



THE UNIVERSITY OF QUEENSLAND
A U S T R A L I A

**Optimising Hearing Services for Adults living with Dementia and
Hearing Impairment in Residential Aged Care Facilities**

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Abstract

Over 90% of adults living with dementia in residential aged care facilities (RACFs) will have a concomitant hearing impairment, resulting in a dual sensory-cognitive communication impairment. Identifying and appropriately managing hearing impairment may lead to improved hearing-related communication, caregiving and quality of life. However, within RACFs, hearing impairment is under-identified and sub-optimally managed. Therefore, the overarching aim of this thesis was to explore ways to optimise the delivery of hearing services to adults living with dementia and hearing impairment in RACFs.

This thesis is comprised of a systematic review (chapter 2) and three original studies, advancing knowledge in diagnostic audiology (chapter 3), and rehabilitative audiology (chapters 4 and 5), and developing an intervention that could be used to promote shared decision-making (chapter 6).

In chapter 2, a systematic review explored the proportion of adults living with dementia who could complete the gold standard hearing test, pure-tone audiometry (PTA), and contained two key findings. First, from 1,237 eligible studies only three met all inclusion criteria, highlighting the dearth of research in this area. Second, the proportion of adults completing PTA was identified as 56% to 59%. The facts that approximately 40% of adults living with dementia could not complete PTA indicated that there was a need to explore the feasibility of alternative non-behavioural hearing tests.

In chapter 3, a prospective cross-sectional feasibility study, examined whether Cortical Automatic Threshold Estimation (CATE) – an automated late auditory-evoked potential (AEP) test – was a suitable alternative to PTA for estimating hearing threshold for adults living with dementia in RACFs. Sixteen participants completed this study and results demonstrated that CATE was a feasible alternative to PTA, particularly for adults with severe dementia. Using both PTA and CATE also resulted in 87.5% of participants having their hearing thresholds estimated. However, a limitation of estimating hearing thresholds using CATE was the time taken to conduct assessments (approximately 50 minutes).

In chapter 4, a qualitative study consisting of semi-structured interviews with 23 participants from four stakeholder groups (audiologists, RACF staff, family caregivers and individuals living with dementia and hearing impairment) explored (1) the impact of hearing impairment, and (2) current management practices for adults with dementia and hearing impairment living in RACFs. Thematic analysis revealed three key themes: the far-reaching consequences of hearing impairment; hearing impairment should be appropriately managed; and different stakeholder priorities for managing hearing impairment. Importantly, because audiologists and RACF staff prioritised different approaches for managing hearing impairment – audiologists prioritising hearing aids and RACF staff prioritising communication strategies – hearing impairment remained largely sub-optimally managed and thus, the far-reaching consequences remained.

In chapter 5, the interviews reported on in chapter 4, were further analysed to identify the barriers and facilitators underlying five central behaviours that influenced hearing impairment management: (1) recognition of hearing impairment, (2) assessment of hearing impairment, (3) referral to and provision of hearing services, (4) management of hearing aids, and (5) shared decision-making. A framework analysis that applied the Capability, Opportunity, Motivation, and Behaviour model (COM-B) identified inter-related barriers to all behaviours, in terms of caregivers' capability, opportunity and motivation. Two prominent barriers impacting many behaviours was that hearing impairment management was not prioritised by the staff in RACFs (motivation) and caregivers (family and RACF staff) lacked knowledge on hearing services (capability).

Taken together, the qualitative findings in chapters 4 and 5, demonstrated that there are contrasting practices for managing hearing impairment for adults living with dementia and hearing impairment in RACFs. Audiologists focused on the provision of hearing aids whereas RACF staff focussed on communication strategies. Caregivers (family and RACF staff) also lacked knowledge but wanted information on all options available for treating hearing impairment.

A decision aid, HEARMyChoice®, was developed in chapter 6 as a result, and then piloted using a mixed-methods, pre-exposure post-exposure design. Three dyads, consisting of an adult living with dementia and hearing impairment in an

RACF and a family caregiver, took part in the study. The pilot study showed that the decision aid helped to improve participants' knowledge of treatment options and assisted dyads to reach agreement in choosing options for treating hearing impairment, suggesting utility of the decision aid in this context.

Findings in this thesis indicated that hearing services for adults living with dementia and hearing impairment in RACFs could be optimised by: (1) audiologists' using CATE to assess hearing for those people unable to complete PTA; (2) audiologists using a decision aid to present a range of hearing intervention options to residents and caregivers; and (3) RACF staff prioritising the management of hearing impairment.

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

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Publications included in this thesis

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Research Involving Human or Animal Subjects

UQ Human Research Ethics Committee (HREC) approved all empirical studies conducted in this thesis. Churches of Christ Care approved two of the studies conducted in this thesis. HREC approval notices from both organisations are included in the appendix at the end of this thesis (see Appendix A).

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List of Abbreviations used in the thesis

3FA	Three Frequency Average
4FA	Four Frequency Average
AD	Alzheimer's disease
AEP	Auditory-evoked potential
ALD	Assistive listening device
AM	Ante meridiem
AMNIAAA	American National Institute on Aging and Alzheimer's Association
APA	American Psychological Association
ARHL	Age related hearing loss
ASSR	The auditory steady state response
AUD	Audiologist
BCW	Behaviour Change Wheel
CATE	Cortical Automatic Threshold Estimation
CDR	Clinical Dementia Rating scale
CDR-CC	Clinical Dementia Rating scale – Chronic Care Version
CMO	Context Mechanism Outcome
COM-B	Capability, Opportunity, Motivation – Behaviour model
CPS	Cognitive Performance Scale
CRC	Cooperative Research Centre
Cz	Vertex
dB	Decibel
dB eHL	Decibel estimated Hearing Level
dB HL	Decibel Hearing Level
dB SPL	Decibel Sound Pressure Level
DNT	Did Not Test
DPOAEs	Distortion Product Otoacoustic Emissions
DSM-V	Diagnostic and Statistical Manual of Mental Disorders (5 th Edition)
EEG	Electroencephalogram
EQUATOR	Enhancing the QUALity and Transparency Of health Research
FAM	Family caregiver

Fz	Forehead
HA	Hearing aid
HL	Hearing Loss
HI	Hearing Impairment
Hz	Hertz
ICF	International Classification of Functioning, Disability and Health
IPDAS	International Patient Decision Aid Standards
ISO	International Standards Organization
kHz	Kilohertz
kOhm	Kiloohm
LE	Left Ear
LTC	Long Term care
M1	Right Mastoid
M2	Left Mastoid
MCI	Mild Cognitive Impairment
MDS CPS	Medical Data Set Cognitive Performance Scale
MMSE	Mini-Mental State Examination
NA	Not Applicable
OHR	Ottawa Health Research institute
PCC	Person Centred-Care
PM	Post Meridiem
PROSPERO	International Prospective Register of Systematic Reviews
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
RACF	Residential Aged Care Facility
RE	Right Ear
PTA	Pure-Tone Audiometry
SD	Standard Deviation
STROBE	STrengthening the Reporting of OBservational studies in Epidemiology
μV	Microvolts
VD	Vascular Dementia

WHO World Health Organization

WNL Within normal limits

Chapter 1 Introduction

Over 90% of adults living with dementia in residential aged care facilities (RACFs) have a concomitant hearing impairment (Hopper, Slaughter, Hodgetts, Ostevik, & Ickert, 2016). The frequent co-occurrence of these two conditions is known to have negative psychosocial and communication consequences for individuals (Hopper & Hinton, 2012). Managing hearing impairment through the use of hearing aids, assistive listening devices and/or the provision of communication strategies may ameliorate some of these consequences (Dawes, Wolski, Himmelsbach, Regan, & Leroi, 2019; Mamo et al., 2018), however, hearing impairment is under-identified and sub-optimally managed within this population. Previous research that has explored the management of hearing impairment for adults living with dementia in RACFs has focused on RACF staff. In contrast, there is limited research that has explored the delivery of hearing services provided by audiologists, such as how hearing is tested and how rehabilitation decisions are made. The proportion of adults who can complete the most common hearing test, pure-tone audiometry (PTA), is unclear, with one study suggesting that within RACFs, only 32% of residents are able to do so (Burkhalter, Allen, Skaar, Crittenden, & Burgio, 2009). Moreover, fewer than 20% of adults living in RACFs who are eligible for hearing aids have the devices (Cohen-Mansfield & Taylor, 2004a, 2004b). Prior to designing an intervention that may assist audiologists' management of hearing impairment, an understanding of current practices is needed. This thesis therefore investigated options for optimising the delivery of hearing services to adults living with dementia and hearing impairment in RACFs by, firstly, exploring the appropriateness of current assessment and management processes and, secondly, by developing and piloting an intervention that could potentially improve hearing impairment management in the long term.

This chapter provides: (1) the background to this research by defining key terms and reporting research on the prevalence of hearing impairment and dementia within RACFs as well as the co-occurrence of the two conditions; (2) a synthesis of the key studies that have explored the association between, and the consequences of, dementia and hearing impairment; and (3) proposes research avenues due to the gaps-in-literature relevant to both diagnostic audiology and rehabilitative audiology

that may lead to optimising hearing services for adults living with dementia and hearing impairment in RACFs. Moreover, the research aims, overview of methodologies used, and thesis structure are presented.

1.1 Background

1.1.1 Dementia

Dementia is an umbrella term for more than 100 diseases of the brain (Australian Institute of Health and Welfare, 2012). The most common of these is Alzheimer's disease, estimated to account for up to 70% of all dementia diagnoses (Dementia Australia, 2019). Adults living with dementia experience greater than expected age-related changes in areas such as language, memory, executive function, personality, attention and global cognitive function (Smits et al., 2015). These changes interfere with an individual's ability to complete normal daily activities and, as the disease progresses, increasing assistance from caregivers is required for people to complete daily tasks including self-care (Australian Institute of Health and Welfare, 2012). The American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders volume 5 (DSM 5) replaced the term "dementia" with those of "mild/major neurocognitive disorder" (American Psychiatric Association, 2013). A salient difference between mild and major neurocognitive disorder is whether the condition interferes with activities of daily living. That is, adults who have a decline from their normal level of functioning and this functioning interferes with their ability to complete activities of daily living are classified as having major neurocognitive disorder (American Psychiatric Association, 2013). Throughout this thesis, the more common term of "dementia" is used rather than mild/major neurocognitive disorder.

Worldwide, an individual is diagnosed with dementia every three seconds (Prince et al., 2015). In 2015, 46.8 million people around the world were reported to be living with dementia and, as a result of the ageing population, this number is predicted to double every 20 years, reaching approximately 131 million by 2050 (Prince et al., 2015). The direct (medical and social care) and indirect (unpaid caregiving) economic cost of dementia is imposing. In America, this cost accounts for 1.3% of gross domestic product, with slightly lower costs reported for Australasia

(World Health Organization [WHO], 2012). Due to this current and predicted social and economic burden, dementia is recognised as a public health priority (WHO, 2012), and researchers are encouraged to explore opportunities for dementia prevention as well as optimisation of the quality of life for individuals living with the disease and their caregivers (WHO, 2012).

In Australia, dementia is the leading cause of death in women and the second leading cause of death in men behind coronary heart disease (Australian Institute of Health and Welfare, 2018a). In 2018, 436,366 Australians were reported to be living with dementia and this number is predicted to rise to more than 1,000,000 Australians by 2058 (Australian Institute of Health and Welfare, 2018b). Currently, one in 10 people aged over 65 years and three in 10 people aged over 85 years are reported to have a dementia diagnosis (Australian Institute of Health and Welfare, 2016). By 2066, adults over the age of 65 years are anticipated to make up a quarter of Australia's population (Australian Bureau of Statistics, 2018).

Most dementia diagnoses occur in adults aged over 65 years (Dementia Australia, 2019); however dementia is not considered a normal part of ageing. Figure 1-1 depicts a continuum of cognitive function on a visual scale. To the left of the scale is age-related cognitive decline, in the middle is mild cognitive impairment and to the right is dementia, broken into three sub-groups (mild, moderate and severe). Cognitive function has specific categories/domains including: processing speed; attention; memory; language; visuospatial abilities; and executive function/reasoning (Harada, Natelson Love, & Triebel, 2013). Decline in many domains of cognitive functioning, including memory, attention, processing speed and executive functioning, occurs naturally as part of the ageing process (Deary et al., 2009; Harada et al., 2013). However other cognitive domains, such as vocabulary and knowledge, are resilient to ageing (Bayles, Tomoeda, & Boone, 1985). Cognitive functions that decline more than expected with ageing may result in a diagnosis of mild cognitive impairment or dementia. As described by Petersen et al. (2014), mild cognitive impairment is "an intermediate stage of cognitive impairment that is often, but not always a transitional phase from cognitive changes in normal ageing to those found in dementia." (Petersen et al., 2014, p. 214).



Figure 1-1 Continuum of Cognitive Function

Because over 95% of all dementia diagnoses occur in adults over the age of 65 years (Dementia Australia, 2019), adults living with dementia have on average, five other comorbid chronic health conditions (Australian Institute of Health and Welfare, 2012). Hearing impairment is a very common chronic condition in older adults and in Australia, men and women over the age of 65 years will live approximately half of their remaining years with a mild or greater hearing impairment (Kiely et al., 2016). Moreover, hearing impairment is among the top 10 health conditions causing burden to people aged over 65 years and is the third most common chronic health condition to co-occur among adults living with dementia (Australian Institute of Health and Welfare, 2018b).

1.1.2 Hearing Impairment

The terms “hearing impairment” and “hearing loss” are often used interchangeably, and “hearing impairment” will be used throughout this thesis. Different definitions for “hearing impairment” currently exist. For example, the WHO has different definitions for hearing impairment and for disabling hearing impairment. The WHO defines a hearing impairment as a complete or partial loss of the ability to hear from one or both ears; that is mild or worse hearing impairment (26 dB HL or greater hearing thresholds), averaged across 500, 1000, 2000 and 4000 Hz (WHO, 2019). In contrast, disabling hearing impairment in adults is defined as a loss greater than 40 dB HL in the better hearing ear (WHO, 2019). Because the WHO definition of disabling hearing impairment excludes adults with a mild impairment, though this is still known to affect communication (Timmer, Hickson, & Launer, 2015), the classification of hearing impairment by grades ensures that adults with a mild hearing impairment are included. The WHO grades of hearing impairment are: no impairment (≤ 25 dB HL); slight/mild impairment (26-40 dB HL); moderate impairment (41-60 dB HL); severe impairment (61-80 dB HL); and profound impairment (>81 dB HL; WHO, 2018), based on the better hearing ear pure-tone

average across 500, 1000, 2000, and 4000 Hz. This classification system has been used throughout the studies reported in this thesis. Typical age-related hearing impairment is bilateral.

As described above, measuring hearing impairment, via standard audiometric evaluations allows for the classification or grading of hearing impairment. However, universally, different criteria exist for defining hearing impairment. As highlighted in a systematic review by Timmer, Hickson, and Launer (2015), organisations such as the American Speech-Language-Hearing Association (ASHA), the WHO, the British Society of Audiology, and National Acoustic Laboratories in Australia all have slightly different criteria for classifying a mild hearing impairment. The different criteria used for defining hearing impairment has some consequences in the context of RACFs, specifically around prevalence rates.

In Australia, hearing impairment affects 48% of people aged over 60 years and 64% of people aged over 70 years (Access Economics, 2006). However, both internationally and in Australia, there is wide variation in the reported prevalence of hearing impairment within RACFs, ranging from prevalence rates from as low as 35% (Burnip & Erber, 1996) to over 90% (Linssen et al., 2013). The difference in reported prevalence may be due to how hearing impairment has been determined. For example, higher prevalence rates are reported when objective measures of hearing, such as PTA, have been used (Cohen-Mansfield & Taylor, 2004a; Worrall, Hickson, & Dodd, 1993), as compared to subjective, self-report measures (Burnip & Erber, 1996; Garahan, Waller, Houghton, Tisdale, & Runge, 1992; Kiely, Gopinath, Mitchell, Luszcz, & Anstey, 2012). Moreover, Kiely et al. (2012) reported that adults over the age of 70 years underestimated their hearing impairment by as much as 20% when using subjective measures.

Ageing affects peripheral and central structures of the auditory system, resulting in hearing impairment. As described by Gates and Mills (2005), peripheral changes occur due to a combination of life-long factors, including exposure to ototoxic agents and excessive sound levels, as well as genetic susceptibility to hearing impairment. These changes cause damage to and a reduction in the number of functioning outer and inner hair cells in the cochlear (Schuknecht & Gacek, 1993), particularly above 1000 Hz (Wingfield, Tun, & McCoy, 2005), negatively impacting

speech discrimination (Frisina & Frisina, 1997). Changes to central structures such as reductions in temporal and spectral resolution – temporal resolution being the ability to detect and maintain the order of sounds and spectral resolution being the ability to isolate and discriminate speech frequencies – are also observed in older adults with hearing impairment (Profant et al., 2015; Wingfield et al., 2005).

Advancements in imaging techniques, namely functional magnetic resonance imaging, have allowed for increased insights into changes in central auditory structures with ageing. However, this research is still in its infancy. For example, Profant et al. (2015) examined 15 older adults with severe hearing impairment, five older adults with mild hearing impairment, and 18 younger adults with normal hearing. More activation, particularly in the right temporal lobe, was observed in both older adult groups, as compared to younger adults. The authors attributed this finding to be a compensatory mechanism for the impaired auditory processing that resulted from ageing (Profant et al., 2015). Longitudinal studies have also demonstrated right temporal lobe reductions and whole brain atrophy in adults with hearing impairment, compared to adults without hearing impairment (Lin et al., 2014).

Research that seeks to understand and explain changes in central auditory structures with ageing and with hearing impairment is important in the context of hearing impairment and dementia. Some research groups postulate that there may be a biological association between hearing impairment and dementia (Gates et al., 2010). Although the use of imaging techniques has started to advance knowledge regarding central hearing impairment, the interaction between central hearing impairment, peripheral hearing impairment and cognitive decline/dementia requires further evaluation.

1.1.3 The Association between Dementia and Hearing Impairment

Audiological literature has contained reports of the association between hearing impairment and dementia in adults for 30 years. Uhlmann, Larson, Rees, Koepsell, and Duckert (1989), were the first to report this link when they conducted a case-control study on 100 individuals with dementia and 100 age-, sex- and education-matched controls. Their study found that individuals with dementia were twice as likely to have a hearing impairment greater than 30 dB as compared to

controls. In addition, severity of hearing impairment was found to be correlated with severity of cognitive impairment as measured with the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975), such that people with more severe hearing impairment had poorer scores on the MMSE (Uhlmann et al., 1989). More recently, Lin et al. (2011) reported the association between dementia and hearing impairment in the Baltimore Longitudinal Study of Aging. The authors followed 639 community-dwelling individuals without cognitive impairment, aged 36 to 90 years, over a 12-year period. Participants had their hearing assessed via PTA at study entry and were assessed biennially for dementia. Over the study duration, 58 participants were diagnosed with dementia. Compared to participants assessed as having normal hearing thresholds at baseline, individuals with mild, moderate or severe hearing impairment had a hazard ratio of 1.89, 3 and 4.94 for developing dementia, respectively (Lin et al., 2011). Recently, a cross-sectional analysis from the English Longitudinal Study of Ageing further explored the association between hearing impairment, cognitive decline, untreated hearing impairment and social isolation (Ray, Popli, & Fell, 2018). This study found that hearing impairment was associated with cognitive decline, but only for adults who did not treat their hearing impairment with hearing aids. Moreover, social isolation was significantly associated with cognitive decline in people who treated and did not treat their hearing impairment.

In addition to the aforementioned key longitudinal studies, recently, a growing number of meta-analyses have combined the findings from cross-sectional and longitudinal studies that have explored the association between hearing impairment and dementia. In 2017, Livingston et al. published a review in the *Lancet*, identifying that treating hearing impairment in the mid-years could reduce the risk of developing dementia by 9%. Since this publication, three additional meta-analyses have confirmed the association between hearing impairment and dementia (Ford et al., 2018; Loughrey, Kelly, Kelley, Brennan, & Lawlor, 2018; Wei et al., 2017). Loughrey et al. (2018) completed a meta-analysis of cohort and cross-sectional studies that used objective measures of hearing (i.e., PTA) to explore the associations between hearing impairment and cognitive impairment, hearing impairment and dementia, and hearing impairment and Alzheimer's disease. A significant association between hearing impairment and dementia was observed, within both cohort and cross-

sectional studies, and an odds ratio of 1.28 for dementia was reported in the cohort studies (Loughrey et al., 2018). However, further subgroup analysis (by type of dementia) found no significant relationship between hearing impairment and Alzheimer's disease nor vascular dementia in cohort studies and no significant relationship between hearing impairment and Alzheimer's disease in cross-sectional studies. The authors report this could be due to the small sample size. From the meta-analysis, the overall percentage of cases (i.e. participants diagnosed with cognitive impairment, dementia, Alzheimer's disease or vascular dementia) was 4.6% for Alzheimer's disease based on cross-sectional studies; and 5.2% and 4.4% for Alzheimer's disease and vascular dementia, respectively, based on cohort studies. Ford et al. (2018) conducted a meta-analysis of cohort studies that had classified hearing impairment according to the International Classification of Diseases system and reported a slightly higher association between hearing impairment and dementia than that reported by Loughrey et al. (2018). For the 14 studies included in the meta-analysis by Ford et al. (2018), a hazard ratio of 1.49 was reported. Wei et al. (2017) reported the highest association between hearing impairment and dementia (risk ratio of 2.39) in a meta-analysis of seven cohort studies. This meta-analysis did not, however, consider how these seven studies measured hearing impairment. That is, studies that had used subjective or objective measures of hearing impairment were included. While the meta-analyses summarised here mostly conclude that hearing impairment is associated with an increased risk for developing dementia, it must be noted that heterogeneity exists in study design, how hearing impairment is assessed, how dementia/cognition is measured and the sample size of the population. Furthermore, while there is evidence that there is an association between hearing impairment and dementia, causality has not been established (Taljaard, Olaithe, Brennan-Jones, Eikelboom, & Bucks, 2016).

The relationship between hearing impairment and increased risk of dementia is poorly understood and attempts to explore some of the mediating factors are limited by research designs. Arguably, researchers present four common hypotheses regarding the link between hearing impairment and dementia (Lin & Albert, 2012; Nixon, Sarant, & Tomlin, 2019; Wayne & Johnsrude, 2015). First, the sensory deprivation theory suggests that reduced sensory input (from hearing impairment)

leads to permanent cognitive deterioration and reallocation of cognitive resources. However, there is no evidence to support this theory in full, because for this theory to be true, hearing impairment would always precede dementia: not all people with dementia have hearing impairment (Nirmalasari et al., 2017). Second, the resource allocation theory proposes that because of hearing impairment, cognitive resources from working memory or attention are redirected to speech recognition (Pichora-Fuller, 2003). However, if this theory were true, cognitive deficits would be temporary and following treatment for hearing impairment, such as fitting hearing aids, cognitive deficits would reverse. Currently, there is no high-quality evidence to suggest that hearing aids reduce the risk of cognitive decline long-term (Dawes et al., 2019; Mamo et al., 2018) nor that hearing aids improve cognitive performance of adults with Alzheimer's disease (Nguyen et al., 2017). Third, the common cause hypothesis, suggests that hearing impairment and dementia share the same underlying cause, such as degeneration of the central nervous system with ageing. However, as argued by Nixon, Sarant and Tomlin (2019), while age related neurodegeneration occurs in both sensory and cognitive structures, any theory that considers 'age' as a factor should also consider other age-related comorbidities that affect these two areas. The fourth theory, coined the alternative framework, suggests that hearing impairment and dementia may be associated due to the effect that hearing impairment has on social isolation and depression; and the association that social isolation and depression has on dementia (Dawes et al., 2015). While this theory has some evidence in research (Dawes et al., 2015; Ray, Popli, & Fell, 2019), it cannot be explored to a causal level as it would be unethical to conduct a randomized controlled trial that explored 'social isolation' or 'depression' as the independent variable.

