathologists
- Check out the **links and resources** below in order to interact with others!

[Facebook](#)[Blog](#)

Dementia & Speech Pathology
A Resource Guide.
Prototype

[Home](#) [Blog](#) [Groups](#) [More](#) [f](#) [Log In](#)

Groups

Sort by **Recent Activity** ▾



Network: SPs & Dementia

Public · 1 Member

[Join](#)