As highlighted, it is challenging to explore some of these theories to a causal level. Arguable, only the resource allocation hypothesis could be explored via a randomized controlled trial. One previous longitudinal study found that hearing aids moderated the effect of hearing impairment on cognitive decline (Amieva et al., 2015). However, up to 20% of adults do not recognise they have a hearing impairment via self-report measures (Kiely et al., 2012). Previous randomized controlled trials of adults with Alzheimer's disease do not show improved cognitive performance following hearing aid fitting (Nguyen et al., 2017). Currently, a

randomized controlled trial is being conducted to explore if hearing aids are a mediating factor against dementia for adults with hearing impairment (Lin et al., 2016). Irrespective of the effect that hearing aids have on preventing dementia or the underlying mechanisms that link hearing impairment and dementia, it remains that many adults with dementia will have hearing impairment. Thus, there is a current need to explore interventions that support the wellbeing of adults living with dementia and hearing impairment and their caregivers (WHO, 2012).

1.1.4 Residential Aged Care Facilities (RACFs)

In Australia, several interchangeable terms are often used to describe RACFs. Aged care homes, residential aged care facilities and nursing homes are all commonly used terms to describe an environment where a person can receive “suitable accommodation and related services (such as laundry, meals and cleaning), as well as personal care services (such as assistance with daily living)” (Australian Institute of Health and Welfare, 2011, p. 2). In the United States and Canada, RACFs are often referred to as “long-term care” and in the United Kingdom, RACFs are known as care homes. For this thesis and associated studies, the term “residential aged care facilities (RACFs)” is used.

The characteristics of an RACF can be described in terms of the level of care provided. In Australia, retirement villages, assisted living and RACFs all provide different levels of care and support to older adults. For example, in retirement villages adults can access personal care, such as assistance with laundry and meals, and health care such as podiatry, whilst still living in their own home. In an RACF, adults typically have their own room (including bathroom), but live in a shared facility, with multiple other residents. RACFs can provide temporary (respite) or permanent, 24-hour care to people. Some Australian RACFs also have separate “secure” sections within the facility where adults living with dementia reside. Furthermore, in the context of residents with dementia, the majority will receive high level care, whereby they receive full-time supervised health care (Access Economics, 2010).

On the 30 June 2018, 282,000 Australians were living in RACFs (Australian Institute of Health and Welfare, 2019), of which 50% are reported to have a dementia diagnosis (Australian Institute of Health and Welfare, 2016). In 2013, 7.8% of

Australians aged over 65 years lived in RACFs (Australian Institute of Health and Welfare, 2014). Although only a small proportion of adults over the age of 65 years live in an RACF, these adults are complex in their healthcare needs, often having multiple comorbidities and communication impairments.

Communication is compromised in RACFs for a number of reasons. Firstly, communication disabilities, such as hearing impairment, is often high in prevalence (Cohen-Mansfield & Taylor, 2004a; Worrall, Hickson, & Dodd, 1993) but is also often overlooked by RACF staff (Burnip & Erber, 1996; Garahan et al., 1992). Worrall, Hickson and Dodd (1994) examined 535 residents across five RACFs and five hostels in Queensland. Participants were screened for hearing impairment, cognitive impairment, aphasia, poor speech intelligibility, dysphonia and pragmatic deficits. Within RACFs, 84% of participants were identified with a hearing impairment and 83% with cognitive impairment. Furthermore, 70% of residents failed two or more communication screening assessments, with the most commonly failed dual assessment being for hearing impairment and cognitive impairment, which 21.1% of residents failed (Worrall et al., 1993). Despite the high prevalence of hearing impairment in RACFs, several research groups have reported that RACF staff underestimate hearing impairment in residents (Burnip & Erber, 1996; Garahan et al., 1992) which in turn impacts on communication interactions and quality of care.

Secondly, the physical environment of RACFs is often not optimal for communication with high levels of noise and reverberation reported (Lubinski, 1995; Worrall & Hickson, 2003). The relationship between hearing impairment and difficulty hearing in noise is well known. RACFs typically consist of hard surfaces, resulting in poor acoustic environments, excessive noise levels and reverberation (Lubinski, 1995; Worrall & Hickson, 2003), limiting hearing-related communication. The poor acoustic environment is often compounded by shiny surfaces, affecting residents' ability to use visual cues – further impeding communication interactions (Jones, Sloane & Alexander, 1992). High levels of noise may also have consequences for residents living with dementia, such as, leading to higher levels of agitation among these residents (Joosse, 2012).

Thirdly, the social environment in RACFs means there are few opportunities for communication (Hickson, Worrall, Wilson, Tilse, & Setterlund, 2005). Hickson et al.

(2005) found that environmental factors including: limited stimulating activities and limited opportunities to engage in conversations affected communication interaction of residents. This is further evidenced by RACF staff-resident communication, of which RACF staff are often the main communication partner for residents (Worrall & Hickson, 2003). RACF staff have high workloads and are pushed to focus on physical care rather than social care (Tappen, William-Burgess, Edelstein, Touhy, & Fishman, 1997). Therefore, topics of conversation are limited to everyday needs and restrict residents' opportunities for meaningful communication exchanges (Carpac-Claver & Levy-Storms, 2007).

Finally, older adults living in RACFs are typically frailer than the community-dwelling population. This frailty often leads to the inability to live independently in one's own home, due to declining physical and cognitive capabilities, necessitates the transition into an RACF. This means that for audiologists who provide hearing services to residents living in RACFs, they are working with older adults who are typically frailer, have more health conditions and have more severe disabilities, as compared to community-dwelling adults (Matthews et al., 2016).

The characteristics of RACFs, the complex residents, poor acoustic environments, high staff workload and limited opportunities for communication, infer that optimising communication for residents living in RACFs is complex. Moreover, for those residents living with dementia, it also suggests that a different model of care for managing hearing impairment is required as compared to community-dwelling adults living with dementia. For example, in the RACF setting, RACF staff are responsible for ensuring that hearing-related communication is optimised (Crosbie et al., 2019). However, in the community setting, family caregivers and the individual are responsible for ensuring hearing-related communication is optimised. Accordingly, research is required to help identify the most appropriate means for optimising hearing-related communication for adults living with dementia and hearing impairment in RACFs.

1.2 The Need for this Research

Limited research has explored optimising the delivery of hearing care from hearing services to adults living with dementia and hearing impairment in RACFs. Figure 1.2 depicts results from a crude database search conducted using Scopus on 9 January 2019. Key terms of “dementia” were combined with “hearing loss” or “hearing impairment” and “aged care” or “nursing home” and a count by year was completed to examine the number of publications in these areas. In 2018, over 100 articles were published that related to dementia and hearing impairment. However, of these, only two were relevant for adults living with dementia and hearing impairment in RACFs. Moreover, only one study to date has specifically reported the prevalence of hearing impairment among adults living with dementia in RACFs. Hopper et al. (2016) evaluated the hearing of 36 RACF residents with dementia and found that 33 (92%) were assessed to have a mild or greater hearing impairment.

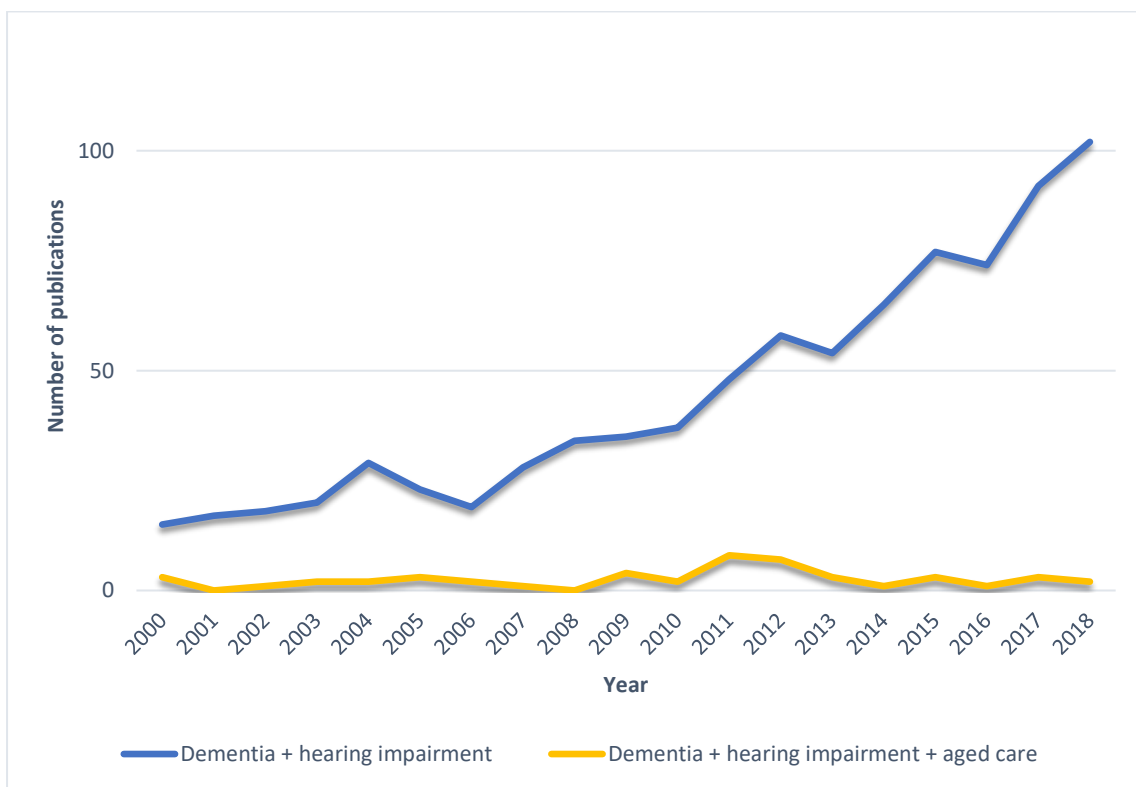


Figure 1-2 Crude Database Search of Articles Published in Scopus from 01 Jan 2000 to 31 December 2018 Relating to Dementia and Hearing Impairment and RACFs

One reason for the dearth of clinically driven research conducted with this population could be due to challenges with recruitment, namely obtaining consent, of participants with dementia (Looi et al., 2004). Despite this challenge, further research is required to support clinicians who provide hearing services to this population (Wright et al., 2014), as previous research indicates that hearing impairment results in additional communication consequences for adults living with dementia (Hopper & Hinton, 2012). One way to conceptualise the consequences of hearing impairment is by using a framework, such as the WHO's International Classification of Functioning, Disability and Health (ICF; WHO, 2001).

The ICF is a framework that details the broad consequences a health condition has on an individual (WHO, 2001), and ICF terminology is used throughout this thesis. Figure 1.3 presents the ICF framework, which considers how “body structures and body functions” (the physiological functions of the body system and the anatomical parts of the body) and “activities and participation” (the execution of a task or action and involvement in life situations) are either positively or negatively influenced by a health condition (WHO, 2001). Negative terms of the ICF include: “Impairments” referring to a problem in body function or structure; “activity limitations” difficulties the individual may have performing activities; and “participation restrictions” problems that an individual may experience involving life situations (WHO, 2001). The overarching term for the negative consequences of a health condition (impairment, activity limitation, participation restriction) is “disability” (WHO, 2001b). The ICF also considers the impact of contextual factors including “environmental factors” (the physical, social and attitudinal environment) and “personal factors” (e.g., age and gender) on the health condition (WHO, 2001). The ICF is multidirectional, acknowledging that impairment, activity limitations and participation restrictions are compounded or mitigated by these contextual factors (WHO, 2001).

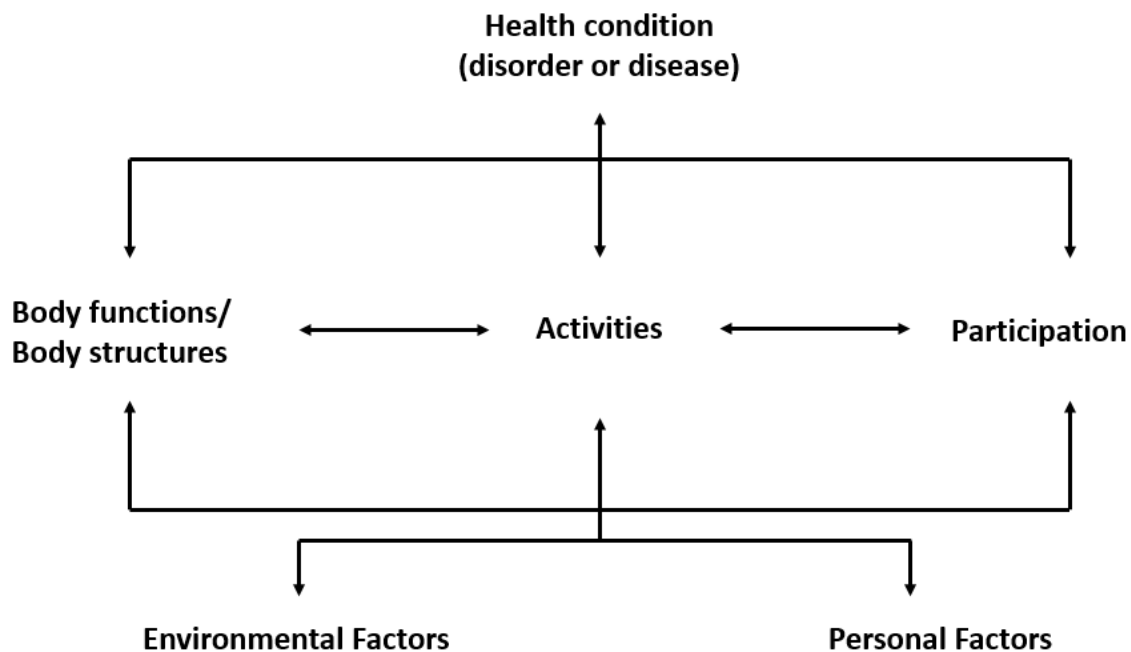


Figure 1-3 The ICF Framework (adapted from WHO, 2001)

Two recent systematic reviews (Ludlow, Mumford, Makeham, Braithwaite, & Greenfield, 2018; Punch & Horstmanshof, 2018) explored the impact of hearing impairment upon residents in RACFs. The review by Ludlow et al. (2018) investigated how hearing impairment affected person-centred care (PCC) in RACFs and included six articles in its final appraisal. The authors found that hearing impairment resulted in activity limitations of understanding and engaging in conversations, which restricted residents' participation in RACF activities. Moreover, cognitive impairment intensified these communication difficulties. The authors concluded that future research is required to better understand the combined effect of hearing and cognitive impairment upon residents of RACFs. The review by Punch and Horstmanshof (2018) contained 22 studies and again found that hearing impairment was associated with communication breakdowns as well as affecting mood, social interactions and participation in activities within the RACF. These two recent reviews clearly demonstrate that hearing impairment has negative consequences for residents of RACFs.

An increasing number of studies have considered the activity limitations and participation restrictions that hearing impairment imposes upon adults living with dementia in RACFs. Hearing impairment is reported to further affect physical, social and emotional functioning (Guthrie et al., 2018) and communication (Hopper & Hinton, 2012) of adults living with dementia in RACFs, and is also found to reduce engagement and participation in social activities (Cohen-Mansfield, Marx, Regier, & Dakheel-Ali, 2009; Pryce & Gooberman-Hill, 2012), as compared to adults living with dementia and normal hearing. For example, Cohen-Mansfield et al. (2009) found that, in 193 residents with dementia, those who also had a hearing impairment participated less in social activities as compared to those with dementia and normal hearing. Similarly, Guthrie et al. (2018) reported on a large cross-sectional study of residents living in RACFs ($N=110,578$), and found that hearing impairment contributed to greater disability such as reduced social engagement, loneliness and reduced independence for completing activities of daily living as compared to residents with cognitive impairment and normal hearing. However, neither study reported whether use of hearing aids or treatment of hearing impairment altered outcomes (Cohen-Mansfield et al., 2009; Guthrie et al., 2018).

In the ICF, environmental factors comprise the physical, social and attitudinal environment in which people conduct their lives (WHO, 2001). Noise in RACFs is known to affect communication (Lubinski, 1995; Worrall & Hickson, 2003) and has been reported to lead to higher rates of agitation among residents with dementia (Joosse, 2012). The social environment of the RACF has also been documented to adversely influence communication, for adults living with dementia and hearing impairment. Pryce and Gooberman-Hill (2012) conducted an ethnographic and qualitative study in two RACFs in the United Kingdom, exploring factors that affected communication of 18 residents with hearing impairment, eight of whom had a dementia diagnosis. This study found that there were few opportunities for those with hearing impairment to engage in conversations at the RACF, and that hearing impairment and the high level of background noise in the RACF setting restricted participation in these social opportunities.

Hearing impairment results in activity limitations and participation restrictions for adults living in RACFs (Punch & Horstmanshof, 2018). However, little empirical

research describes the consequences of this for adults living with dementia. Environmental factors, such as social opportunities and background noise, are likely to exacerbate the consequences of hearing impairment for adults living with dementia in RACFs (Pryce & Gooberman-Hill, 2012). To optimise hearing-related communication and address both activity limitations/participation restrictions and environmental factors, holistic interventions – addressing disability and contextual factors – may be required. From a hearing services perspective, a first step toward managing the hearing-related needs of adults living with hearing impairment and dementia in RACFs is the accurate identification of hearing impairment.

1.2.1 Diagnostic Audiology

For adults living with dementia in RACFs, hearing impairment is under-identified (Cohen-Mansfield & Taylor, 2004a), due to several contributing factors. As highlighted by Cohen-Mansfield and Taylor (2004a), RACF staff do not routinely screen hearing in all residents and, as further explored by Slaughter et al. (2014), it is difficult for RACF staff to distinguish sensory-communication impairments from cognitive-communication impairments due to their similarity in presentation (Hopper & Hinton, 2012; Woodward, 2013). For example, people with dementia (Woodward, 2013) and people with a hearing impairment (Caissie & Rockwell, 1994) both display difficulty following conversations, inappropriate responding to questions/ conversational topics; and question repetition. Because of this, RACF staff may unintentionally overlook hearing impairment among residents with dementia (Crosbie et al., 2019), a problem which could be overcome by routine hearing screening for all residents in RACFs (Cohen-Mansfield & Taylor, 2004b).

Further issues regarding the identification of hearing impairment amongst adults living with dementia in RACFs, from a hearing services perspective, is their ability to complete PTA. PTA is the most commonly used test by audiologists for hearing threshold estimation. The primary purpose of PTA is to determine degree and nature of hearing impairment. Knowing such information can then be used by clinicians to help determine treatment options, which can include but is not limited to hearing aids. For adults living with dementia, knowing degree and nature of hearing impairment may have additional value to caregivers as clinicians can provide more specific communication strategies than what can be ascertained from screening

hearing and observations of behaviour related to hearing. Moreover, in Australia, audiologists receive funding from the Australian Government Hearing Service Program to conduct hearing threshold estimation.

Research indicates that some proportion of adults living with dementia cannot complete this test. For example, Burkhalter et al. (2009) conducted audiological evaluations using: PTA air and bone conduction (500 – 4000 Hz); speech reception threshold testing; speech recognition scoring; and uncomfortable and most comfortable level of speech with 307 residents of an RACF, of whom 23% had a dementia diagnosis. Only 5% of residents were able to complete all diagnostic tests, and only 32% could complete PTA. The authors do not report the proportion of the 72 participants living with dementia who were able to complete these tests. Hedner, Broms, Harris, and Steen (1987) similarly found that only 55 residents (27%) of 197 adults living in RACFs were able to have their hearing measured using PTA, attributing this to the high prevalence of dementia in the sample (Hedner et al., 1987). Thus, the limitations of PTA for evaluating the hearing of adults living in RACFs, including those with dementia, have been reported for over 30 years (Hedner et al., 1987). Despite this, no research group has specifically investigated the proportion of adults living with dementia who can or cannot complete PTA, and only one study has explored the validity of an alternative non-behavioural measure of hearing for adults living with dementia (Villeneuve et al., 2017).

Auditory-evoked potentials (AEPs) have been widely applied to estimate hearing thresholds in infants (Chang, Dillon, Carter, Van Dun, & Young, 2012; Van Dun, Carter, & Dillon, 2012) and adults without cognitive impairment (Carter, Dillon, Seymour, Seeto, & Van Dun, 2013; Lightfoot, 2016; Lightfoot & Kennedy, 2006), demonstrating their strong correlation with behavioural thresholds in adult populations (Lightfoot & Kennedy, 2006). The American Speech-Language-Hearing Association recommend the use of objective auditory evoked potential tests for those adults who are unable to complete behaviour tests, such as PTA (ASHA, 1997). One study has used AEP testing with adults living with dementia, although not within an RACF environment (Villeneuve et al., 2017). Villeneuve et al. (2017) examined the association of the auditory steady state response (ASSR) to PTA amongst 12 adults with mild cognitive impairment or dementia. A moderate, statistically significant,

positive correlation was observed between PTA and ASSR at 500 Hz, 1000 Hz, 2000 Hz and 4000 Hz. However, cortical AEPs have been shown to have a closer correlation with behavioural thresholds compared to the ASSR (Tomlin, Rance, Graydon, & Tsialios, 2006; Yeung & Wong, 2007).

The Cortical Automatic Threshold Estimation (CATE), recently developed by the HEARing Cooperative Research Centre and National Acoustics Laboratories, is a novel, fully automated AEP test (Bardy, Van Dun, et al. 2016). In the time domain, CATE is an auditory late evoked potential test, estimating hearing sensitivity at the P1-N1-P2 complex. The clinical feasibility of CATE for assessing the hearing of adults living with dementia should be explored because, for adults without cognitive impairment, CATE is highly correlated with behavioural thresholds and can estimate four frequencies in adults with a hearing impairment in two ears in under 40 minutes (Bardy, Van Dun, et al. 2016). Utilising non-behavioural hearing tests may increase the detection of hearing impairment among people living with dementia who reside in RACFs, particularly among those who are unable to complete PTA.

1.2.2 Rehabilitative Audiology

Managing hearing impairment amongst adults living with dementia in RACFs is complex. Limited research has evaluated the longer-term outcomes of treating hearing impairment within this population. In 2018, two systematic reviews summarised the evidence for hearing interventions for adults with dementia, not specifically within RACFs (Dawes et al., 2019; Mamo et al., 2018). Both reviews found that hearing interventions – hearing aids, assistive listening devices (ALDs) and/or communication training – improved communication and reduced problem behaviours for people living with dementia, but also identified that these studies were typically of low quality and contained a high risk of bias because of their design (e.g., quasi-experimental). Furthermore, the review by Mamo et al. (2018) highlighted the dearth of research involving adults living with dementia in RACFs and proposed that randomised controlled trials comparing assistive listening devices (ALDs)/ communication training to hearing aids should be conducted.

Findings from research investigating hearing aid use and function in the RACF environment are equivocal. Early studies examining the uptake of hearing aids within RACFs report a gross underuse of the devices. Schow (1982) reported

that only 8% of potential hearing aid users within RACFs adopted them. This is consistent with findings from a more recent study by Cohen-Mansfield and Taylor (2004a) who identified that only 14% of 108 residents of an RACF with hearing impairment had hearing aids. However, the study by Cohen-Mansfield and Taylor (2004a) may underestimate the presence of hearing impairment, as hearing assessments were not included in the study. Rather residents completed self-report questionnaires on hearing which were then compared to medical data in residents' files, nurses' perception of hearing impairment and finally to that of the research assistant observation of residents. Cohen-Mansfield and Taylor (2004b) further reported that, of those few residents who had a hearing aid, 69% reported they had problems with the device including a poor fit, discomfort or painful to wear and/or poor function. This finding is inconsistent with the report of Lewsen and Cashman (1997), who surveyed 115 residents of a Canadian RACF who owned hearing aids or ALDs and found that 93% of hearing aids were in working order. Furthermore, over 80% of study participants who owned a hearing aid self-reported regularly used the device. The regular use and working order of hearing aids and ALDs was attributed to integrated audiological services which were regularly available within the RACF (Lewsen & Cashman, 1997).

However, provision of onsite audiological services to residents within RACFs does not necessarily significantly improve hearing aid uptake. A study conducted by Linssen et al. (2013) in the Netherlands explored whether onsite audiological screening programs improved hearing aid use among 705 residents across eight RACFs. Only 34% of eligible residents took part in the study, with most refusals reportedly due to residents being "more concerned with attempts to improve other aspects of their functioning, which they perceived as more problematic than their hearing loss" (Linssen et al., 2013, p. 188). Prevalence rate of hearing impairment was high among participants (91%). Hearing aid ownership increased from 28% to 33% over the study period, which was below expectations. Given the equivocal findings regarding the use and functionality of hearing aids for managing hearing impairment among residents in RACFs (Cohen-Mansfield & Taylor, 2004a, 2004b; Lewsen & Cashman, 1997; Linssen et al., 2013), a paradigm shift away from managing hearing impairment solely through the use of hearing aids and towards

other interventions appears likely and would be consistent with recommendations of other researchers (Hickson et al., 2005; Mamo et al., 2018).

Recently, several studies have evaluated ALDs for adults living with dementia in RACFs, exploring their utility as a potential aid for improving cognition (Hopper et al., 2016; Jupiter, 2016) as well as residents' perception of the devices (Aberdeen & Fereiro, 2014). Hopper et al. (2016) examined the short-term effect of providing an ALD (Sennheiser model A200 ALD) to 31 residents with dementia and hearing impairment living in an RACF. The research group used a quasi-experimental repeated-measures crossover design, whereby participants completed five cognitive tests with and without the ALD, and tests were repeated within 4 and 14 days. The study found that all participants could tolerate the ALD; however, use of the ALD did not improve performance on the cognitive tests (Hopper et al., 2016). Several methodological factors may have influenced this. First, participants were tested in quiet, well-lit environments and were able to use visual cues to aid in understanding cognitive tests with and without ALDs. Second, sample sizes were too small to conduct a sub-group analysis by degree of hearing impairment and finally, researchers were unable to control for the possible influence of hearing aid use. Fourteen of the 31 participants were reported to have hearing aids, but the researchers were unable to determine frequency of hearing aid use. In contrast, Jupiter (2016), provided an ALD (SuperEar personal sound amplifier Model SE4000) to 10 residents with dementia and found, over an eight-week period, only two residents persisted with the device (Jupiter, 2016). A third study conducted by Aberdeen and Fereiro (2014), explored the short-term perception of an ALD (Williams Sound Pocketalker Ultra Model PKT D1) amongst 20 residents living in an Australia RACF. Most participants reported positive perceptions of the ALD in terms of understanding speech and sound quality. Although the study by Aberdeen and Fereiro (2014) was not specific to residents with dementia, it does demonstrate that there are a variety of approaches for improving communication of residents living in RACFs, extending beyond provision of hearing aids. Heterogeneity of research methods is evident across the three studies (Aberdeen & Fereiro, 2014; Hopper et al., 2016; Jupiter, 2016). However, all research groups highlighted that ALDs are an option for managing hearing impairment and should be used in conjunction with

education regarding device use (Aberdeen & Fereiro, 2014) and communication training programs for residents and caregivers (Hopper et al., 2016; Jupiter, 2016).

To date, no research group has explicitly explored the outcomes of ALDs for improving hearing-related communication for adults living with dementia and hearing impairment in RACFs. However, Mamo et al. (2017) investigated the outcomes of an ALD used in conjunction with a two-hour communication program with 20 community-dwelling adults living with dementia and hearing impairment and an accompanying caregiver. Findings of this pilot study were positive, in that the majority of individuals wore the device daily, and the intervention resulted in improvement across the seven domains of the International Outcomes Inventory-Alternative Intervention-Significant-Other (Noble, 2003). Furthermore, this study highlights that alternative audiological management options for people living with dementia are available and, within an RACF where hearing aid adoption is notoriously low, use of these devices and strategies may result in improved hearing-related communication for adults living with dementia.

Two studies have explored outcomes of holistic approaches to audiological rehabilitation for residents of RACFs (Looi et al., 2004; Pichora-Fuller & Robertson, 1997), with mixed results. Looi et al. (2004) conducted a novel mixed-methods study involving 15 residents of an RACF. Outcomes of individual (hearing aids and communication programs) and environmental (staff education and training) interventions were explored. Eight participants completed the individual intervention (were fitted with hearing aids, participated in communication programs or both) and no significant change in self-reported hearing disability was observed as measured with the Nursing Home Hearing Handicap Index – Self Version (Schow & Nerbonne, 1977). Informal training of RACF staff regarding audiological management resulted in changes at the environmental level including individualised information sheets about residents' hearing status being placed in each room and availability of information regarding management of hearing aid devices for staff.

Pichora-Fuller and Robertson (1997) conducted an ecological audiological rehabilitation program within RACFs in Ontario, Canada to explore the outcomes of an on-site audiological rehabilitation program. The study consisted of two-phases and was a within-subject within-site design. Each phase lasted for one year and

included 6-months baseline observation, followed by the intervention. Thirty residents with hearing impairment, nine of whom used hearing aids, took part in the study. Over the two-year program, residents and staff received training across several different areas such as hearing aid management, communication, and management of ALDs. The program was considered effective in terms of improving resident's knowledge of managing hearing aids, improved understanding during activities such as when attending church, and resident and staff knowledge of operating ALDs (Pichora-Fuller & Robertson, 1997). However, this study was still limited by the small percentage of residents who were involved (30 out of 362). The equivocal findings from these previous hearing intervention studies, particularly regarding residents' participation in such studies as well as desired outcomes, suggests that optimisation of hearing-related communication in the RACF context is complex.

Recently, one research group demonstrated that a theory-driven approach is helpful in conceptualising interventions required by RACF staff to help optimise hearing related communication for residents living with dementia in RACFs (Crosbie et al., 2019). Crosbie et al. (2019) used a realist synthesis of 43 papers, as well as expert opinions, to explore how RACFs staff can be effective in optimising hearing communication for residents living with dementia. This approach resulted in the identification of key intervention elements, including communication training for RACF staff and managers promoting positive regard and empathy through PCC. However, an overarching theme of RACFs staff being permitted to provide PCC was reported. A limitation of this synthesis is that Crosbie et al. (2019) did not report elements that other key stakeholders, such as audiologists, could use to aid in optimising hearing-related communication for adults living with dementia and hearing impairment in RACFs.

Improving hearing-related communication for adults living with dementia and hearing impairment in RACFs is complex. There is limited research that contributes to how hearing services, that is, how audiologists diagnose and provide hearing care, can be optimised for this population. Therefore, prior to the design of any future interventions aimed at improving long-term outcomes of hearing-related communication, an in-depth understanding of audiologists' current assessment and

management practices and the hearing-related needs of adults living with dementia in RACFs should be gained. Given that management of hearing impairment for this population involves multiple stakeholders, such as RACF staff, audiologists, family members and the individual, these stakeholders' perceptions should be considered when designing interventions aimed at improving hearing services.

1.3 Thesis Aims and Methodology

This thesis aimed to explore options for optimising the delivery of hearing services, by audiologists, to adults living with dementia and hearing impairment in RACFs by, firstly, exploring the appropriateness of current assessment and management processes and, secondly, by developing and piloting an intervention that could potentially improve how hearing impairment is managed in the long term.

Figure 1-4 provides an overview of the studies reported in this thesis, the methodology used for each study, and the specific aims that each study addresses. This thesis is comprised of a systematic review and three original research studies covering two areas of clinical audiology: diagnostic and rehabilitative.

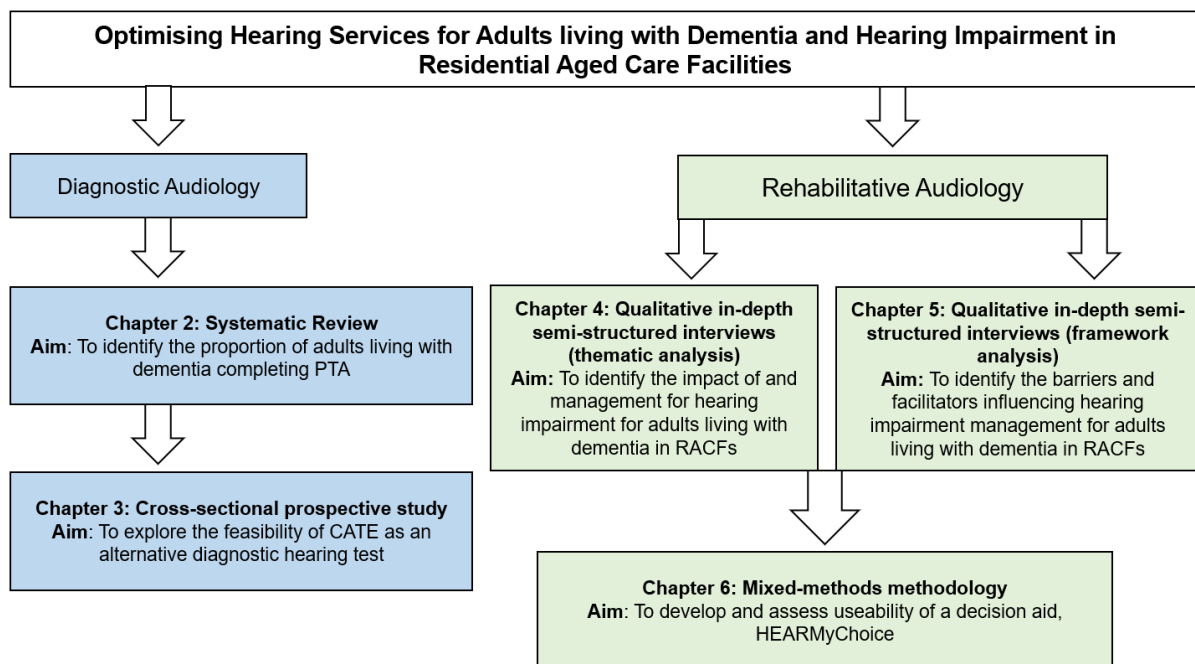


Figure 1-4 Overview of Studies Completed in this Thesis

This thesis has four key aims:

Aim 1: PTA is the most commonly used hearing test by audiologists to determine hearing thresholds in adults. However, there are reports that some proportion of adults living with dementia are unable to have their hearing assessed via PTA, thus audiologists are unable to determine nature and degree of hearing impairment. Therefore, the first aim of this thesis was to identify the proportion of adults living with dementia completing PTA.

Aim 2: The American Speech Language and Hearing Association (ASHA) recommends the use of AEP tests as an alternative for hearing threshold estimation for adults with cognitive impairment who are unable to complete PTA (ASHA, 1997). To date, only one study has explored the ability of adults with dementia to complete AEP tests, namely the auditory steady-state response (Villeneuve et al., 2017). Recently, the National Acoustic Laboratories in Australia has developed a novel AEP test, CATE, that has been reported to determine hearing thresholds in healthy adults in 20 minutes (Bardy et al., 2016). Given that ASSR takes on average between 30 and 60 minutes to evaluate hearing thresholds (Rance et al., 1995), the second aim of this thesis was to explore the feasibility of CATE as an alternative diagnostic test compared to PTA for adults living with dementia in RACFs.

Aim 3: Previous research exploring hearing impairment management for this population has been limited to RACF staff and/or individuals living with dementia. To date, no research has explored audiologists' perspectives nor family caregivers' perspectives toward hearing impairment management for adults living with dementia in RACFs. Accordingly, the third aim of this thesis was to explore the hearing-related communication needs of adults living with dementia and hearing impairment who reside in RACFs by gaining key stakeholders' perspectives on:

- the impact of hearing impairment on people living with dementia in RACFs;
- how hearing impairment is currently managed for adults living with dementia and hearing impairment in RACFs; and
- the barriers and facilitators underlying key behaviours that influence management of hearing impairment for adults living with dementia and hearing impairment in RACFs.

Aim 4: A key finding from the investigation of the management of hearing impairment and dementia in RACFs was that some audiologists do not recommend all available options for treating hearing impairment for this population. Moreover, RACF staff and family caregivers expressed an interest in knowing what options were available for managing hearing impairment, in addition to hearing aids. Decision aids are one tool that are used to promote choice for treatment options. Thus, the final aim of this thesis was to develop and pilot a patient decision aid aimed at helping adults living with dementia and hearing impairment in RACFs and family caregivers manage hearing impairment.

1.4 Thesis Structure

This thesis is submitted for examination under the University of Queensland guidelines as a “thesis with publications”. Chapters 2 to 6 contain published manuscripts (chapter 2), submitted manuscripts (chapters 3 and 4), and manuscripts in preparation for publication in peer-reviewed journals (chapters 5 and 6). Chapters 3, 4, 5 and 6 describe original studies that were conducted in accordance with the National Statement on the Ethical Conduct of Human Research (National Health Medical Research Council, 2007). This chapter (chapter 1) and chapter 7 are unpublished chapters. Chapter 1 has described the background and rationale for the research and chapter 7 summarises the key findings and clinical implications of the research, discusses the strengths and limitations of the studies and presents future research opportunities.

For consistency within this thesis, all chapters have been formatted using Australian English and according to the American Psychological Association (APA) guidelines, 6th edition (American Psychological Association, 2012). Moreover, all references are presented together at the end of the thesis.

Chapter 2 Can Adults Living with Dementia Complete Pure-Tone Audiometry? A Systematic Review

Pure-tone audiometry (PTA) is the gold-standard for establishing hearing thresholds for adults. However, within residential aged care facilities (RACFs), using PTA as the only means for determining hearing sensitivity is limiting. Two studies (Burkhalter et al., 2009; Hedner et al., 1987), identified that approximately only 30% of residents living in RACFs can complete PTA. Currently, the proportion of adults living with dementia who can complete PTA is unclear.

This chapter reports the findings of a systematic review that explored the proportion of adults living with dementia who can completed PTA.

This chapter has been published in the peer-reviewed journal, *International Journal of Audiology*: Bott, A., Meyer, C., Hickson, L., & Pachana, N. (2019). Can adults living with dementia complete pure-tone audiometry? A systematic review. *International Journal of Audiology*, 58(4), 185-192.
doi:10.1080/14992027.2018.1550687.

The content included in this chapter contains an additional paragraph in the discussion to that of the published manuscript.

2.1 Abstract

Objective: It is estimated that over 60% of adults with dementia will also have a hearing impairment, resulting in a dual sensory-cognitive communication disability. Hearing interventions may lessen the impact of hearing impairment on a communication disability; yet, for audiologists to recommend appropriate hearing interventions, the individual's hearing thresholds must first be accurately established. The gold standard test for establishing hearing thresholds is pure-tone audiometry (PTA). However, the ability of adults with dementia to successfully complete PTA is uncertain. This systematic review examined studies of adults with dementia to better determine the proportion who could complete PTA.

Design: Systematic review.

Study Sample: Studies were included that assessed hearing in older adults who were reported as having mild and greater dementia. From a total of 1,237 eligible studies, only three were found to meet all inclusion criteria.

Results: Across these three studies, the proportion of adults with dementia who could successfully complete PTA ranged from 56% to 59%.

Conclusions: Further research is needed in this area, particularly for adults with moderate and severe stages of dementia. Future research should also consider the feasibility of complementary, non-behavioural hearing tests. This systematic review was registered with the PROSPERO database, registration number CRD42017073041.

2.2 Introduction

In 2012, the World Health Organization (WHO) identified dementia as a public health priority, driven by the ageing population, and predicted an exponential increase in the number of adults aged over 65 years living with dementia by 2050 (WHO, 2012). A systematic review drawn from the 2015 World Alzheimer's Report reported that 4.3% of adults aged over 70 years and 39.8% of adults aged over 90 years in America, Australia and Europe were reported to have dementia (Prince et al., 2015), suggesting that prevalence rates for dementia increase with age. Furthermore, due to the ageing population, the incidence of dementia is anticipated to double, every 20 years, reaching approximately 2 billion people by 2050 (Prince et al., 2012). Prevalence rates by dementia severity differ based on where individuals reside. For example, Matthews et al. (2016) reported that 98.6% of 137 adults living with dementia in residential aged care facilities (RACFs) had severe functional impairments compared to 56.6% of 302 community-dwelling adults with dementia. It is important to consider the different prevalence rates by dementia severity, as the support needs increase as the disease progresses (Chung, 2006). Therefore, policy makers should be aware that within RACFs, adults with dementia have more severe functional impairments compared to community-dwelling adults and should accommodate this accordingly. It is also well recognised that the prevalence of other health conditions, including hearing impairment, is age-related (WHO, 2015). Given these findings, it is likely that elderly adults with dementia may also be found to have other concurrent age-related health conditions. Studies by Gurgel et al. (2014) and Teipel et al. (2015) have reported links between the prevalence of hearing impairment and prevalence of dementia in the German population.

However, reported prevalence rates of hearing impairment among adults with dementia vary across studies. For example, Nirmalasari et al. (2017) reported that 60% of 100 community-dwelling adults with dementia and mild cognitive impairment had a mild or greater hearing impairment, with a mild hearing impairment being classified as a loss greater than 25 dB HL across 500 – 4000 Hz, in the better hearing ear. Hopper, Slaughter, Hodgetts, Ostevik and Ickert (2016) reported that 92% of 36 adults with dementia living in an RACF had a mild or greater hearing impairment, with a mild hearing impairment being classified as a pure-tone average loss greater than 25 dB (frequencies not specified) in the better hearing ear. Gold,

Lightfoot and Hnath-Chisolm (1996) reported that 90% of 52 adults with Alzheimer's disease failed a hearing screening test, with a fail being considered as "no response" at 40 dB HL, a score of 18 or higher on the Hearing Handicap Inventory for the Elderly (Ventry & Weinstein, 1982), or a score <18 on the Hearing Handicap Inventory for the Elderly and "no response" at 25 dB HL (one or both ears not specified). The differing prevalence rates reported across studies may be explained by differences in: testing methodologies; classification of hearing impairment; and participant group (i.e. community versus RACF). However, whilst prevalence rates varied, overall, these studies confirm a high prevalence of hearing impairment among adults with dementia, suggesting that many adults with dementia will experience a combined sensory-cognitive communication impairment.

When dementia and untreated hearing impairment co-occur, communication impairments are exacerbated, a phenomenon referred to as "excess disability" (Slaughter & Bankes, 2007). As highlighted in a review paper by Hopper and Hinton (2012), dementia and untreated hearing impairment can impact communication in similar ways by impairing a person's ability to understand rapid speech, speech in noisy environments, and complex speech. Thus, the person with a dual sensory-cognitive impairment has greater difficulty communicating compared to an individual with a cognitive impairment and no sensory impairment (Guthrie et al., 2018). For adults with dementia living in an RACF home, concomitant hearing impairment has also been associated with a higher refusal rate to engage in social activities (Cohen-Mansfield, Marx, Regier, & Dakheel-Ali, 2009). The ability of nursing staff to provide care to adults with dementia and hearing impairment is also impacted, as nursing staff have difficulty distinguishing between communication impairments due to dementia and hearing impairment (Slaughter, Hopper, Ickert, & Erin, 2014). To decrease excess disability, by appropriately managing the hearing impairment, an accurate diagnosis of hearing must occur first.

PTA is traditionally the most commonly used diagnostic tests used in audiology clinics to evaluate hearing thresholds in adults (Musiek, Shinn, Chermak, & Bamiou, 20). PTA is used by audiologists to identify the degree and nature of hearing impairment, information that cannot be obtained via screening or observing hearing alone. PTA is a behavioural test, requiring the individual to respond by

pressing a button, raising a hand or verbally indicating when they have heard a tone presented through headphones or in a sound-field. This may be problematic for adults with dementia, who, due to declining cognitive function, are unable to reliably complete this task. A retrospective chart review conducted on 307 adults with behavioural and psychological symptoms of dementia, who were living in residential RACF, identified that only 32% could reliably complete PTA (Burkhalter, Allen, Skaar, Crittenden, & Burgio, 2009). Although this study did not specifically examine adults with a confirmed dementia diagnosis, it nonetheless raises questions as to whether adults with dementia can effectively complete this behavioural hearing test.

Accordingly, the aim of this study was to conduct a systematic review of the available literature to investigate the following clinical question: What proportion of adults with dementia can complete PTA? For the remainder of this article, the term “complete” refers to the person’s ability to cooperate to at least establish his or her hearing threshold at a minimum of three frequencies in both ears as assessed by the audiologist. Findings from this review may provide valuable clinical information to those who provide hearing care to adults with dementia and contribute to the limited literature surrounding adults with dementia and hearing impairment.

2.3 Method

This review was conducted following the guidelines established by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff & Altman, 2009).

2.3.1 Search Strategy

The proposed methodology and search strategy was completed and registered with the PROSPERO database (registration number CRD42017073041, 28 September 2017). Three amendments to the original research protocol occurred. First, the original review sought to explore the literature surrounding all stand-alone threshold hearing tests, that is PTA and electrophysiological testing, such as auditory brainstem response and or cortical AEP; however, given that PTA is the most commonly used hearing test to estimate hearing thresholds (Musiek et al., 2017), a decision was made to focus on PTA only. Second, the original review sought to

include studies published in all languages. Suitable translators could not be found for all articles published in languages other than English; as such, the review was limited to studies published in English. Finally, the original review did not apply a limitation to year of publication. However, the final review was limited to studies published from 01 January 2000, as a 17-year review period was considered a reasonable timeframe for examining the literature.

An extensive computer-assisted literature search was conducted on December 11 2017 using electronic databases (MeSH explode and keyword) in PubMed, CINAHL, EMBASE and Scopus, which was accompanied by reference checking. The final search terms (dementia or alzheimer*) were combined with (audiolog* or hear*) and (test* or assess* or measure* or audiometry or “pure tone”) and were found to capture a wide range of studies that assessed hearing via PTA for adults with dementia.

2.3.2 Study Inclusion Criteria

Studies were included in this review if: at least one participant group was identified as having dementia at the commencement of the study (all causes of dementia including unspecified dementia were included); participants with dementia attempted to complete PTA to identify their hearing thresholds and a minimum of three frequencies were measured; the study clearly reported the number of people with dementia who could and could not complete PTA; and the study included participants with a range of dementia severities.

In addition, studies were excluded if: the dementia status of participants was not reported or ambiguous; studies examined participants with dementia and mild cognitive impairment, however results were not reported separately for the two groups; and/or studies conducted PTA screening only and did not determine participants' hearing thresholds. That is, studies that recorded participant hearing results as Yes/No or Pass/Fail were excluded, as were studies that reported on a single subject or that did not report original data.

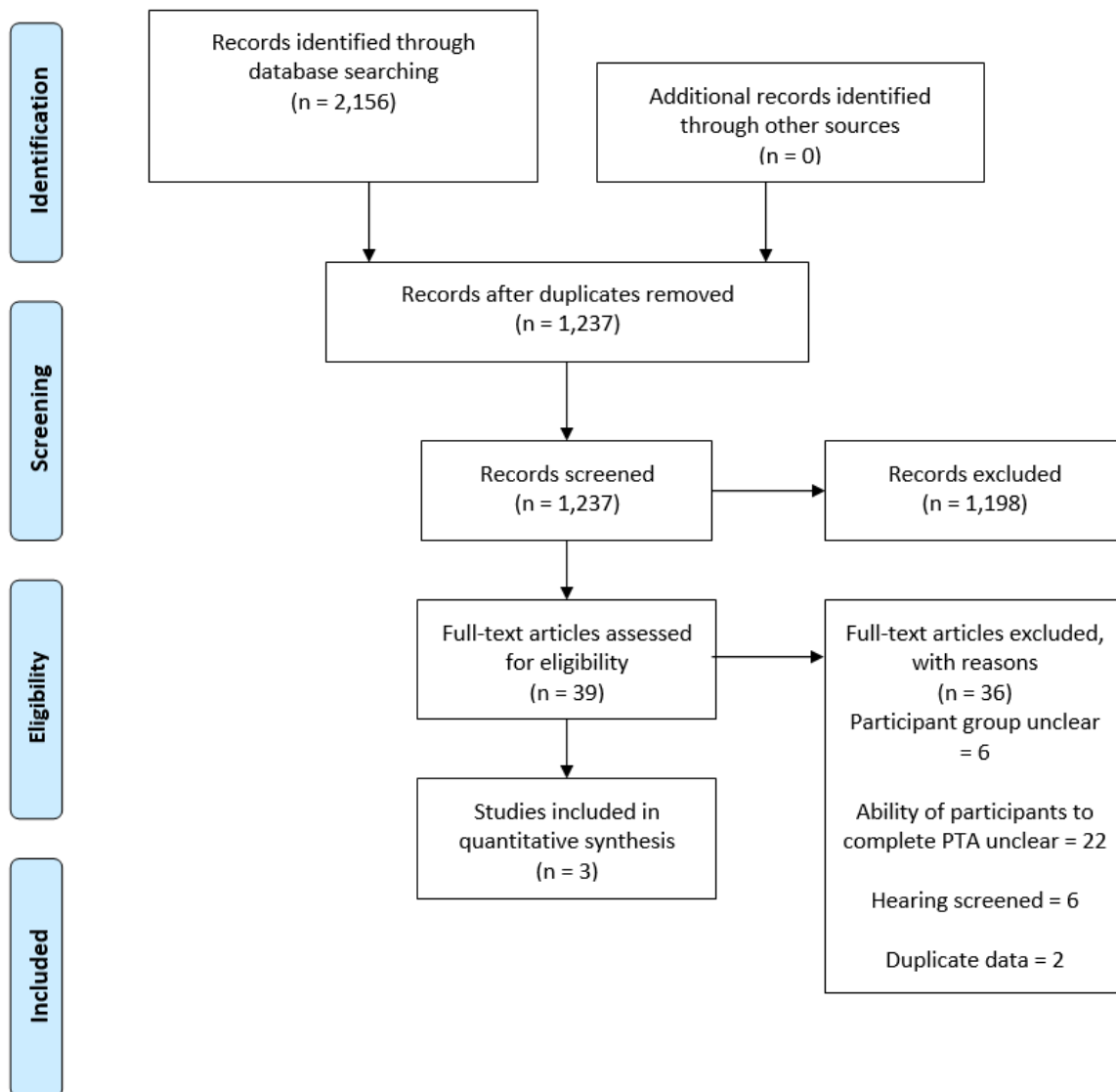


Figure 2-1 PRISMA Flow Chart of Articles Included in this Systematic Review

2.3.3 Search Selection Procedure

The search strategy yielded a total of 1,237 articles, following duplicate removal (see Figure 2-1). EndNote™ X7.2.1 referencing software was utilised to conduct the abstract screening process. Article screening and full-text review was completed by one reviewer; with 50% of the full-text articles being reviewed for suitability by a second reviewer. It is recommended that between 20-30% of studies are evaluated by at least two independent reviewers (Schlosser, Wendt, & Sigafos, 2007). Articles reviewed by the second reviewer were selected using a random number generator and results were discussed between the two reviewers during

team meetings. When a decision could not be reached between the two reviewers, a third reviewer resolved the discrepancy. Reference checking occurred and authors were contacted to clarify missing data relevant to this systematic review. Following this process, three studies were determined to meet the inclusion/exclusion criteria and were appraised.

2.3.4 Data Extraction

A specifically designed form was used to extract data from each included study using Microsoft Excel™. One author extracted data from the three included articles. The following data were extracted under four categories:

1. Study characteristics: authors; title of study; year; journal; study design; sampling method; aims; inclusion criteria and exclusion criteria.
2. Study population: number of participants; age; gender; setting (e.g. laboratory, clinic, community); subtype of dementia; dementia severity tool; severity of dementia.
3. PTA details: thresholds assessed; technical features of equipment; operator characteristics (e.g. training of researchers operating test); location where PTA was conducted (e.g. soundtreated).
4. Target outcome: number of participants with dementia able to complete PTA; severity of participants able to complete PTA; the proportion of people with dementia able to complete PTA; number of people with dementia unable to complete PTA; dementia severity of participants unable to complete PTA; reasons why participants could not complete PTA.

Where information was missing, unclear or not appropriate, responses were recorded as such on the data extraction form.

2.3.5 Quality of Studies

Given the nature of the studies included in this review, that is, observational studies, each study was assessed for quality of reporting via the 22-item STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) checklist (Von Elm et al., 2007). STROBE was developed by a joint committee from Enhancing the QUAlity and Transparency Of health Research (EQUATOR network; see www.equator-network.org). Each paper was independently assessed by two reviewers, with discrepancies being resolved during team meetings.

2.3.6 Bias

Each study was assessed for selection bias given observational studies are particularly susceptible to this form of bias (Hammer, du Prel, & Blettner, 2009). Selection bias occurs when the included participants are not randomly selected from the target population. Each article was assessed as either high risk of selection bias (no attempt to address selection bias in study design), low risk of selection bias (authors have provided a suitable sampling strategy for their study) or moderate risk of selection bias (population based study or unclear attempt to address selection bias). This method for assessing bias is based on The Cochrane Handbook (Higgins & Green, 2008).

2.4 Results

2.4.1 Description of studies

The three studies meeting the inclusion criteria were all cross-sectional studies (Table 2-1). Each study was completed in a different country and recruited participants from different types of locations. Hopper et al. (2016) recruited participants from RACFs in Canada; whereas participants in the study of Villeneuve et al. (2017) were recruited from a geriatric memory clinic in France; and participants in the study by Quaranta et al. (2014) were recruited from a town in Italy. None of the three studies specifically aimed to identify the proportion of adults with dementia who could complete PTA; however, all three studied included aims related to assessing hearing: two aims were specific to adults with dementia and one to adults over the age of 65 years.

Table 2-1 Summary of Study Design, Aim and Inclusion/Exclusion Criteria from the Studies Included in this Review

Author	Year	Title	Study design and sampling procedure	Aim of study	Inclusion criteria	Exclusion criteria
Hopper et al.	2016	Hearing Loss and Cognitive-Communication Test Performance of Long-Term Care Residents With Dementia: Effects of Amplification	Cross-sectional convenience sample	1) To explore the relationship between hearing loss and cognitive-communication test performance of individuals with dementia and 2) to determine if hearing loss is accurately identified by LTC staff using the Resident Assessment Instrument-Minimum Data Set 2.0.	a) had a diagnosis by a physician of AD, vascular dementia, or mixed dementia; b) were literate, fluent speakers of English, c) visual function sufficient to read 24- to 28- point font, as determined using the Vision and Literacy screening subtest of the Arizona Battery for Communication Disorders; and d) presented with a mild-to-moderate hearing impairment.	Participants were excluded if they had a diagnosis of frontotemporal or Lewy body dementia, as these types of dementia often have variable presentation patterns and tend to progress differently from Alzheimer's disease.
Quaranta et al.	2014	The prevalence of peripheral and central hearing impairment and its relation to	Cross-sectional convenience sample; healthy effect*	To evaluate the prevalence of ARHL and cognitive impairment in a large sample of subjects older than 65 years and to correlate	Aged >65 years living in the town of Castellana Grotte in Barilla, Italy.	Not reported

		cognition in older adults		hearing function with cognitive function.		
Villeneuve et al.	2017	Audiometric evaluation in patients with Alzheimer's disease	Cross-sectional convenience sample	To assess the validity of ASSR as a complementary diagnostic test to determine hearing thresholds in AD/MCI subjects	Cognitive impairment in patients: AD according to the AMNIAAA and MCI according to Petersen's criteria. All patients were 75 years or older and had a MMSE under 27/30, determined by their geriatrician. None of the patients had an auditory rehabilitation	Otosopic abnormalities, middle ear surgery, abnormal tympanogram, other types of dementia than AD, retro-cochlear lesion, central nervous system disease altering cerebral lateralisation

Note. LTC = long term care; AD = Alzheimer's disease; ARHL = age related hearing loss; ASSR = auditory steady state response; MCI = mild cognitive impairment; AMNIAAA = American National Institute on Aging and Alzheimer's Association.

*A healthy effect is reported by authors to occur, as only participants that could attend the assessment at the research hospital were included in the analysis. Adults that could not present at the research hospital due to illness were unable to participate in this study.

The three studies were heterogenous in regards to audiometer equipment, type of headphone used, location where PTA was performed and specific frequencies measured as outlined in Table 2-2. In addition, hearing loss classification also varied. For example, Villeneuve et al. (2017) reported the individual pure tone average for each participant as well as the mean pure tone average for participants, whereas Quaranta et al. (2014) reported whether a hearing impairment was present or absent based on a hearing level of 35 dB HL (500, 1000, 2000 Hz), and Hopper et al. (2016) reported whether participants had a mild (26-45 dB HL) or moderate (46-65 dB HL) hearing impairment.

Table 2-2 Summary of Information Pertaining to Aspects of Pure-Tone Audiometry from the Studies Included in this Review

Study	Technical features	Location where PTA was completed	Frequencies measured using PTA	Hearing thresholds of participants
Hopper et al. 2016	AD226 diagnostic audiometer (Interacoustics, Assens, Denmark) with ER-3A insert earphones	In a quiet room at the LTC facility	Air conduction: 0.25 – 8 kHz	WNL (≤ 25 dB HL) = 3 Mild HL (26-45 dB HL) = 19 Moderate HL (46-65 dB HL) = 12
Quaranta et al. 2014	Not reported	Completed at a research hospital*	Air conduction: 0.5 – 8 kHz	HL >35 dB (0.5 – 2 kHz) absent = 5 HL > 35 dB (0.5 – 2 kHz) present = 20
Villeneuve et al. 2017	Madsen Orbiter 922 version 2 audiometer with Sennheiser had200 headphones for air-conduction and a Radio Ear B71 oscillator for bone-conduction	Completed in a soundproof booth	Air and bone conduction: 0.5 – 4 kHz	Pure-tone average 0.5-4 kHz = 50.2 (± 23.1) Individual participant average Hearing thresholds reported in paper

Note. PTA = pure tone audiometry; LTC = Long Term Care; WNL = Within Normal Limits; HL = Hearing Loss; kHz = kilohertz.

2.4.2 Dementia Type and Severity of Participants

Table 2-3 reports the number of participants with dementia, sub-types of dementia, dementia severity assessment tools and the dementia severity of participants reported in each study. Dementia sub-type varied across the three studies. Two studies included participants with a diagnosis of Alzheimer's disease only as determined through a neuropsychological assessment (Quaranta et al., 2015) and through an Alzheimer's questionnaire (Villeneuve et al., 2017). The third study included participants with a combination of dementia causes, that is, Alzheimer's disease, vascular dementia and mixed dementia, with mixed dementia being a combination of Alzheimer's disease and vascular dementia. Alzheimer's disease is the most common cause of dementia, occurring in approximately 70% of all reported cases (WHO, 2012). However, as reported by WHO, Alzheimer's disease can also occur with a secondary dementia, such as vascular dementia or Lewy body dementia (WHO, 2012). Alzheimer's disease and vascular dementia often present with similar impairments to memory and executive function (McGuinness, Barrett, Craig, Lawson, & Peter Passmore, 2010), as such it is anticipated adults with Alzheimer's disease and vascular dementia will have a similar ability to complete, or not complete, PTA.

Each of the three studies used a different measure of cognitive impairment to categorise participants' dementia severity. Villeneuve et al. (2017) used the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). The MMSE is widely used to assess individuals' cognitive function but it is not designed to evaluate dementia severity. The MMSE is a screening instrument, with a cut-off of "normal" versus "further evaluation recommended". Furthermore, adults with a dementia diagnosis can fall into the "normal" category of the MMSE (Shiroky, Schipper, Bergman, & Chertkow, 2007). Quaranta et al. (2014) used the Clinical Dementia Rating scale (CDR; Morris, 1993) which contains five impairment categories: none "0"; questionable "0.5"; mild "1"; moderate "2"; and severe "3". The CDR gathers information from an informant as well as the participant to calculate the overall score. Finally, the MDS-Cognitive Performance Scale (CPS; Morris et al., 1994) is an ordinal scale of cognitive impairment ranging from 0 "intact" to 6 "very severe impairment" that was used by Hopper et al. (2016). The CPS was designed to assess cognitive status of individuals living in RACFs and determines cognitive

severity based on direct and indirect measure e.g. interview with residents and observations of resident.

As shown in Table 2-3, reported dementia severity varied across the studies. All three studies included participants with mild and moderate dementia. Participants in the study by Hopper et al. (2016) ranged from mild to severe dementia, whereas participants in the study by Villeneuve et al. (2017) ranged from normal to moderate (Table 2-3). As identified by Shiroky et al. (2007) adults with a confirmed dementia diagnosis can be assessed as “normal” according to the MMSE.

2.4.3 Sample Size, Quality of Studies and Bias

Table 2-3 also shows the number of adults with dementia included in the final analysis of each study, being 31, 25 and 8. Hopper et al. (2015) included a power calculation, and accordingly the sample size ($N=31$), is appropriate for their study design. Quaranta et al. (2014) recruited participants from the community, and not specifically adults with dementia. A “healthy effect” may be present in the study by Quaranta et al. (2014), as participants who could not attend the clinic for audiological assessment, due to ill health, were not included in the results. Villeneuve et al. (2017) did not include a sample size calculation and this study contained only eight adults with dementia. Quality of reporting of studies according to the STROBE was 19/22 (Hopper, Slaughter, Hodgetts, Ostevik, & Ickert, 2016), 15/22 (Quaranta et al., 2014) and 16/22 (Villeneuve et al., 2017). Selection bias was assessed as high in the study by Villeneuve et al. (2017) as convenience sampling was employed, moderate for the study by Quaranta et al. (2014) as this was a population-based study and low for the study by Hopper et al. (2016) as a sampling strategy was employed in this study. However, a high risk of reporting bias is present in the study by Quaranta et al. (2014), given that the authors did not clearly report the number of adults in the town who did not participate in the study.

Table 2-3 Summary of Information of the Dementia Participants from the Studies Included in this Review

Study	Number of participants with dementia included in the final analysis of the study	Sub-type of dementia (N)	Dementia severity assessment tool	Dementia severity of participants (N)	Mean age of participants with dementia (years)	Gender of participants with dementia (%)
Hopper et al. 2016	31	Unspecified (15) AD (8) VD (5) Mixed (3)	MDS CPS	Mild (7) Moderate (13) Moderate/severe (2) Severe (3) Missing (6)	Not reported	Female (58.1)
Quaranta et al. 2014	25	AD (25)	CDR	Mild (21)* Moderate (4)*	78.7 ± 5.8	Female (32)
Villeneuve et al. 2017	8	AD (8)	MMSE	Normal (3) Mild (2) Moderate (3)	82.1 ± 4.6**	Female (50)

Note. AD = Alzheimer's disease; VD = Vascular dementia; MDS CPS = Medical Data Set Cognitive Performance Scale; CDR = Clinical Dementia Rating Scale; MMSE = Mini-Mental State Examination

*reported in correspondence with authors

**included 4 adults diagnosed with mild cognitive impairment and 8 adults with Alzheimer's disease

2.4.4 Proportion of Adults with Dementia Completing PTA

The proportion of adults with dementia reported as completing PTA was 56% (Quaranta et al., 2014), 57% (Villeneuve et al., 2017), and 59% (Hopper, Slaughter, Hodgetts, Ostevik, & Ickert, 2016) (Table 2-4). Although the proportion of adults completing testing was consistent across the three studies, it is interesting to note that the dementia severity of participants was quite variable.

Two of the studies reported information on participants who were unable to complete PTA. Quaranta et al. (2014) reported that one-third of participants assessed with mild dementia ($N=7$) and no participant assessed with moderate dementia ($N=4$) were able to complete PTA. Furthermore, the average MMSE score of participants that could not complete PTA in the study by Villeneuve et al. (2017) fell into the moderate impairment category (12/30).

Table 2-4 Summary of the Proportion of Adults with Dementia Completing Pure-Tone Audiometry from the Studies Included in this Review

Study	Number of people with dementia unable to complete PTA	Number of people with dementia able to complete PTA	Proportion of people with dementia able to complete PTA	Percentage of people with dementia able to complete PTA	Dementia severity of participants able to complete PTA	Dementia severity of participants unable to complete PTA
Hopper et al. 2016	25	36	36/61	59%	Mild = 7 Moderate = 13 Moderate/severe = 2 Severe = 3 Missing = 11	Not reported
Quaranta et al. 2014	11*	14*	14/25*	56%*	Mild = 14*	Mild (7)* Moderate (4)*
Villeneuve et al. 2017	6	8	8/14	57%	Normal = 3 Mild = 2 Moderate = 3	Mean MMSE score of 12/30

Note. PTA = Pure Tone Audiometry; MMSE = Mini-Mental State Examination;

*reported in correspondence with author

2.5 Discussion

This systematic review confirms that few studies have examined the ability of adults with mild and greater severity of dementia to complete PTA. In fact, no study was identified in the review that specifically examined this question as a primary aim. It is unknown why previous research has not considered the ability of adults living with dementia to complete PTA, given the ubiquitous use of this test for evaluating hearing in adults. Potentially, previous researchers may not have considered it important to report the number of people living with dementia that were excluded because they were unable to complete PTA. Of the three studies that met all inclusion criteria, the proportion of adults with dementia completing PTA was relatively consistent, ranging from 56% to 59% of participants. However, the studies were heterogeneous in nature, included small numbers of participants drawn from very different environments and had varying levels of risk of selection bias. Recruitment of adults living with dementia is often challenging because individuals may not be able to provide consent to take part in research (Zermansky, Alldred, Petty, & Raynor, 2007). In these instances, a legally authorized person is required to provide informed consent, and may explain why the studies included in this review contained low participant numbers. However, further research is needed with larger samples (including more participants with moderate and severe dementia), using consistent measures for quantifying dementia severity and PTA methodology and attempting to reduce selection bias.

Findings from this systematic review suggest that most adults with mild dementia could cooperate enough to establish his or her hearing threshold at a minimum of three frequencies in both ears. This is consistent with the literature that has examined peripheral and central auditory testing with adults with mild cognitive impairment and mild dementia (Gates, Anderson, Feeney, McCurry, & Larson, 2008; Gates et al., 2010). Furthermore, the review suggests that PTA can also be used to evaluate hearing for some adults with moderate and severe dementia. However, conversely, approximately 40% of adults with dementia in the reported studies were unable to complete PTA, findings that suggest it is difficult to evaluate hearing via PTA with all adults with dementia.

Given the reported variance in ability of adults with dementia to complete PTA, it is relevant to consider how audiologists could modify hearing evaluation procedures with adults with dementia. Clinicians should continue conducting PTA first with all clients with dementia, irrespective of patients' dementia severity. However, clinicians may need to adapt testing procedures to obtain accurate thresholds, an approach that is recommended by the American Speech-Language-Hearing Association (American Speech-Language-Hearing Association, n.d.). None of the studies included in this review identified strategies used to obtain PTA results in adults with dementia; however, Burkhalter, Allen, Skaar, Crittenden, and Burgio (2009) and Lemke (2011) suggested modifying PTA procedures to a format similar to that used during paediatric diagnostic assessments. For example, using a more interesting tone, shortening the frequency range to reduce the impact of fatigue and ensuring the environment is relaxed and amenable for the individual with dementia (Burkhalter et al., 2009; Lemke, 2011). Importantly, audiologists evaluating hearing with adults with dementia need to be flexible and adapt testing procedures to the individual's needs. However, even when testing procedures are adjusted by clinicians, this review identified that PTA may still be unsuitable for establishing hearing thresholds across a range of frequencies in both ears in some adults with moderate and severe dementia.

Findings from this review may be limited to adults diagnosed with Alzheimer's disease, vascular dementia or mixed dementia. Of the three studies included in the quantitative appraisal, all three included adults with Alzheimer's disease and one study included adults with Alzheimer's disease, vascular dementia, mixed dementia and unspecified dementia (Hopper et al., 2016). There are over 100 different diseases that fall under the umbrella term of dementia; Alzheimer's disease is the most common, estimated to account for up to 70% of all dementia diagnoses (Dementia Australia, 2019). The four most common types of dementia are Alzheimer's disease, Lewy Body Dementia, vascular dementia and fronto-temporal dementia; each of which present with different aetiologies, cognitive changes and neuropsychiatric symptoms (Holmes & Amin, 2016). Because of this difference, there is likely to be some variability of adults with different types of dementia to complete PTA. Further research is required to explore this.

From a clinical perspective, the challenge identified in this systematic review is that 41% to 43% of adults with dementia in the three studies were unable to complete PTA (Hopper et al., 2016; Quaranta et al., 2014; Villeneuve et al., 2017), thus adaptation of procedures or alternative diagnostic tests are needed for this population. It is unknown how clinicians currently, if at all, identify and address hearing impairment for adults with dementia who are unable to complete PTA. Potentially, clinicians can use previous audiograms, if these are available, or use screening measures such as otoacoustic emissions (Jupiter, 2012), and/or adopt a trial-and-error approach whereby hearing aids are adjusted based on feedback of the person living with dementia and/or caregivers. However, these approaches are sub-optimal as the clinician is required to, in essence, 'guess' the individual's hearing threshold. For over 30 years, auditory-evoked potential (AEP) testing has been recommended as an alternative hearing test for adults with dementia (Hedner, Broms, Harris, & Steen, 1987) and is also recommended by ASHA for use with adults living with dementia during the later stages of the disease (ASHA n.d.). The study by Villeneuve et al. (2017) was the first to examine AEP testing for adults with dementia and demonstrated that it could be tolerated. Further research is needed in this area to examine the clinical feasibility of AEP testing. In addition to PTA and AEP testing, speech audiometry can also be used to evaluate hearing. However, previous research exploring the application of speech audiometry tests for this population has been limited to adults with dementia-like behaviours (Burkhalter et al. 2009) or to adults with mild cognitive impairment only (Aimoni et al., 2015; Boboshko et al., 2016). Therefore, it is unknown whether other behavioural audiometry tests, such as speech audiometry, may be more applicable than PTA for evaluating hearing in adults living with dementia. Further research is needed in this area. Given that conservatively, one in five adult patients seen by audiologists will have dementia (Pichora-Fuller, Dupuis, Reed, & Lemke, 2013; Wright et al., 2014), audiologists need to be aware of the strengths and limitations of all diagnostic tests (behavioural and AEP) for adults with dementia.

Finally, two studies included in this review demonstrated that some adults with more advanced stages of dementia could complete PTA (Hopper et al., 2016; Villeneuve et al., 2017). Accordingly, audiology researchers should consider including adults with more advanced stages of the disease within their research

design. Potentially, a more appropriate inclusion/exclusion criterion when conducting research with adults with dementia might be “ability to complete the test (e.g. PTA/AEP)” rather than “participants with mild dementia only.” Extending research on the ability of adults with all ranges of dementia severity to complete PTA and alternative diagnostic tests, would help to help shape the development of clinical guidelines for the evaluation of hearing for adults with dementia, irrespective of dementia severity.

2.5.1 Methodological Limitations

The current review was limited to quantitative studies published in the English language in peer-reviewed journals and did not include the broader international literature or grey literature. Therefore, there was potential of reporting bias by limiting this review in this way.

2.6 Conclusions

This review identified that the proportion of people with dementia reported as being able to complete PTA was between 56% and 59%, suggesting that PTA can be an effective tool in hearing evaluation for the majority of adults with dementia. However, the review also identified that there are limited studies that have examined the ability of adults with mild and greater dementia severity to complete the traditional hearing test PTA. This review highlights the need for further research to address this important question and should focus on homogeneous research design and the inclusion of adults with the full range of dementia severities. Furthermore, given that approximately 40% of adults with dementia are unable to complete PTA, future research should also examine the feasibility of alternative non-behavioural hearing tests, such as AEP tests.

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Chapter 3 Cortical Automatic Threshold Estimation (CATE) and Dementia

As reported on in chapter 2, there is limited research that describes the proportion of adults living with dementia who can complete pure-tone audiometry (PTA). From 1,237 eligible studies, only three met all inclusion criteria and the proportion of adults living with dementia who could complete PTA was between 56% and 59%. Moreover, there are inconsistent reports on the ability of adults with dementia to complete PTA, by severity. Within Australian residential aged care facilities (RACFs), over 50% of residents are reported to be living with dementia (Australian Institute of Health and Welfare, 2014); experiencing a combined sensory-cognitive communication impairment. Researchers advocate for appropriately managing hearing impairment to improve the quality of life of individuals living with dementia and hearing impairment in RACFs (Flynn, Kennedy, Johns, & Stanbridge, 2002; Slaughter et al., 2014). A fundamental step toward appropriately managing hearing impairment is an accurate assessment of hearing thresholds. As highlighted in chapter 2, 41% of adults living with dementia are unable to have their hearing thresholds determined using PTA. Thus, there is a need to compare the feasibility of objective measures of hearing to PTA. Cortical Automatic Threshold Estimation (CATE) is a novel, fully automated, auditory-evoked potential test developed by The HEARing Cooperative Research Centre and The National Acoustic Laboratories. The clinical feasibility of CATE is currently being investigated with a number of clinical populations (Bardy, Van Dun, et al. 2016).

This chapter reports the findings of a prospective cross-sectional study that explored the feasibility of CATE to PTA for estimating hearing thresholds with adults living with dementia in RACFs.

This chapter is currently under review in the peer-reviewed journal, *International Journal of Audiology*: Bott, A., Hickson, L., Meyer, C., Bardy, F., Van Dun, B., & Pachana, N. (2019) *Is cortical automatic threshold estimation a feasible alternative for hearing threshold estimation with adults living with dementia?*

Manuscript submitted for publication

The content included in this chapter expands on that of the submitted manuscript.

3.1 Abstract

Objective: This study explored the feasibility of Cortical Automatic Threshold Estimation (CATE), an automated auditory-evoked potential (AEP) test, as an alternative hearing test for adults with dementia living in a residential aged care facility (RACF).

Design: A single group cross-sectional study was conducted. Participants' dementia severity was determined through the Clinical Dementia Rating scale. Hearing thresholds were obtained for four audiometric frequencies in at least one ear by using both pure-tone audiometry (PTA) and CATE.

Study sample: 16 adults with dementia of varying severity living in an RACF were included in the final analysis.

Results: Three participants completed PTA only; five completed CATE only; six were assessed with both PTA and CATE; and two participants were unable to be tested with either PTA or CATE. For the five participants with severe dementia, four could be assessed with CATE but not PTA. The average test time for PTA was 10.4 ± 4.4 minutes, and 51.7 ± 16.5 minutes for CATE.

Conclusions: Although more people with severe dementia completed CATE than PTA, CATE took approximately five times longer to run than PTA. The uptake of CATE into audiology practice is unlikely if clinicians adopt the same parameters that were used in the present study.

3.2 Introduction

Over 90% of adults living with dementia in a residential aged care facility (RACF) have a mild or worse hearing impairment (Hopper, Slaughter, Hodgetts, Ostevik, & Ickert, 2016; Jupiter, 2012), meaning they have a dual sensory-cognitive communication disability. Dementia, an umbrella term for a group of neurodegenerative diseases, typically disrupts semantic memory and language function (Verma & Howard, 2012), and impairs conversations as individuals progressively lose the ability to recall words and events (Bayles, Tomoeda, & Trosset, 1992; Caramelli, Leticia Lessa, & Nitrini, 1998). Age-related hearing impairment is caused principally by damage to the sensory structure of the cochlea, which results in difficulty understanding speech, particularly in the presence of noise (Tun, McCoy, & Wingfield, 2009; Wingfield, Tun, & McCoy, 2005). When dementia and hearing impairment co-occur, communication difficulties are exacerbated and the individual experiences a more severe communication disability compared to that of an individual with dementia or hearing impairment in isolation (Guthrie et al., 2018; Slaughter & Bankes, 2007). Thus, hearing services have been proposed to be important for adults with dementia and hearing impairment (Hopper & Hinton, 2012; Pichora-Fuller, Dupuis, Reed, & Lemke, 2013).

Commercially available hearing devices, such as hearing aids (Allen et al., 2003; Palmer, Adams, Bourgeois, Durrant, & Rossi, 1999; Palmer, Adams, Durrant, Bourgeois, & Rossi, 1998) and/or assistive listening devices (Mamo et al., 2017), may be beneficial for improving communication and reducing behavioural and psychological symptoms of dementia in older adults with concomitant hearing impairment. Allen et al. (2003) tested the effects of providing hearing aids to 35 adults with dementia and hearing impairment who had not previously used a hearing aid. A significant reduction in hearing difficulties, as measured through the Nursing Home Hearing Handicap Index Patient and the Nursing Home Hearing Index Carer (Schow & Nerbonne, 1977), was found 6 months after hearing aid fitting. Mamo et al. (2017) explored the outcomes of a multipronged intervention for 20 adults with dementia and hearing impairment and a family caregiver. The intervention consisted of fitting of an assistive listening device and attendance of an education session regarding hearing impairment and communication. There was no significant difference in depression or problem behaviours at one-month post-intervention,

however, those with more severe depression and problem behaviours at baseline showed greater improvement in these areas compared to those with less severe baseline depression and problem behaviours. Although the studies by Mamo et al. (2017) and Allen et al. (2003) were not conducted in RACFs and involved relatively small samples of participants, both identified that adults with dementia and hearing impairment can be provided with hearing interventions and that a dementia diagnosis should not disqualify the individual from exploring options. A first step in the provision of hearing interventions to individuals living in RACFs is the accurate evaluation of hearing sensitivity.

For adults, hearing is traditionally evaluated using PTA. However, given that PTA requires a behavioural response, its effectiveness for determining hearing thresholds for adults with dementia, particularly moderate and severe dementia, is questionable (Bott, Meyer, Hickson, & Pachana, 2019; Burkhalter, Allen, Skaar, Crittenden, & Burgio, 2009; Hedner, Broms, Harris, & Steen, 1987; Villeneuve et al., 2017). Over 30 years ago, Hedner et al. (1987) reported that only 27% of adults living in an RACF ($N=197$) could complete PTA due to the high prevalence of dementia within the group. More recently, Burkhalter et al. (2009) reported that only 32% of adults with behavioural and psychological symptoms of dementia (not a confirmed dementia diagnosis) living in RACFs ($N=307$) could complete PTA. Chapter 2 of this thesis identified that between 56% and 59% of adults living with dementia could complete PTA; however, this number is anticipated to be lower for adults living with moderate and severe dementia. Chapter 2 further identified the dearth of research investigating the ability of adults living with dementia (both in the community and in RACFs) to complete PTA. Thus, there is a need to explore the feasibility of alternative hearing tests for this population.

For over 30 years, Auditory Evoked Potential (AEP) hearing tests have been proposed as an alternative option for evaluating the hearing of adults living with dementia (Hedner et al., 1987). Despite this, to date, only one study appears to have explored the outcomes of using AEPs in this way. Villeneuve et al. (2017) conducted a study with eight adults with dementia and four adults with mild cognitive impairment and examined the correlation between the auditory steady-state response (ASSR) and PTA. Findings demonstrated a significant and strong

correlation between PTA and ASSR thresholds, suggesting that ASSR could be used to evaluate hearing in adults with dementia. However, cortical AEPs have been shown to be more closely related to behavioural hearing thresholds than the ASSR in awake adults (Tomlin, Rance, Graydon, & Tsialios, 2006; Yeung & Wong, 2007). Recently, a methodology using cortical AEPs for the evaluation of hearing has been developed by the HEARing Cooperative Research Centre and National Acoustic Laboratories (Bardy, Sjahalam-King, Van Dun, & Dillon, 2016). Termed 'the cortical automatic threshold estimation' (CATE), the software-based test has been implemented in the HEARLab[®] system (HEARworks₁) and its value for research and clinical applications is currently being assessed in a range of studies.

CATE aims to provide a hearing threshold estimate based on the P1-N1-P2 complex analysed in the time domain. The presence of the cortical response is a marker of a sound being processed at the auditory cortex level. CATE contains five important testing features, which may make it advantageous compared to other AEP tests (Bardy, Sjahalam-King, et al., 2016). First, a multi-tone stimulus is used for 1000, 2000 and 4000 Hz increasing the size of the AEP (Bardy, Sjahalam-King, et al., 2016). Second, a two-channel electroencephalogram (EEG) is set-up and a weighting average algorithm is utilised, allowing for a 5% sensitivity improvement as compared to one-channel recording (Bardy, Sjahalam-King, et al., 2016). Third, stimuli are presented in a random order to reduce habituation. Fourth, CATE automatically interprets the waveform response, using the Hotelling's T^2 statistic (Carter, Golding, Dillon, & Seymour, 2010), removing the need for subjective interpretation of the waveform. Fifth, CATE automatically determines whether stimulus intensity should be reduced or increased depending on the detection or non-detection of a waveform, making it fully automated after set-up. Furthermore, CATE has been used to evaluate hearing with 20 adults with normal hearing (mean age: 24 years), creating normative data (Bardy & Van Dun₂).

Twenty adults with normal hearing (mean age 24 years; range 18 to 67 years; 18 female) and 27 adults with a hearing impairment (mean age 74 years; range 54 to 89 years; 9 female) completed PTA and CATE at four frequencies (500, 1000, 2000 and 4000 Hz; Bardy, Van Dun, et al. 2016). On average, cortical thresholds were 7 dB higher than behavioural thresholds (SD = 12 dB) in adults with a hearing

impairment. The sensitivity of CATE was found to be 96%, with a 95% specificity for stimuli presented above 20 dB HL, demonstrating its overall validity for hearing threshold estimation (Bardy & Van Dun₂).

Therefore, in the present study, we aimed to explore the feasibility of CATE as an alternative hearing assessment to PTA in adults living with dementia in RACFs. To determine feasibility, two main outcomes were assessed: 1) the ability of participants to complete CATE compared to PTA; and 2) the time taken to complete both tests. Secondary outcomes explored the relationship between behavioural and cortical thresholds, as well as potential confounding factors that might influence test completion.

3.3 Method

3.3.1 Participants

The study was conducted in accordance with the National Statement on the Ethical Conduct of Human Research (National Health Medical Research Council, 2007). The University of Queensland Human Research Ethics Committee and Churches of Christ Care Ethics Committee approved this research project. Participants were recruited through three RACFs in the Darling Downs region of Queensland between July 2017 and April 2018. Participants were included in this study if they lived permanently in the RACF and had a dementia diagnosis.

Figure 3-1 depicts the recruitment process and participant progress through this study. Several approaches were taken to recruit participants. Initially, advertising posters were placed in the RACF and the RACF promoted the study internally through the resident newsletter. In addition, 72 enduring powers of attorney of residents with dementia were posted written information about the study and invited to attend an information session. From the initial recruitment drive, four potential participants expressed interest in the study and one declined to participate. The second approach to recruitment was more hands-on. Over a nine-month period, the first author frequently visited the three RACFs, usually over the weekend, to discuss the study with visiting family members. Discussions were held with 12 family members and residents with dementia, of whom 10 consented to participate in the

study. The final recruitment approach involved the first author liaising with the clinical care coordinator of each RACF to identify potential participants. The clinical care coordinator identified residents with a dementia diagnosis who had family that frequently visited or had regular contact with the resident. The first author attempted to contact 10 of these family members who were the enduring power of attorney by phone. This resulted in four additional participants entering the study.

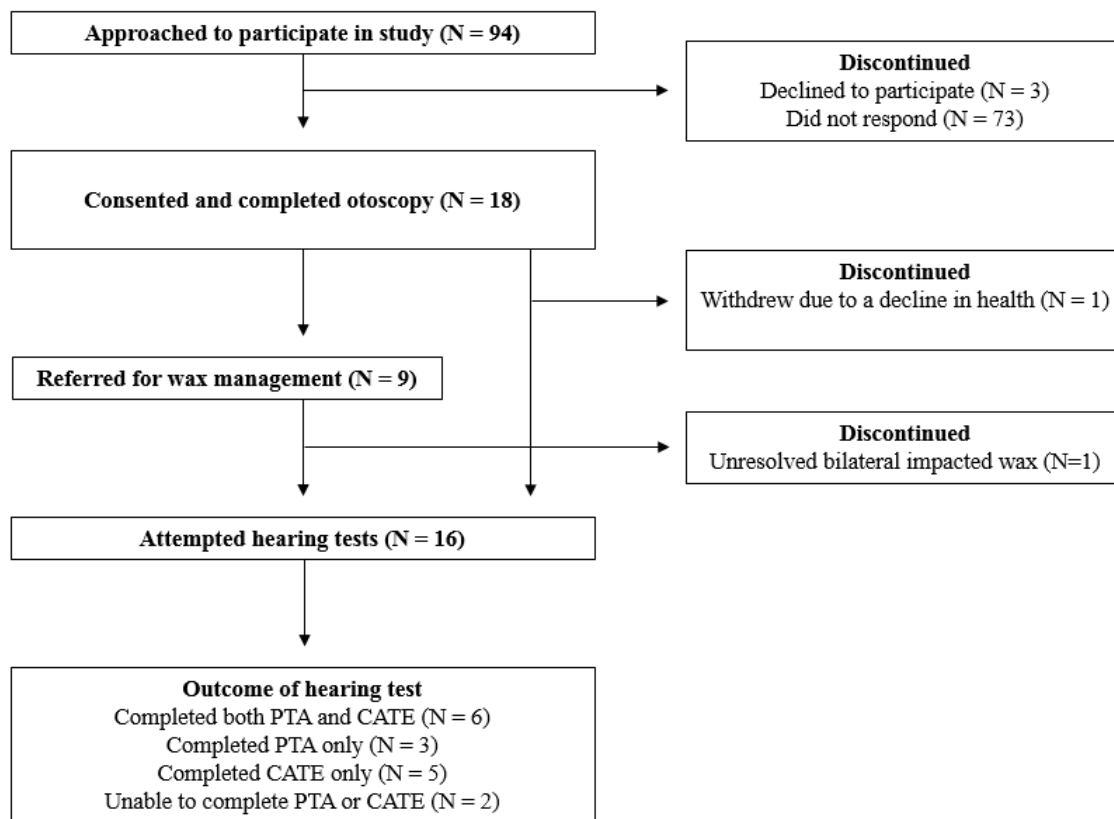


Figure 3-1 Flow Chart of Participant Recruitment and Progress Through the Study

Of the 18 participants who provided consent, 16 were included in the final participant sample (see Table 3-1). Of these, 14 completed at least one of the hearing tests and six ($n = 12$ ears) completed both PTA and CATE. Six participants had previously used hearing aids, three of whom were currently using them. Hearing impairment was not reported in the RACF medical charts of most participants.

Table 3-1 Participant Demographic Information (*N* = 16)

Variable	Number
Gender	
Male	7
Female	9
Mean age in years	86.5 (<i>SD</i> 6.2)
Highest level of education	
Primary school	4
Year 10	6
Senior certificate	2
Higher education	4
Length of time in RACF	
0-6 months	4
6-12 months	2
1-2 years	3
2+ years	7
Hearing impairment identified by RACF	
Yes	3
No	11
Unknown	2
Currently using hearing aids	
Yes	3
No	13
Previously used hearing aids	
Yes	6
No	8
Unknown	2
Dementia severity	
Questionable	1
Mild	1
Moderate	9

Severe	5
Dementia Type	
Alzheimer's disease	8
Vascular Dementia	5
Parkinson's type dementia	2
Unspecified / unknown	1

3.3.2 Materials

3.3.2.1 Participant demographic and medical history.

A demographic and medical history form was used to collect the following information on participants: gender, age, education level, medical history, hearing history, dementia history, and length of time residing in the RACF.

3.3.2.2 Communication assessment.

Participants' communication abilities were rated informally using a three-point scale (1, 2 or 3) by the first author (AB). A score of '3' was assigned to participants who were unable to speak, '2' to participants who had unintelligible speech, and '1' to participants who had intelligible speech.

3.3.2.3 Clinical Dementia Rating Scale – Chronic Care Version.

The Clinical Dementia Rating Scale – Chronic Care Version (CDR-CC; Marin et al. 2001) is a tool that quantifies the severity of dementia specifically for individuals who are living in RACFs. Informant and participant interviews were conducted to assess cognitive function across six domains (memory, orientation, judgement and problem solving, community affairs, home and hobbies and personal care). Each domain was assigned a score of 0, 0.5, 1, 2 or 3 which corresponds to a severity of none, questionable, mild, moderate or severe respectively. The overall severity rating was determined by averaging the six domain scores, with a higher weighting being given to the memory domain. For example, when memory equals 2, CDR-CC will only equal 1 or 3 when at least three of the other categories are scored as such. The CDR contains 71 items across the six domains; yet, the CDR-CC is flexible and allows for the interviewer to ask a variable number of questions to determine dementia severity. The CDR-CC has excellent inter-rater reliability (correlation coefficient of .99) when the interview is conducted with two raters

present and scores are calculated independently. The CDR-CC also has excellent one-month test-retest reliability with a correlation coefficient of 0.92 (Marin et al., 2001).

3.3.3 Procedure

Written informed consent was obtained from the legally authorised person for all participants with dementia. In instances where the individual with dementia was deemed to have capacity to provide written informed consent, written consent was also obtained from the individual. In instances where the individual with dementia was deemed unable to provide written informed consent (due to cognitive impairment), assent was obtained. Assent is the verbal agreement to participate in research (Batchelor-Aselage, Amella, Zapka, Mueller, & Beck, 2014).

Following consent/assent, a family member or the individual completed the participant demographic questionnaire and the first author confirmed participants' medical history with the clinical care coordinator of the RACF and rated the participant's communication as described above. Informant and participant interviews were completed by the first author using the CDR-CC to assess dementia severity. To reduce the impact of audibility on CDR-CC rating, participant interviews were conducted using a Pocket Talker Pro personal sound amplifier (William Sound, Minnesota, USA) or using their hearing aids. Following this, an ear examination was performed (otoscopy). For residents with cerumen occlusion, a referral for wax management was arranged and where possible, testing was performed following cerumen removal. Where participants had unilateral cerumen occlusion, testing was performed on the non-occluded ear. Testing was attempted using both ears for most participants.

Hearing test order was randomised to begin with either PTA or CATE. Participants were assessed in a room (usually their bedroom) within the RACF. Sound level measures were taken during the test using the NoiSee phone application and were on average 40.4 dB SPL. Testing was usually scheduled to take place in the morning as it has been suggested people with dementia display fewer problem behaviours in the morning than in the afternoon (Burgio, Scilley, Hardin, & Hsu, 2001).

PTA air conduction thresholds were obtained at 500, 1000, 2000 and 4000 Hz binaurally or monaurally using a calibrated Madsen Micromate portable audiometer (Otometrics, Denmark) with TDH39 supra aural headphones (Telephonics, Huntington, NY, United States) using the Hughson-Westlake procedure (International Standards Organization [ISO], 2011). The initial presentation level was 70 dB HL. To ensure reliability of results, the hearing threshold was re-measured at 1000 Hz. Where thresholds deviated by more than 5 dB, all thresholds for that ear were repeated. The time taken to set-up PTA (explanation and practice) and the time taken for participants to complete PTA were recorded.

The CATE module, which had been developed by the HEARing Cooperative Research Centre and National Acoustic Laboratories, was implemented in the HEARLab® system (HEARworks₁) for the purpose of this study. Stimuli were presented through E-A-RTONE insert Earphone 3A (Etymotic Research, IL, USA) and responses were automatically recorded by the calibrated HEARLab® system. In preparation for CATE, the participant's skin was cleaned and prepared using an abrasive skin gel and a water-soluble electrode paste to ensure a good connection between the electrodes and the skin. Four Ambu N disposable electrodes (Ambu, Copenhagen, Denmark) were placed on participants in the following positions: reference electrode on the vertex (Cz), two active electrodes on the right and left mastoid (M1 and M2), and a ground electrode on the forehead (Fz); electrode impedance at all electrode sites was kept below 5 kOhm. The impedance check of electrodes was measured through the HEARLab® system. The recorded EEG was amplified with a factor of 1210 and filtered between 0.16 and 30 Hz. EEG sweeps exceeding $\pm 150 \mu\text{V}$ were rejected. For the 50-ms stimuli, a rise-fall time of 10 ms and a plateau time of 30 ms was used. The recording window was set for 200 ms pre-stimulus to 700 ms post-stimulus for display purpose. The objective response detection was computed using Hotelling's T^2 statistic on the time window starting from 51 to 348 ms post-stimulus using 9 bins of 33 ms.

Where possible, participants were assessed while awake. When participants fell asleep during testing, the audiologist attempted to gently wake them. Tone burst stimuli were used at 500 Hz and multi-tone stimuli were used at 1000, 2000 and 4000 Hz. A multi-tone stimulus was chosen as it has been shown to increase cortical

amplitudes at 1000, 2000 and 4000 Hz in adults (Bardy, Sjahalam-King, et al., 2016). The maximum number of sweeps was set at 90 and the initial presentation level was set at 60 dB nHL. The initial step size before a reversal was equal to 20 dB. After a reversal, the step size was reduced to 10 dB for one final recording. For example, if the threshold was present at 60 dB nHL the stimulus was reduced by 20 to 40 dB nHL. If the threshold was absent at 40 dB nHL the stimulus was increased by 10 dB to 50 dB nHL. If the threshold was absent at 50 dB nHL the threshold was recorded as 60 dB nHL.

Individual hearing levels were reported for the better hearing ear as the average four-frequency (500 – 4000 Hz). Hearing thresholds were graded according to the WHO grades of hearing impairment as: no impairment (≤ 25 dB HL), slight impairment (26-40 dB HL), moderate impairment (41-60 dB HL), severe impairment (61-80 dB HL), and profound impairment (>81 dB HL; WHO, 2018). Where the hearing threshold at any frequency fell outside the upper limits of the audiometer (90 dB HL) or HEARLab® system (100 dB HL), the threshold was recorded as 105 dB HL to allow for comparison between behavioural and corrected cortical thresholds. 105 dB HL was chosen because this was the maximum presentation level (100 dB HL) plus the smallest step size (5 dB). Furthermore, the CATE system includes a specific symbol to indicate thresholds that were above the maximum presentation level. Hearing test results were explained to family members and individuals after the conclusion of all testing and a written summary of results was provided to family members for their records. Where participants indicated an interest in accessing hearing services, information on local hearing services was provided.

3.4 Results

Of the 16 participants included in the final analysis, 14 were able to complete at least one of the hearing tests. Figure 3-2 Outcome of Participants Completing PTA and CATE and the Reasons for Not Completing Each Test Figure 3-2 presents participants ability to complete each hearing test and the reason why participants could not complete the hearing test. Table 3-3 reports the four-frequency average hearing impairment, the WHO grade of hearing impairment, and the average set-up and test-time for PTA and CATE. All participants were assessed with at least a slight impairment and most had a moderate impairment. On average, PTA was

approximately four times faster to set-up and five times faster to evaluate hearing than CATE (assumptions were not met to perform a paired *t*-test). There was large variability in the testing time of CATE, with CATE taking between 27 and 80 minutes (excluding set-up time).

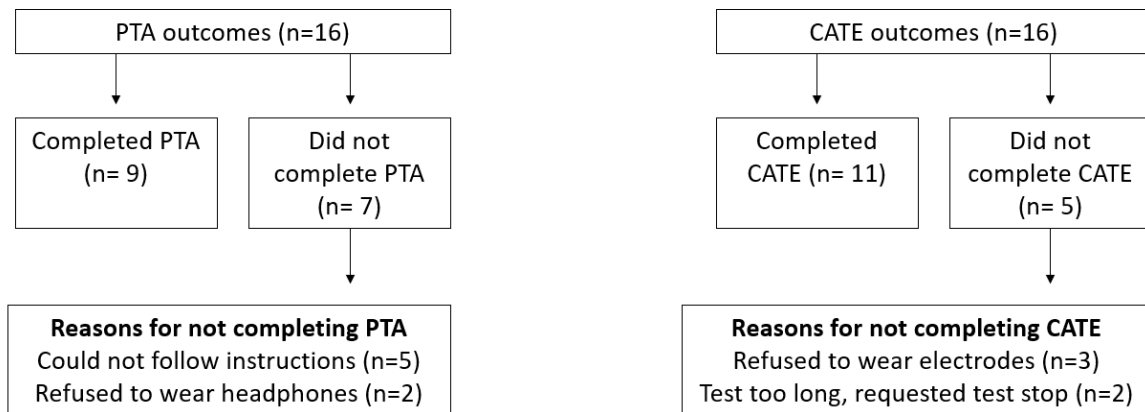


Figure 3-2 Outcome of Participants Completing PTA and CATE and the Reasons for Not Completing Each Test

Table 3-2 Average Hearing Impairment, WHO Grade of Hearing Impairment and the Time Taken to Set-up and Complete Pure-Tone Audiometry and Cortical Automatic Threshold Estimation

	4FA (SD)	WHO grade of hearing impairment					Set-up time (min)		Test time (min)		Total time (min)	
		No impairment	Slight	Moderate	Severe	Profound	M (SD)	Range	M (SD)	Range	M (SD)	Range
PTA (n = 9)	56.4 (13.9)	0	1	5	2	1	6 (2.2)	5 – 15	10.4 (5.2)	5 – 20	16.6 (6)	10 – 30
CATE (n = 11)	56.6 (12.9)	0	1	5	5	0	23.5 (3.9)	19 – 30	51.7 (16.5)	27 – 80	75.3 (18.7)	46 - 105

Note. WHO = World Health Organization; 4FA = four frequency average of the better hearing ear (500 – 4000 Hz); SD = Standard Deviation; M = Mean; WHO grade of hearing impairment “No impairment” = <25 dB HL; slight = 26-40 dB HL; moderate = 41-60 dB HL; severe = 61-80 dB HL; profound >81 dB HL.

Given the small sample size, participants' ability to complete both hearing tests are reported descriptively, along with information about possible confounding variables. Participants' ability to complete PTA and CATE appeared to differ based on dementia severity. Five participants were assessed as having severe dementia, of whom four completed CATE, none completed PTA, and one was unable to complete either test. Nine participants were assessed as having moderate dementia: one completed CATE; three completed PTA; four completed PTA and CATE; and one was unable to complete either test. The two participants with less severe dementia (mild and questionable) completed PTA and CATE.

In addition to dementia severity, time of day of testing and presence of a family caregiver during the test was recorded. Most hearing tests were attempted in the morning with a family caregiver present. However, three participants attempted the hearing tests without the presence of a family caregiver. Of these three participants, two were able to have their hearing evaluated by both tests (CDR-CC of 0.5 and 2), and the third (CDR-CC of 2) was unable to complete either test (refused to wear electrodes and refused to wear headphones). In addition, two participants had a family caregiver present during PTA but not during CATE. In both instances, the participant only completed PTA. One of these participants requested CATE testing stop due to the long testing time and the other participant refused to have the electrodes placed on him.

The six participants who completed both PTA and CATE had an average age of 85 (\pm 5.9) years. Three participants were female and three were male. According to the CDR-CC, four participants were assessed to have moderate dementia, one to have mild and one to have questionable dementia.

A Pearson's *r* analysis explored the relationship between PTA and CATE thresholds expressed in dB HL across the four frequencies (500 – 4000 Hz) with the six participants who completed both tests (12 ears). Figure 3-2 shows the relationship between cortical and behavioural thresholds for the four frequencies. There were strong, significant correlations for all frequencies. In addition, the difference between behavioural and cortical thresholds was determined by subtracting the PTA threshold from the corrected cortical threshold (CATE-PTA). On average, CATE thresholds were 1.2 dB (*SD* = 16), 1.4 dB (*SD* = 12.7) and 5.1 dB

($SD = 10.5$) worse than PTA thresholds at 500, 1000 and 4000 Hz respectively. CATE thresholds were on average 9.5 dB ($SD = 16$) better than behavioural thresholds at 2000 Hz.

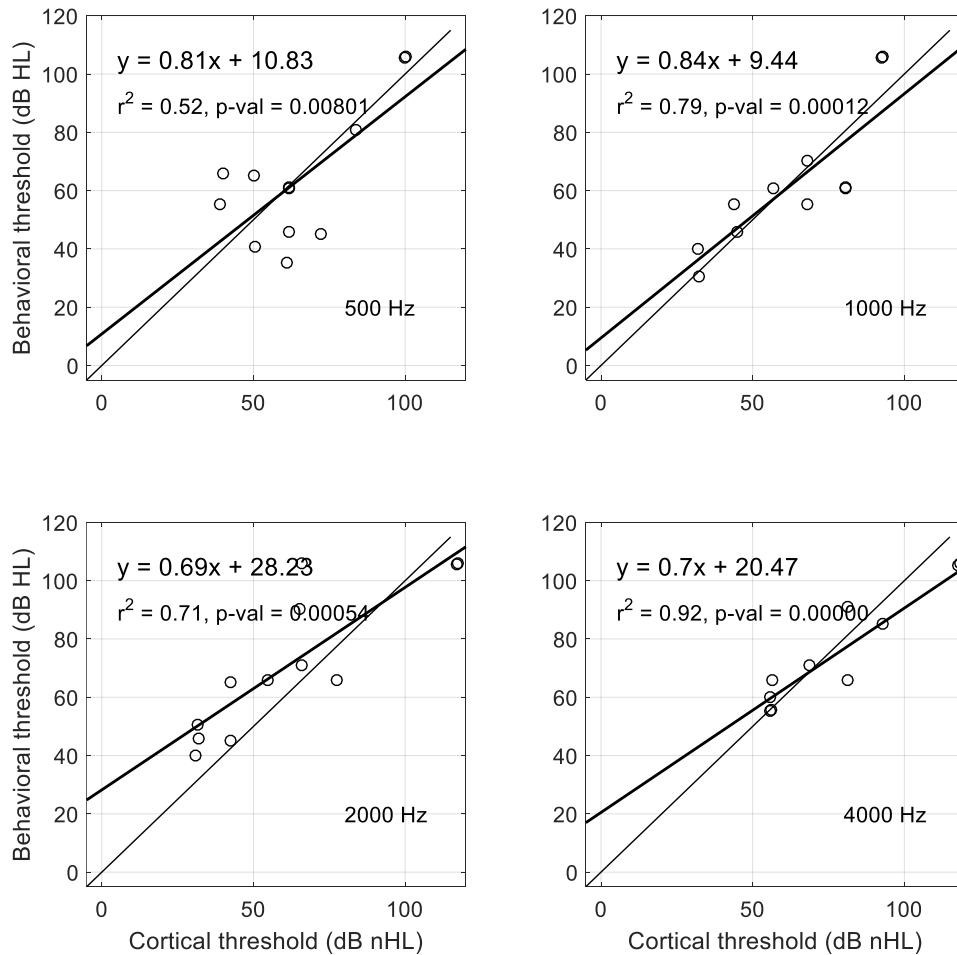


Figure 3-3 Correlation Between Cortical and Behavioural Thresholds ($N=12$ ears)

3.5 Discussion

This study explored the feasibility of CATE, as an alternative hearing test to PTA for adults living with dementia in an RACF. Results suggest that adults with a range of dementia severity were able to have their auditory thresholds estimated using CATE. Overall, threshold assessment was possible for more adults using CATE compared to PTA. This was particularly evident for the five adults with severe dementia, four of whom were able to have thresholds assessed using CATE, but

none of whom were able to be assessed using PTA. However, the average time taken to estimate hearing for CATE was 51.7 minutes compared to 10.4 minutes for PTA, and this is a potential limitation of its use in clinical practice. Corrected CATE thresholds were within 10 dB of the PTA thresholds across all test frequencies, demonstrating that CATE can be used as a standalone measure of hearing for adults with dementia. Time of day did not appear to have an impact on participants' ability to complete the hearing tests. Two participants were tested in the afternoon and showed variable ability to complete PTA and CATE, with one participant only completing CATE and the other only completing PTA. Presence of a family member during testing may influence outcome as, in two instances, family members were present for PTA but not for CATE and neither of these participants completed CATE.

CATE was shown to be particularly useful for hearing threshold estimation in adults with severe dementia. According to the WHO grades of hearing impairment, two out of the four participants with severe dementia tested with CATE, two had a severe impairment, one a moderate impairment, and one a slight impairment. In these cases, CATE provided valuable information to families and professional caregivers on the hearing status of these individuals and could lead to the development of appropriate management strategies to improve communication. Overall, CATE appears to be a feasible test for hearing threshold estimation specifically for adults with severe dementia, although the time required to complete the test is challenging.

In contrast, PTA appeared to be more appropriate for evaluating the hearing of adults with moderate, mild or questionable dementia severity. Of the nine participants assessed to have moderate dementia, seven completed PTA and five completed CATE (four participants completed both tests). Of the two participants with less severe dementia (mild and questionable), both participants completed PTA and CATE. Given that, on average, PTA is four times faster to complete than CATE, findings suggest behavioural testing is more appropriate for this population.

The findings of this study regarding the application of PTA and CATE for adults with dementia are consistent with two review papers that discuss hearing evaluations in this population. Pichora-Fuller et al. (2013) and Hopper and Hinton (2012) report that behavioural hearing tests can be used to evaluate hearing in most

adults with dementia, and that AEPs may be required for adults with severe dementia. Authors of these review papers note that modifications to PTA testing protocols may need to occur to achieve results for adults with dementia, and a flexible approach for accepting PTA responses was adopted in the present study.

Presence of a family caregiver during testing might have influenced individuals' ability to complete the hearing test. Two participants with moderate dementia severity who had family present for PTA and not CATE only completed PTA. To our knowledge, presence of a family caregiver during testing for adults with dementia has not previously been examined in research. Certainly, family involvement in hearing care is recommended (Meyer, Scarinci, Ryan, & Hickson, 2015), and often family caregivers take over decision-making responsibility as dementia progresses (Miller, Whitlatch, & Lyons, 2014). Findings from the present study suggest family may play an important role in assisting to obtain hearing test results for adults living with dementia and further exploration of family-centred care in this context should be explored. In the meantime, clinicians might consider including family caregivers in audiological appointments with adults with dementia.

There was a moderate (500 Hz) or high (1000 – 4000 Hz) correlation between behavioural and cortical thresholds across all four frequencies, and Table 3-4 compares these findings to other studies. The correlation between CATE and PTA at 1000, 2000 and 4000 Hz was higher than that reported in the study by Villeneuve et al. (2017), who used the ASSR and PTA with 12 participants with cognitive impairment. This finding suggests that CATE may be more suitable than the ASSR for evaluating hearing at 1000, 2000 and 4000 Hz in adults with dementia.

The moderate correlation at 500 Hz (compared to the high correlation between 1000, 2000 and 4000 Hz) observed in the present study may be due to the testing environment. The average ambient noise during behavioural and cortical testing was 40.4 dB SPL, which is higher than the American National Standard Institute maximum permissible ambient noise levels recommended for 500 – 4000 Hz using supra-aural headphones (21 – 37 dB), but lower than the levels for insert earphones (47 – 50 dB; Frank 2000). In the present study, different transducers, supra-aural headphones and insert earphones were used for PTA and CATE respectively. Background noise is known to affect the accuracy of threshold

estimation for frequencies below 1000 Hz (Robinson, 1992) and may explain the spread in correlation between PTA and CATE at 500 Hz. Because this is the first time AEPs have been used to measure hearing in adults living with dementia in RACFs, we chose to include hearing threshold estimation from 500 Hz. The findings from this study suggest that future research could start hearing threshold estimation from 1000 Hz.

Overall, the correlations found in this study between CATE and PTA are similar to other studies that have used AEPs with adults who do not have a cognitive impairment (Durante et al., 2016; Lightfoot & Kennedy, 2006; Tsui, Wong, & Wong, 2002; Van Dun, Dillon, & Seeto, 2015). Typically, after applying correction factors, cortical thresholds are within 10 dB of behavioural thresholds across all frequencies and the trend is for cortical thresholds to be slightly worse than behavioural thresholds. The exception in the present study was the fact that CATE thresholds at 2000 Hz were, on average, 9.5 dB better than the behavioural thresholds at that frequency. This is not consistent with the studies by Durante et al. (2016) and Van Dun et al. (2015), who used the HEARLab® in typical adults and older adults and found cortical thresholds were worse than behavioural thresholds at all frequencies. The reason for the differences in findings is not clear and further research is necessary in larger samples of adults with and without dementia. In addition to the correlation between behavioural and cortical thresholds, testing time is also an important factor for clinicians and researchers to consider.

Table 3-3 Studies that have compared pure-tone audiometry (PTA) and Cortical Auditory-Evoked Potential or the Auditory Steady-State Responses (ASSRs) in various adult populations

Authors, year	Population			Test	Comparison between PTA (dB HL) and CATE (dB eHL) or Cortical AEP or ASSR (dB eHL)			
	<i>n</i> (number of ears)	Typical or cognitively impaired	Mean age (SD)		500 Hz	1000 Hz	2000 Hz	4000 Hz
Van Dun et al. (2015)	66	Typical	71 (9)	Cortical AEP	<i>r</i> = 0.82	<i>r</i> = 0.77	<i>r</i> = 0.71	<i>r</i> = 0.64
Durante et al. (2016)	21	Typical	48.9 (7.2)	CATE	<i>r</i> = 0.71	<i>r</i> = 0.72	<i>r</i> = 0.83	<i>r</i> = 0.8
Villeneuve et al. (2017)	23	Cognitively impaired	82.1 (4.6)	ASSR	<i>r</i> = 0.55	<i>r</i> = 0.58	<i>r</i> = 0.61	<i>r</i> = 0.66
Present study (2018)	12	Cognitively impaired	86.5 (6.2)	CATE	<i>r</i> = 0.52	<i>r</i> = 0.79	<i>r</i> = 0.71	<i>r</i> = 0.92

Note. ASSR = auditory steady state response; AEP = auditory-evoked potential (N1-P2 complex).

Only studies that tested 500 – 4000 Hz and reported the correlation between PTA and cortical auditory evoked potential or auditory steady state response or cortical automatic threshold estimation in adult populations were included for comparison.

A previous limitation of cortical AEP tests compared to the ASSR is that, on average, testing takes 30 minutes longer to complete (Yeung & Wong, 2007). CATE utilises a multi-tone stimulus, which may help to reduce AEP testing times. In normal hearing adults, CATE is reported to estimate hearing thresholds in four frequencies in both ears in under 40 minutes (Bardy, Van Dun, et al., 2016). This has been reduced further down to 21.1 minutes for 90 sweeps per frequency (Bardy & Van Dun₂). In the present study, on average, hearing thresholds were estimated for four frequencies in both ears in 51.7 minutes. Given that AEP amplitudes are smaller with age (Tremblay & Burkard, 2007), more presentations may have been required to detect the AEP at each presentation level, which may have contributed to the slightly longer testing times in the present study compared to that reported by Bardy, Sjahalam-King, et al. (2016). Although the use of multi-tone stimuli is believed to be the main contributing factor for shorter recording times with CATE, the optimised decision process on when to conduct a statistical test for response presence, when to stop collecting data at a specific frequency, and which level to test next without any required input by the clinician all contribute to faster determination of the client's audiogram. Other modifications to the current set-up of CATE that may further help to reduce testing time but maintain integrity include:

- (1) Increasing the initial presentation level to 70 or 75 dB nHL
- (2) Reducing the minimum and maximum presentation levels to between 30 and 90 dB HL

Although the average time taken to estimate hearing in the present study was higher than that reported by Bardy, Sjahalam-King, et al. (2016), it was comparable to that of the ASSR. Rance, Rickards, Cohen, De Vidi and Clark (1995) reported hearing thresholds estimation using the ASSR for four frequencies in both ears took between 30 and 60 minutes. Further research comparing the ASSR and CATE to PTA for this population is warranted. Before exploring this with people with moderate and severe dementia, researchers should first complete studies with people without cognitive impairment and people with mild cognitive impairment.

In the present study, the use of both PTA and CATE allowed for 14 out of 16 (87.5%) participants to have their hearing evaluated; a result that much improves on that reported by Hedner et al. (1987) and Burkhalter et al. (2009). Findings therefore

indicate that CATE could be integrated into the diagnostic test battery, particularly for adults with severe dementia. However, PTA reliably evaluated hearing in more than half of the participants in the present study and was on average four times quicker than CATE. It is therefore recommended that PTA is attempted first and followed by CATE for those unable to complete PTA.

Several limitations exist in the present study. First, although we were able to gather information from participants with a range of dementia severities, our sample size was small. Ideally, the minimum sample size for testing the feasibility of a device is 30 (Wiklund, Kendler, & Strohlic, 2016), which would make statistical analysis of the data possible. Future research conducted with adults with dementia should aim to recruit larger numbers into studies. This would also allow for the evaluation of other variables such as time of day of testing and presence of family members. Second, this study may contain measurement bias due to the same tester having conducted the CDR interview, PTA assessment and CATE assessment. We attempted to reduce the impact of measurement bias by randomising the order of testing. Where possible, future studies evaluating hearing in adults with dementia should attempt to blind investigators from dementia severity and hearing test results to reduce the impact of measurement bias.

3.6 Conclusion

Results from this study suggest that CATE could be used as an objective measure of hearing for adults with dementia living in an RACF, particularly for adults with severe dementia who are unable to complete PTA testing. A limitation of CATE compared to PTA was the additional testing time required. It is feasible that modifications to CATE may result in faster testing times, and this should be explored in a larger population to establish clinical viability and usefulness.

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1 The HEARLab system, developed by the HEARing Cooperative Research Centre and National Acoustic Laboratories, was previously commercially available through Frye Electronics.

2 Normative data are currently unpublished and a manuscript is currently being prepared for publication by Fabrice Bardy and Bram Van Dun. The information reported in this chapter is based on personal correspondence with these authors.

Chapter 4 “It’s huge in a way.” Impact and Management of Hearing Impairment for People Living with Dementia in Residential Aged Care Facilities

Chapters 2 and 3 of this thesis presented research that advanced knowledge in diagnostic audiology. Chapters 4, 5 and 6, change the focus from diagnostic audiology to rehabilitative audiology. Within residential aged care facilities (RACFs), fewer than 20% of residents who would benefit from hearing aids use these devices, demonstrating that hearing impairment is often undertreated. However, few studies have sought to gain an in-depth understanding of current management practices from the perspectives on all parties who are involved in managing it.

This chapter reports the findings of a qualitative investigation, using in-depth semi-structured interviews, to gain insight into key stakeholders’ perspectives on (1) the impact of hearing impairment for adults living with dementia in RACFs and (2) how it is currently managed.

A pragmatic paradigm shaped the qualitative research presented in this chapter. This approach was chosen as it allows for flexibility in data analysis, and at its core, seeks to ensure that the research findings answer the research question (Creswell & Plano Clark, 2007; Feilzer, 2010). Given the clinical nature of the aforementioned research questions of this chapter, more common qualitative methodologies such as phenomenology, grounded theory or ethnography did not appear suitable methodological standpoints for this research.

This chapter is currently under review in the peer-reviewed journal, *Journal of Speech-Language-Hearing Research*: Bott, A., Meyer, C., Hickson, L., & Pachana, N. (2019b). “*It’s huge in a way.*” *Impact and management of hearing impairment for adults living with dementia in residential aged care facilities*. Manuscript submitted for publication.

The content included in this chapter is per the submitted manuscript.

4.1 Abstract

Purpose: The aim of this study was to a) explore the impact of hearing impairment on people living with dementia in residential aged care facilities (RACFs) and b) investigate management of hearing impairment for this population.

Method: A qualitative approach, consisting of one-on-one or dyadic interviews, was conducted with 23 participants across four stakeholder groups (audiologists, RACF staff, family caregivers and individuals with dementia and hearing impairment living in RACFs).

Results: Thematic analysis revealed the far-reaching consequences of hearing impairment for people living with dementia and the importance and benefit of appropriate treatment. An overarching theme of 'different priorities for managing hearing impairment' emerged from the data. Audiologists and RACF staff prioritised different practices for managing hearing impairment (audiologists emphasised hearing aids and RACF staff emphasised communication strategies). RACF staff also identified that current management of hearing impairment was sub-optimal, and that they did not often refer residents with dementia to hearing services.

Conclusions: Residents with dementia and hearing impairment living in RACFs are not receiving optimal hearing management. Further research is required to understand the factors that influence this.

4.2 Introduction

The co-occurrence of hearing impairment and dementia among people living in residential aged care facilities (RACFs) is high, with prevalence rates reported to be around 90% (Hopper, Slaughter, Hodgetts, Ostevik, & Ickert, 2016; Jupiter, 2012; Worrall, Hickson, & Dodd, 1993). Several reasons explain the high concomitance of hearing impairment and dementia. First, prevalence of hearing impairment and dementia increase exponentially with age. Approximately 55% of adults aged over 60 years and 80% of adults aged over 80 years have a bilateral hearing impairment (Lin, Niparko, & Ferrucci, 2011); and approximately 10% of adults aged over 65 years and 43% of adults aged over 85 years have a dementia diagnosis (Australian Institute of Health and Welfare, 2012). Second, hearing impairment is independently associated with increased risk of dementia (Ford et al., 2018; Livingston et al., 2017; Loughrey, Kelly, Kelley, Brennan, & Lawlor, 2018). For example, one prospective cohort study identified that, over an 11-year period, adults with a mild hearing impairment were almost twice as likely to develop dementia, and adults with a severe hearing impairment were nearly five times more likely to develop dementia, compared to adults without a hearing impairment (Lin, Metter, et al., 2011). Finally, population trends from 2011 showed that, compared to 2003, older adults in Australia are waiting longer before moving into RACFs (Australian Institute of Health and Welfare, 2014), and are therefore more likely to have multiple age-related health conditions such as dementia and hearing impairment when they do so. Despite the evidence for the commonality of hearing impairment among people living with dementia in RACFs, few studies have considered the impact that hearing impairment has for this population.

Hearing impairment likely exacerbates the negative consequences of dementia on communication and quality of life for adults residing in RACFs (Hopper & Hinton, 2012; Hubbard, Mamo, & Hopper, 2018; Pichora-Fuller, Dupuis, Reed, & Lemke, 2013; Punch & Horstmanshof, 2018), yet, in research, this has been investigated sparingly. Cohen-Mansfield et al. (2009) found that poorer hearing, as determined through a four-point scale where “1” represented those with highly impaired hearing and “4” represented those with adequate hearing, was associated with a higher refusal rate to engage in activities in 193 residents with dementia. However, this study did not consider whether the use of a hearing device altered

residents' engagement in activities. Furthermore, a large Canadian cross-sectional study ($n=110,578$) demonstrated that hearing impairment adds additional communication and functional difficulties to residents with cognitive impairment, compared to residents with cognitive impairment and no hearing impairment (Guthrie et al., 2018). Despite demonstrating the link between hearing impairment and greater disability in residents with dementia, these studies do not provide a comprehensive insight into how this impact is experienced by individuals or their caregivers.

Qualitative methods are used in audiology to examine participants' perceptions and experiences regarding hearing impairment (Knudsen et al., 2012) and have been applied to investigate the consequences of hearing impairment for people living with dementia in RACFs (Pryce & Goberman-Hill, 2012; Pryce & Goberman-Hill, 2013; Slaughter, Hopper, Ickert, & Erin, 2014). Pryce and Goberman-Hill (2012) conducted an ethnographic study and in-depth interviews with 18 people living with dementia in an RACF. Of these participants, eight were current hearing aid users, eight self-reported problems with their hearing but had not sought help, and two reported adequate hearing. Participants reported that factors within the RACF environment (noise and lack of social opportunity) placed restrictions upon their communication choices beyond those imposed by their hearing ability. Furthermore, a mixed-methods study conducted by Pryce and Goberman-Hill (2013) – consisting of qualitative observations and interviews with 10 RACF staff, quantitative surveys with 65 RACF staff, and stakeholder meetings with 30 managers and senior RACF staff – found that RACF staff played an important role in supporting residents to access hearing services, yet RACF staff did not necessarily have the knowledge to facilitate this referral. Finally, Slaughter et al. (2014) conducted qualitative interviews with 12 RACF staff and found that they had trouble identifying a mild-to-moderate hearing impairment in adults with dementia, further highlighting the challenges of managing hearing impairment in this population. A limitation of these studies is that family caregiver perspectives were not explored.

Caregivers, both family and professional, play an important role in assisting residents living with dementia to manage their health conditions. People living with dementia can have difficulties expressing themselves and understanding information

(Bayles, Tomoeda, & Trosset, 1992), necessitating caregiver advocacy for their needs (Groen-van de Ven et al., 2016). Family involvement is also encouraged within audiology appointments (Meyer, Scarinci, Ryan, & Hickson, 2015) and for people living with dementia who reside in RACFs (Stans, Dalemans, de Witte, & Beurskens, 2013). To date, previous qualitative research that has explored the management and consequences of hearing impairment for people living with dementia within RACFs has not explored family caregivers' perspectives, nor has it explored multiple stakeholder perspectives in the one study. Therefore, the aims of this study were to a) explore the impact of hearing impairment on people living with dementia in RACFs and b) investigate management of hearing impairment for this population. Because multiple stakeholders are involved in healthcare decision making for adults living with dementia in RACFs – audiologists, RACF staff, family caregivers and individuals – we sought perspectives from representatives of these stakeholder groups.

4.3 Method

4.3.1 Study Design

A qualitative study using one-on-one ($n = 21$) or dyadic ($n = 2$) in-depth, semi-structured interviews was conducted. Qualitative methods were chosen because they allowed for the exploration of key stakeholders' beliefs, experiences and perceptions (Knudsen et al., 2012). Thus, qualitative interviews can provide a 'richness' of data that cannot be achieved using purely quantitative methodologies. This study was approved by the University of Queensland Human Research Ethics Committee and Churches of Christ Care Ethics Committee and was conducted according to the National Statement on the Ethical Conduct of Human Research (National Health and Medical Research Council & Australian Vice Chancellor's Committee, 2007).

4.3.2 Participants

Four participant groups were included: 1) audiologists or audiometrists that provided hearing services to people living with dementia and hearing impairment in RACFs (audiologists); 2) RACF staff; 3) individuals with dementia and hearing impairment living permanently in RACFs (individuals); and 4) family caregivers of

individuals living with dementia and hearing impairment in RACFs (family caregivers). A total of 23 participants across the four groups took part in this study.

4.3.2.1 Audiologists.

Audiologists were recruited using convenience sampling. Participants were included if they had provided hearing services to an adult living with dementia and hearing impairment who resided in one of the three participating RACFs within the past 12 months. No additional exclusion criteria were applied. Participants were recruited through a two-step process. First, all audiology clinics within the geographical region were identified by searching the Australian Government Office of Hearing Services provider portal. Each audiology clinic was then contacted by the primary author to determine whether the clinic met the inclusion criteria, which six of these practices did. Second, audiologists from each clinic were invited to take part in the study. Five audiologists, three women and two men, participated in the study.

4.3.2.2 RACF staff.

RACF staff were recruited using purposeful sampling, specifically maximum variation sampling, to ensure variation in employment position within the RACF. For example, managers, registered nurses, and personal care workers were invited to take part in the study. Participants were recruited directly from the RACF and were included if they were employed by the RACF and had provided care to residents living with dementia within the past 2 months. After attempting to recruit for several months, no RACF staff members had volunteered to participate in the study as potential participants were not available to be interviewed outside of work hours. To ensure inclusion of the perspectives of RACF staff, qualitative interviews were adjusted to run for a maximum of 20 minutes during staff breaks at the RACF. Nine RACF staff, seven women and two men, participated in the interviews, representing clinical care coordinators, registered nurses, endorsed enrolled nurses, lifestyle coordinators, and personal care workers.

4.3.2.3 Individuals with dementia and hearing impairment.

Individuals with dementia and hearing impairment were recruited using convenience sampling through the study presented in chapter 3. Of the 16 participants who took part in that study, those who met the following criteria were invited to take part in the current study: assessed with questionable, mild, or

moderate dementia severity ($n = 11$) according to the Clinical Dementia Rating Scale-Chronic Care Version (Marin et al., 2001); had a mild or greater hearing impairment ($n = 9$); were able to converse in English ($n = 9$); and had a family caregiver who could be present during the interviews ($n = 4$). Presence of a family caregiver during semi-structured interviews was a requirement stipulated in the ethical approval for this research project and was included to assist create a comfortable and familiar environment for the individual living with dementia. Of the four people eligible, two consented to take part in the study. The two participants, one male and one female, aged 90 and 92 years, respectively, were assessed to have moderate dementia severity and currently used hearing aids.

4.3.2.4 Families.

Participants were identified and recruited using convenience sampling through the study described in chapter 3 (see Table 3.2). Of the 13 family members who were present for the hearing evaluation appointments one was excluded from this study as their family member was unable to complete either hearing test and two were excluded because they were only present for part of the hearing evaluation appointment. Of the 10 family members invited to take part into this study, three declined to take part in the interviews. As such, seven family members (two of whom were family members of the same individual living with dementia), all female, completed the interviews and had an average age of 65 (± 26) years. Four family members identified as being the wife of the individual living with dementia and three as the daughter. Family members' experiences varied with respect to engagement in hearing services: one had previous experience with a hearing service, but their family member did not adopt hearing aids; three reported their family member previously used hearing aids but did not currently; and two reported their family member currently used hearing aids. Table 4-1 presents the demographic information for the residents with dementia who were the foci of the interviews with families.

Table 4-1 Demographic Information of Residents with Dementia that were the Focus of Family Caregiver Interviews

ID	Age (years)	Sex	PWD relationship to the family caregiver who took part in the interview	Dementia severity	PTA (dB HL)	Previously used hearing aid	Currently using a hearing aid
1*	92	F	Mother	Moderate	50	Yes	Yes**
2	93	F	Mother***	Severe	65	No	NA
3	90	M	Husband	Severe	62.5	Yes	No
4	80	M	Husband	Moderate	38.75	No	NA
5*	90	M	Husband	Moderate	62.5	Yes	Yes
6 & 7****	86	M	Husband and Father	Moderate	60	No	NA

Note PTA = pure-tone average of the better hearing ear 500 – 4000 Hz;

*Individual with dementia who also took part in dyadic interview.

**Device was currently being repaired.

*** Family caregiver also discussed her father who had dementia and hearing impairment and had lived in a residential aged care facility.

**** Family caregivers of the same individual living with dementia.

4.3.3 Procedure

The study was conducted across three RACFs in South West Queensland between July 2017 and March 2018. A topic guide was developed and piloted with an audiologist and an RACF employee prior to participant interviews. The interviews aimed to gain insight into the impact and management of hearing impairment for people living with dementia who reside in RACFs. For example, questions asked during the interviews included: what impact does hearing loss have for people living with dementia? How is hearing loss managed for adults with dementia and hearing loss living in aged care? And, how can hearing loss management be improved? Interviews were semi-structured in nature, meaning open-ended questions from the topic guide were asked; however, interviews were also flexible in nature and driven by participant responses. A copy of the topic guide (family caregiver version) has been provided in the appendix. This approach allowed areas to be discussed by participants that may not have been considered by the research group (Given, 2016). The interviews were completed by the first author (an audiologist), either over the phone ($n = 3$: an audiologist and two family caregivers) or face-to-face ($n = 20$) at a location convenient to the participant. All participants were unknown to the first author prior to taking part in the study. Moreover, as the first author is an audiologist, she was mindful not to introduce her own clinical bias into the interviews, and attempted to seek clarification of common audiology terms. Interviews ranged from 10 to 67 minutes, and were audio recorded and transcribed by a professional transcription service. Transcripts were checked for accuracy by the first author before coding.

4.3.4 Data Analysis

Transcripts were analysed via inductive thematic analysis (Braun & Clarke, 2006). Thematic analysis is a method for identifying, analysing, and reporting common themes among participants and contains six steps that were followed in the present study. Each step of thematic analysis was undertaken separately for the two research questions and was led by the first author (AB). To enhance rigor and ensure transparency of findings, the second author (CM), a speech pathologist and experienced qualitative researcher, and the third author (LH), an audiologist/speech pathologist with extensive qualitative research experience, reviewed and reflected on the analysis as described below. Initially, transcripts were read and re-read by the

first author to become familiar with the data, and initial ideas were written down. Next, the first author (AB) systematically coded a transcript creating a list of meaning units and codes relevant to each research question. This list was reviewed by the second author (CM) and discussions were held to reflect and refine codes and meaning units. After this, the first author coded all remaining transcripts, adding new codes and meaning units to this list. Once all transcripts had been coded, the third step involved gathering the codes into potential themes, ensuring all data relevant to each potential theme was collated and the fourth step involved refining themes, whereby all potential themes were reviewed at the level of the coded data extracts and then against the entire data set for each participant group. This process resulted in the development of a thematic map. During the third and fourth step of the thematic analysis, the first (AB) and second author (CM) met regularly to review and discuss how codes were grouped and refined into themes. Where disagreements arose, the third author (LH) was consulted to reach agreement. After this, the fifth step, defining and naming themes, involved assigning names to each theme and ensuring each theme and category told a coherent story relating to the specific research question. This stage was reviewed by the third author (LH), where further reflection aided in refining of codes and proceeding to the final step of thematic analysis involved producing the report, whereby extracts from the data were used to support the themes and categories relating to the research questions.

4.4 Results

Themes that emerged from the data for each research question are presented in Tables 4-2 to 4-6. An overview of each theme and associated categories are presented in the text below.

Two interrelated themes emerged in relation to the first research question: *What is the impact of hearing impairment for people living with dementia who reside in RACFs?* These themes were: (1) far-reaching consequences to the individual; and (2) appropriate management of hearing impairment can be beneficial and important for people living with dementia.

4.4.1 Theme 1: Far-Reaching Consequences to the Individual “It’s actually huge in a way”

The far-reaching consequences of hearing impairment on the individual were categorised as: (1) emotional consequences; (2) social consequences; (3) behavioural consequences; and (4) communication consequences (see Table 2). Emotional consequences reported by stakeholder groups to be associated with hearing impairment in people with dementia living in RACFs included frustration, grumpiness, distress, and feeling stupid. One RACF staff member summed up the emotional consequences by saying: *“It’s really going to affect them emotionally when they can’t hear.”* Stakeholder groups also identified that consequences of hearing impairment affected residents’ social interactions during activities and mealtimes, describing examples of loneliness, decreased engagement, avoidance, and confusion. RACF staff identified that hearing impairment contributed to behavioural consequences for people living with dementia, and that these behaviours impacted residents’ ability to receive care from nursing staff. Lastly, all stakeholder groups discussed the pervasive consequences that hearing impairment had for communication. Specifically, hearing impairment made resident-staff communication more difficult and affected residents’ ability to follow caregiver conversations.

Table 4-2 Theme 1: Far-Reaching Consequences to the Individual

Categories	Codes	Example participant quotes
Emotional consequences of HI for residents with dementia	Frustration	They [PWD] probably have the feeling but when they can't hear what somebody is trying to say to do or things like that. It's really frustrating as well. (RACF Staff)
	Grumpiness	I've seen other people do it now, even his daughter, when they approach him from his left side he would also get cranky and yell "I can't hear you. What do you want?" just grumpy responses (RACF Staff)
	Distressed	Those sort of misunderstandings [not hearing] can also distress a person with dementia. (RACF Staff)
	Feel stupid	I just take it that it's just me stupid, not listening properly. (PWD)
Social consequences of HI for residents with dementia	Feel lonely	I guess with the hearing impaired or even lost their hearing, they should be... I guess that they would feel very, very lonely (RACF Staff)
	Do not take part in activities in RACF	And it's hard for him. And he's not doing activities in there like he used to because he has that feeling of, "oh I can't hear people." (FAM)
	Engagement in activities is influenced by HI severity	The ones with the milder hearing loss are still happy. I see them smiling and laughing and engaging a bit more; whereas when they have a significant loss they're just not engaged as much (AUD)
	HI creates confusion during activities	At times, it [HI] probably creates a little bit of confusion. (RACF Staff)

	Communication partners avoid talking to PWD	If they (RACF staff) don't understand him or he can't understand them, I think they just walk out. (FAM)
Behavioural consequences of HI for residents with dementia	Maladaptive behaviours	If you can't hear what other people are saying, then obviously you would be distressed, anxious, and because of dementia you are not able to express that the right way, so that's why you have maladaptive behaviours. (RACF Staff)
	Defensive behaviours	I think one or two of them tried to undress him because they were saying it's time for a shower or whatever and then he got quite defensive when they started trying to undress him. I think that was all part of the accents, his hearing loss, and his dementia that just about ... If he could have heard better that often would have overcome (FAM)
Consequences of HI on communication for residents with dementia and their caregivers	Resident-caregiver communication is more difficult	Very bad. I find it [talking to husband] impossible. (FAM)
	Emotional response to not hearing makes it harder to hear	The big point is that I get annoyed, and then that makes it worse, because then I can hear less. (IND)
	Unable to follow conversations	They are not able to follow conversation. (AUD)

Unable to hear
conversations in the dining
room

Biggest complaint we get is in the dining room, just that they are not able to hear what people are saying. (AUD)

Loss of privacy during
resident-caregiver
conversations

When somebody is deaf and you're trying to have an intimate conversation with someone you lose a lot of the intimacy and you lose a lot of the privacy. (RACF Staff)

Note. RACF = residential aged care facility; AUD = audiologist; FAM = family caregiver; HI = hearing impairment; PWD = person living with dementia.

4.4.2 Theme 2: Appropriate Management of Hearing Impairment can be Beneficial and Important for People with Dementia

The second theme that emerged from the participant data in relation to the impact of hearing impairment for people living with dementia in RACFs was the importance of and benefits associated with appropriately managing hearing impairment (see Table 4-3). Participants from all stakeholder groups discussed how addressing hearing impairment was important for the individual, describing that the effective use of hearing aids and/or communication strategies improved residents' mood, energy levels and engagement in conversations.

Table 4-3 Appropriate Management of Hearing Impairment is Beneficial and Important for People living with Dementia

Codes	Example participant quotes
Addressing hearing is important to the individual	Absolutely important! He doesn't... if he doesn't hear he doesn't know what's going on. That's the world to him. (FAM)
Using hearing aids effectively improves communication	So, once he got wearing those (hearing aids), the staff members all commented on how his dementia seemed to be a lot better. Purely because he could respond now. (AUD)
Using hearing aids effectively helps residents engage	The patient or client themselves can engage a bit more (AUD) <i>discussing outcomes of HA fitting.</i>
Using hearing aids effectively reduces fatigue in residents with dementia	They're [PWD] not as tired. (AUD) <i>discussing outcomes of HA fitting.</i>
Using effective communication strategies improves conversations and residents' mood	If you come over to him gently on the other side, his right hand side of his body speaking to that ear I just found that was like opening a door. He could hear what I was saying, he smiled and we started talking and I sat down near him. (RACF Staff)
Effective communication is part of a person's dignity	Well it's important because I think it's part of the person's dignity, it's kind of wrapped up in the dignity of communicating well with somebody. (RACF Staff)

Note. RACF = residential aged care facility; AUD = audiologist; FAM = family caregiver; HA = hearing aid

One overarching theme emerged in relation to the second research question: *How is hearing impairment managed for residents with dementia?* The overarching theme was acknowledgement of different priorities for the management of hearing impairment in residents with dementia. Each stakeholder group emphasised different practices for managing hearing impairment, creating four categories under this overarching theme. The four categories were: (1) audiologists emphasised device management; (2) RACF staff emphasised communication strategies; (3) family caregivers had mixed views on hearing aids and used communication strategies; and (4) individuals with dementia and hearing impairment had mixed views on the benefits of their hearing aids.

4.4.2.1 Category 1: Audiologists emphasised device management.

For the management of hearing impairment, all audiologists prioritised hearing devices, specifically hearing aids (see Table 4-4). For example, an audiologist said *“Well, obviously, if the client can’t hear or is really struggling to hear, I would consider hearing aids first.”* Audiologists identified that hearing aid use and level of technology is influenced by the presence of dementia, highlighting that many people living with dementia were unable to manage their hearing aids. Audiologists also discussed using assistive listening devices (ALDs) to manage hearing impairment for this population; however, audiologists only considered ALDs when hearing aids were thought to be inappropriate, and expressed somewhat negative views about ALDs. Lastly, audiologists discussed provision of counselling and communication strategies to caregivers in place of or alongside hearing devices.

Table 4-4 Category 1: Audiologists Emphasised Hearing Aids

Sub-category	Codes	Example participant quotes
Hearing aid use influenced by presence of dementia	Independent management of hearing aid is important	RA: who is responsible for the hearing aid? Fam: you mean inserting it? He is ... I think it's important (FAM)
	PWD may be unable to manage their hearing aids	Usually with the dementia client they can't do it [manage HAs] themselves. (AUD)
	PWD rely on caregivers to manage hearing aids	We rely on the nursing home staff and nurses to help basically manage the hearing aids for these clients (AUD)
	Caregivers might not always manage hearing aids	If I am not here, who's going to do it [manage HA]? (FAM)
Level of hearing aid technology influenced by presence of dementia	Entry level HA is suitable because residents are not very socially active.	Most people in that situation are not very active socially, so generally the entry level with subsidised options are the way we would go. (AUD)
	Rechargeable HAs are appropriate for residents who pull apart their HAs	His dementia meant that he was always fiddling with the hearing aid, pulling them apart. So, the solution we found was to get a better hearing aid that he couldn't. (AUD)
	HAs that have better noise reduction features are best for people with dementia	I agree that the better hearing aids are the best for that [adult with dementia] type of client, because they have better noise reduction features. (AUD)
ALDs typically considered after	ALD is considered if HA is considered inappropriate	It [HA fitting] would depend on what level of dementia they're at and if they're eating things, if they're putting things in their ... If they can tolerate

hearing aids have been ruled out		things in their ears. If not, we might fit something like the pocket talker, which is pretty ancient. Or just a little device that the family bring in when they visit to use when they communicate; try to keep them engaged that way. (AUD)
	ALD is considered if HA management is unlikely to be supported by RACF	If we don't set something like that up [getting HA put on care plan & involving RACF STAFF in management of hearing aid] then we might consider an ALD. (AUD)
	ALDs work quite well	You know, I've fit quite a few of those, it's like a pocket talker. It's an assistive device that they put on a headphone and just use it when they have visitors, and they seem to work quite well. (AUD)
	ALDs aren't ideal	Obviously, it's [ALD] not an ideal option for a lot of people that don't like the idea of wearing some big, chunky earphones for most of the day. (AUD)
Counselling and communication strategies provided to caregivers in place of or along side devices	Audiologists provides counselling and communication strategies in place of HAs to caregivers	I wouldn't always recommend a hearing aid or even a hearing device. For example, I'd focus more on the carer, because they're struggling a lot, and just ways for them to engage their partner better. (AUD)
	Counselling is important in hearing rehabilitation for people with dementia	Someone with dementia I feel like that is even more important rehabilitation side of it, the counselling side of it is even more important (AUD)

Note. RACF = residential aged care facility; ALD = assistive listening device; AUD = audiologist; FAM = family caregiver; HA = hearing aid; HI = hearing impairment; IND = individual; PWD = person living with dementia

4.4.2.2 Category 2. RACF staff emphasised using communication strategies.

In contrast to audiologists, RACF staff emphasised using communication strategies to manage hearing impairment in residents with dementia (see Table 4-5). RACF staff discussed strategies such as: moving closer to the individual; maintaining eye contact; and slowing down their speech to improve resident-caregiver communication. RACF staff members also discussed using visual aids to facilitate communication, however identified that these were not always an available resource in the RACF. RACF staff reported supporting management of hearing aids among residents, but acknowledged that hearing impairment was poorly managed for this population in that they did not tend to refer residents with dementia and hearing concerns to hearing services.

Table 4-5 Category 2: RACF Staff Emphasised using Communication Strategies

Sub-categories	Codes	Example participant quotes
RACF Staff use multiple communication strategies to overcome the impact of HI	Use multiple communication strategies	So, it really comes down to clear pronunciation, not yelling at them, but speaking clearly, definite eye contact, and definite body language... use of if needed, written word. (RACF Staff)
	Speak to the better ear	If they've got one ear better than the other, choosing that side to speak to. (RACF Staff)
	Use gestures/body language/ demonstrate	All the hand gestures and things seem to help. (RACF Staff)
	Slow down / simplify speech	I tend to slow down and simplify what I am saying. (RACF Staff)
	Maintain eye contact	Well, usually just make sure they've got eye contact if they can. (RACF Staff)
	Clarify	And if necessary sometimes, approach the resident and clarify that one on one. (RACF Staff)
	Move closer	I try to move a little closer. (RACF Staff)
RACF Staff use visual aids to overcome consequences from HI	Use visual aids	I think we should always have visual aids. (RACF Staff)
	Write things down	Another thing that sometimes helped, too, is to write things down. (RACF Staff)
	RACF services don't always have visual resources for staff to use	I think we should always have visual aids. I must admit, finding or trying to ... Yeah, pretty much finding anything in an age care facility that has actual visual and printed off and labelled, you know is very rare. (RACF Staff)

RACF Staff support residents who have HAs to wear them	RACF Staff manage HAs	Regularly upkeeping the hearing aids is really important. Changing the batteries on a regular basis to making sure they're clean, that they're functioning well. (RACF Staff)
	RACF staff has HA management plan	But how we are managing it here, is that we keep them [HA] in their case and kept in the medication trolley. That's what I've implemented here, similar to what I implemented at the other place, because it's very costly. So, I make sure that the RN puts the hearing aids on in the morning, because it's on the medication trolley. The evening shift RN, before going out ... During their 8:00 medication rounds at night, they take the hearing aid off and put it back in the trolley. (RACF Staff)
RACF Staff identified that HI is sub-optimally managed for residents with dementia	HI isn't managed for residents with dementia	I couldn't say that it is particularly managed. (RACF Staff)
	HI is overlooked	It's really hard because sometimes it's just the natural progression that you don't always see that it could be that [HI], you just think it's part of dementia so it's probably skipped over quite a bit. (RACF Staff)
	RACF Staff don't realise PWD isn't wearing HA when talking to them	You can talk to them but not realising that they don't have their hearing aid in there. (RACF Staff)
	RACF Staff don't refer PWD and hearing concerns to hearing services.	I must admit, I have never seen that [refer to hearing services] happen. (RACF Staff)

Note. HI = hearing impairment; PWD = person living with dementia; HA = hearing aid; RACF = residential aged care facility.

4.4.2.3 Category 3: Family caregivers had mixed views on hearing aids and used communication strategies.

Family caregivers presented mixed views on the benefits of hearing aids for managing hearing impairment in this population (see Table 4-6). For example, some caregivers felt hearing aids were vital to their family member's communication and quality of life, yet others felt hearing aids were of no benefit, attributing communication problems to dementia rather than hearing impairment. Family caregivers also discussed using multiple communication strategies to improve interactions and provided these strategies to RACF staff to use.

Table 4-6 Category 3: Family Caregivers had Mixed Views on the Benefits of Hearing Aids and used Communication Strategies

Sub-categories	Codes	Example participant quotes
HA of benefit to PWD	Using HAs improves communication	He doesn't hear anything if he doesn't have his hearing aid in. (FAM)
	HA helps PWD hear instructions, which is important to them	I know that I have to be on track [changing HA batteries] so that she's comfortable up here and can hear instructions because that's really important to her. (FAM)
	Family support PWD to manage their HA in the RACF	I leave notes on the near the HA box. Gradually staff has probably passed it onto new staff to say that her HAs have to come out at night and to open the battery case so that they're disconnected. (FAM)
HAs aren't of benefit to PWD	Communication problem is from dementia not HI	I don't honestly think it is because of his hearing. I think it's because of his dementia ... He might call a pen a rock or something, just something that doesn't even relate to it. But, that's to do with the dementia, not the hearing. (FAM)
	PWD doesn't want HAs	When we've said before, earlier on, "would you like to go somewhere to see if they can put a hearing aid in his good ear?" he said, "Oh no, just no, no. Don't worry." (FAM)
	HAs are no longer appropriate due to dementia progression	Well, with mum and dad. There just came a time where HA was of no use, really. Dad couldn't manage it, mum can't. (FAM)
	Speak at family member	I just try to be in the right position and try and speak directly at her and all that sort of thing. (FAM)

Families use communication strategies	Get close to family member	You've just got to remember to try and stand near him, closer, and see your face where he's watching what you're saying. (FAM)
	Speak louder	So I would have to speak louder. That's all I did to compensate most of it. (FAM)
	Repeat	I sometimes have to repeat a few things. (FAM)
	Family provide communication strategies to RACF STAFF	I leave notes and I tell staff, and if I'm there and they're speaking to her, and I can tell Mum's not picking up the conversation, I just say, "You'll have to speak a bit louder," or "Come closer." (FAM)

Note. HA = hearing aid, PWD = person living with dementia; FAM = family caregiver; RACF = residential aged care facility;

4.4.2.4 Category 4: Individuals with dementia and hearing impairment had mixed views on the benefits of their hearing aids.

The two individuals with dementia and hearing impairment who took part in the interviews both wore hearing aids. Both participants reported mixed feelings regarding their benefits, with one participant saying, “*Oh, to a degree. But not real good. But sometimes they [hearing aid] could be alright.*” One individual discussed that it took him time to get used to his hearing aids, saying, “*Early in the piece, it [hearing aid] wasn’t that hot, but when I got used to it, it’s pretty good.*”

4.5 Discussion

This study explored the impact and management of hearing impairment for people living with dementia in RACFs from the perspective of four stakeholder groups. The participants discussed the far-reaching psychosocial and communication consequences that hearing impairment has for people living with dementia. Participants also identified that appropriately managing hearing impairment would be beneficial and important for residents living with dementia. This study found that stakeholder priorities for managing hearing impairment are different: audiologists emphasised hearing aids whereas RACF staff emphasised communication strategies. Additionally, RACF staff identified that current management of hearing impairment was sub-optimal, as they did not routinely refer residents with dementia and hearing concerns to hearing services. Therefore, to improve the management of hearing impairment and reduce the far-reaching consequences, modifications to both hearing and RACF services should occur.

All stakeholder groups discussed the far-reaching consequences that a hearing impairment has for people living with dementia in RACFs, which is largely consistent with other research conducted in this area (Ludlow, Mumford, Makeham, Braithwaite, & Greenfield, 2018; Punch & Horstmanshof, 2018; Slaughter, Hopper, Ickert, & Erin, 2014). In the present study, participants reported that hearing impairment interferes with communication and has psychosocial consequences; thus, hearing impairment is likely to impact residents’ quality of life and ability to receive care. This finding is consistent with that of Slaughter et al. (2014) who identified that hearing impairment resulted in poorer quality of care and reduced

quality of life of residents with dementia. Additionally, in the present study, the two individuals with dementia and hearing impairment who participated reported emotional consequences of their hearing impairment, for example, feeling stupid when they misheard conversations. This finding is consistent with the findings reported by Pryce and Gooberman-Hill (2012) where some participants also described the pervasive psychosocial consequences of their hearing impairment.

Generally, participants in the present study felt it was both important and beneficial to manage hearing impairment in residents living with dementia. Participants discussed how the effective use of communication strategies or hearing aids improved communication interactions and residents' mood, and resulted in improved engagement in activities within the RACF. Again, this finding is consistent with previous research, highlighting the importance of treating hearing impairment to improve communication, social engagement, and quality of life of people living with dementia (Dawes et al., 2019; Hopper, 2007; Hubbard, Mamo, & Hopper, 2018; Mamo et al., 2018; Pichora-Fuller, Dupuis, Reed, & Lemke, 2013). However, in the present study, audiologists and RACF staff emphasised different priorities for managing hearing impairment, and family caregivers presented mixed views on the use of hearing aids for people living with dementia. These juxtaposing practices and attitudes among key stakeholders are a new finding and may provide some insight into why hearing impairment is currently not well managed or prioritised for residents with dementia.

Hearing aids are the most commonly recommended option for managing hearing impairment and, accordingly, audiologists involved in the present study prioritised hearing aid fitting over other hearing rehabilitation options. However, there is limited high-level evidence demonstrating the benefits of hearing aids for older people living with dementia (Dawes et al., 2019; Mamo et al., 2018). Furthermore, emphasis on hearing aids is not compatible with many clinical guidelines. For example, the American Speech-Language-Hearing Association (ASHA) guidelines for the delivery of hearing services to people living in RACFs (including those with cognitive impairment) identifies that ALDs may be more appropriate for this population (American Speech-Language-Hearing Association, 1997). In the present study, only two audiologists discussed offering ALDs to manage hearing impairment

for adults with dementia living in RACFs, and their views were somewhat negative, reporting that ALDs were old and bulky and that many residents did not like wearing them. This expressed perception is similar to findings reported by Jupiter (2016), who found most participants did not persist with the ALD because it was too bulky or they had difficulty learning how to use it. However, audiologists 'reluctance' toward recommending ALDs suggest that hearing services for this population may not be person-centred.

RACF staff who participated in this study emphasised the use of communication strategies, as opposed to hearing devices, to best manage hearing impairment in adults with dementia. Evidence-based communication strategies have been recognised as effective in improving resident-caregiver communication interactions for people living with dementia (Conway & Chenery, 2016; Eggenberger, Heimerl, & Bennett, 2013; Sprangers, Dijkstra, & Romijn-Luijten, 2015) and for assisting adults with hearing impairment and their caregivers (Hickson, Worrall, & Scarinci, 2006). However, the communication strategies identified by caregivers in this study may not be the most effective for residents who have both a sensory and a cognitive communication impairment. For example, background noise interferes with communication and is particularly problematic within RACFs (Pryce & Gooberman-Hill, 2012). Yet, in the present study, only one participant discussed how the environmental noise of the RACF may interfere with communication. This finding is consistent with that of Slaughter et al. (2014), who identified that communication strategies used by RACF staff may not be evidence-based for residents living with dementia. Therefore, RACF staff may benefit from training in evidence-based cognitive-sensory communication strategies in the context of an RACF setting.

Although RACF staff acknowledged the negative consequences of hearing impairment for residents living with dementia, they reported that they did not routinely refer these residents to hearing services. In the present study, RACF staff discussed various reasons for this, including: (1) hearing impairment is under-recognised among residents living with dementia; (2) hearing impairment is not a priority; and (3) RACF staff question the appropriateness of hearing aids for this population. These findings are largely consistent with other research groups who have identified that hearing impairment is under-recognised and not a priority for

RACF staff (Adams-Wendling, Pimple, Adams, & Titler, 2008; Cohen-Mansfield & Taylor, 2004a, 2004b; Crosbie et al., 2019; Pryce, Hall, Laplante-Lévesque, & Clark, 2016; Slaughter et al., 2014). Further exploration of why RACF staff do not routinely refer residents to hearing services should be explored in larger quantitative studies.

RACF staff practice of non-referral may not wholly align with current dementia and RACF clinical guidelines. For example, in 2016, the Australian Government National Health and Medical Research Council supported the development of clinical practice guidelines and principles of care for people with dementia (Guideline Adaptation Committee, 2016). These guidelines stipulate that people with dementia should not be excluded from any health care services because of their diagnosis, whatever their age. Similarly, the Australian Aged Care Home Quality Standards state that residents of RACFs should receive ongoing needs assessment and receive suitable personal and clinical care (Aged Care Quality and Safety Commission, 2019). Given the high prevalence and far-reaching consequences of hearing impairment among residents with dementia, the provision of hearing services should be an essential part of this care.

In the present study, individuals living with dementia and hearing impairment and their family caregivers had mixed views regarding the benefits of hearing aids, and family caregivers reported using multiple communication strategies to further manage this impairment. Hearing impairment management often requires a holistic approach, such as hearing aids used in conjunction with communication training and environmental modifications of the RACF environment (Pichora-Fuller et al., 2013; WHO 2001) and previous research groups have explored the outcomes of providing ALDs and communication training for people living with dementia in the community and their caregivers (Mamo et al., 2017). However, family caregivers involved in the present study were unaware of device options other than hearing aids. Therefore, increasing family caregiver knowledge of all options available for treating hearing impairment may be an important step to achieving holistic hearing care.

4.5.1 Clinical Implications and Future Research Directions

Findings from this study have clinical implications for hearing and RACF services. First, RACFs should arrange for all residents to have their hearing routinely screened. For this to be successful, audiology services should become integrated

into RACF services and seen as an essential component of care rather than an adjunct (Lewsen & Cashman, 1997). Second, audiologists should be mindful of all options available for managing hearing impairment, not limited to hearing aids, and provide person-centred care. Developing a dementia-friendly decision aid, may help to facilitate this, and the authors of this study are currently developing such a tool.

The present study identified that improving the management of hearing impairment for RACF residents living with dementia requires behaviour change by audiologists and RACF staff. For example, audiologists involved in the present study discussed the limitations of hearing aids – that is, that many adults with dementia could not manage their hearing aids – yet, continued to prioritise this option. However, the underlying reasons behind this pattern of behaviour are currently not known. As such, future research should consider utilising behaviour change frameworks (Coulson, Ferguson, Henshaw, & Heffernan, 2016) to further explore this and other factors that influence hearing impairment management for people living with dementia who reside in RACFs. The authors of this study are currently conducting such a study.

In the present study, the foci of the interviews was on the consequences of hearing impairment for adults living with dementia. Caregivers/family members of adults living with a hearing impairment are known to experience third-party disability (Scarinci, Worrall, & Hickson, 2012) and future research could explore caregiver consequences of hearing impairment for this population.

4.5.2 Limitations

Several limitations exist in the present study. First, this research is limited by the small number of individuals living with dementia and hearing impairment who took part in the interviews, both of whom were assessed with moderate dementia severity. It is important to include individuals' with dementia in qualitative research (Kitwood, 1997). However, only having two participants living with dementia limits whether findings are applicable to the broader population of people living with dementia who reside in RACFs and whether two participants constitute a 'group'. Ultimately, data from these two participants in the present study as these participants provided valuable insight into the impact of their hearing impairment and

perspectives on managing it. Further research with larger sample size is required to confirm findings.

Second, family caregivers and RACF staff who took part in the study did not have their hearing screened in the present study. Given that, one RACF staff participant and all family caregiver participants were over the age of 50 years, by not screening these participants hearing, we cannot examine whether their own hearing ability biased findings.

Finally, this study was undertaken within a small geographical region of Australia RACFs, therefore careful consideration should be made of the transferability of findings to different contexts – for example, community-dwelling adults living with dementia – and geographical areas – both inside Australia and overseas.

4.6 Conclusions

The far-reaching consequences of hearing impairment on people living with dementia in RACFs was clearly reported in the qualitative interviews, along with the need for appropriate management. However, different stakeholder priorities for managing hearing impairment – audiologists emphasising hearing aids and RACF staff emphasising communication strategies – suggest that changes to hearing services are required. To improve management of hearing impairment for this population, audiologists should be mindful of all promoting all options available for managing hearing impairment, aligning their practice with a person-centred approach.

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Chapter 5 “It’s just not a priority.” Barriers and Facilitators to Managing Hearing Impairment for Adults living with Dementia in Residential Aged Care Facilities

The research reported in chapter 4 identified that in order to improve hearing impairment management for adults living with dementia and hearing impairment in residential aged care facilities (RACFs), behaviour change is required from health care professionals who provide hearing services. For example, where audiologists typically recommend hearing aids to people with dementia and hearing impairment, our data suggest that audiologists need to be recommending a variety of options for managing hearing impairment. Moreover, our data suggest that RACF staff do not commonly refer residents to hearing services, identifying another area requiring healthcare professional behaviour change to help optimise hearing impairment management. Designing interventions that target changing people’s behaviour is challenging and complex. Therefore, before designing such an intervention, data from chapter 4 were further analysed in chapter 5 to identify the barriers and facilitators underlying a range of possible target behaviours which could optimise hearing impairment management for adults living with dementia and hearing impairment in RACFs.

This chapter is presented as a stand-alone chapter that is in preparation for peer-review in the *International Journal of Audiology*.

5.1 Abstract

Objective: The aim of this study was to explore the barriers and facilitators underlying a range of possible target behaviours that influence hearing impairment management for adults living with dementia and hearing impairment in residential aged care facilities (RACFs).

Design: A qualitative method, consisting of in-depth semi-structured interviews, which were analysed using a deductive framework analysis.

Study Sample: Data from 21 semi-structured interviews that explored audiologists, RACF staff and family caregivers' perceptions of the impact of, and management for, hearing impairment for adults living with dementia and hearing impairment in RACFs were further analysed. First, five potential target behaviours for managing hearing impairment were identified: (1) recognition of hearing impairment; (2) assessment of hearing impairment; (3) referral to and provision of hearing services; (4) management of hearing aids, and (5) shared decision-making. Then, a deductive framework analysis using the Capability, Opportunity, Motivation, Behaviour (COM-B) model identified the barriers and facilitators that influenced these behaviours.

Results: Inter-related barriers and facilitators were identified in terms of audiologists, RACF staff and family caregivers' capability, opportunity and motivation. A salient barrier that influenced recognition of hearing impairment, referral to hearing services and management of hearing aids, was that RACF staff in this study did not prioritise hearing impairment (motivation). Moreover, shared decision-making emerged as a realistic area for future intervention-based research, as audiologists involved family caregivers/ RACF staff in audiology appointments (opportunity) and RACF staff and family caregivers believed it was important to increase their knowledge on the options available for managing hearing impairment (motivation).

Conclusions: To optimise hearing impairment management, RACF systems, managers and staff need to increase their motivation for prioritising the management of hearing impairment. Audiologists should ensure they provide information on all the options available for managing hearing impairment, optimising the behaviour of shared decision-making. Future research avenues are presented that address capability, opportunity and motivation barriers underlying the five target behaviours.

These findings could be used as a catalyst for implementation science and to optimise hearing-related communication for adults living with dementia and hearing impairment in RACFs.

5.2 Introduction

Within residential aged care facilities (RACFs), over 90% of adults living with dementia have a concomitant hearing impairment (Hopper, Slaughter, Hodgetts, Ostevik, & Ickert, 2016). The co-occurrence of hearing impairment for adults living with dementia in RACFs has far-reaching consequences for individuals including affecting psychosocial behaviours (Bott, Meyer, Hickson, & Pachana, 2019b; Pryce & Gooberman-Hill, 2012), resident-caregiver communication (Bott, Meyer, Hickson, & Pachana, 2019b; Slaughter, Hopper, Ickert, & Erin, 2014), engagement and participation in social activities (Cohen-Mansfield, Marx, Regier, & Dakheel-Ali, 2009; Pryce & Gooberman-Hill, 2012), and causing increased functional difficulties (Guthrie et al., 2018). Thus, treating hearing impairment is considered important for improving the overall wellbeing of adults living with dementia who reside in RACFs (Hopper & Hinton, 2012; Hubbard, Mamo, & Hopper, 2018; Pichora-Fuller, Dupuis, Reed, & Lemke, 2013).

Despite the identified importance of managing hearing impairment for this population, it is currently under-treated and previous research conducted to optimise hearing-related communication for adults living in RACFs has had low participation. Researchers consistently report a gross underuse of hearing aids for this population, with fewer than 40% of the residents who would benefit from hearing aids reported to use them (Cohen-Mansfield & Taylor, 2004a; Erber & Heine, 1996; Flynn, Kennedy, Johns, & Stanbridge, 2002). In addition to this low uptake of hearing aids, participation in research projects aimed at improving hearing impairment management is also low. Researchers have attributed low participation in research aimed at optimising hearing-related communication of residents in RACFs (which may include residents with dementia) to: residents being more concerned with addressing other health areas (Linssen, Joore, Theunissen, & Anteunis, 2013); challenges obtaining consent for residents with dementia (Looi et al., 2004); and participants withdrawing due to their declining health when interventions are too lengthy (Pichora-Fuller & Robertson, 1997). These findings highlight some of the challenges regarding designing interventions aimed at optimising hearing-related communication in this context and suggest that the factors contributing to this are multifaceted.

Multiple research groups have presented an array of barriers that influence optimal hearing impairment management for adults living with dementia in RACFs. For example, in the study described in chapter 4 (Bott, Meyer, Hickson, & Pachana, 2019b) – interviews with stakeholders involved in managing hearing impairment for this population (Note: this is the same dataset used in the research described in this chapter) indicated that audiologists and RACF staff prioritise different approaches for managing hearing impairment. That is, audiologists prioritised hearing aids and RACF staff prioritised communications strategies. Moreover, RACF staff did not prioritise management of hearing impairment nor did they routinely refer residents with dementia and hearing impairment to hearing services. Other researchers (Pryce & Goberman-Hill, 2012; Pryce & Goberman-Hill, 2013; Slaughter et al., 2014) have identified additional barriers to that reported in chapter 4. For example, Slaughter, Hopper, Ickert, and Erin (2014) completed an exploratory study with 12 RACF staff and identified that they had difficulty recognising mild-to-moderate hearing impairment among residents with dementia and, central to optimising this, was RACF staff knowing residents. Moreover, RACF staff reported using a variety of strategies to enhance resident-caregiver communication; yet, not all communication strategies used by RACF staff were evidence-based. Pryce and Goberman-Hill (2012) completed an ethnographic observation and qualitative investigation with 18 residents living in RACFs, exploring the factors affecting communication for residents with hearing impairment and found that both environmental noise and limited opportunities to engage in activities were barriers. Moreover, Pryce and Goberman-Hill (2012) reported that accessing hearing services and use of hearing aids did not necessarily improve communication.

Recently, Crosbie et al. (2019) conducted a realist synthesis – a theory-driven approach for reviewing literature from a range of sources (Pawson, 2006) – to explore underlying generative reasons (mechanisms) that influence expected or unexpected results (outcomes), for optimising hearing-related communication for residents living with dementia and hearing impairment in RACFs (context). This approach is known as context-mechanism-outcomes (CMOs; Pawson, 2006). Crosbie et al. (2019) identified five CMOs that would facilitate improved management of hearing impairment: (1) managers giving permission for RACF staff to provide person-centred care; (2) RACF staff participating in communication training; (3)

RACF staff knowing residents; (4) RACF staff maintaining and monitoring hearing communication through care planning; and (5) RACF staff managing noise. One limitation of the realist synthesis described by Crosbie et al. (2019) is that the findings focused on changes for RACF staff or systems only and previous research has highlighted the complexity in changing RACF staff behaviour. For example, staff ratios, RACF policies and lack of resources have been identified as organizational level barriers for RACF staff implementing person-centred care (Abbott, Heid & Haitsma, 2016). Furthermore, in Australian RACFs, a key facilitator for achieving RACF staff behaviour change is that a 'whole of system approach' is adopted (Batchelor et al., 2019). Further consideration of the complexities surrounding managing hearing impairment for adults living with dementia in RACFs may be found when the barriers and facilitators are explored from the perspectives of all key stakeholders, such as audiologists, family caregivers as well as RACF staff. Thus, the aim of this study was to further explore the barriers and facilitators to effectively managing hearing impairment for adults living with dementia and hearing impairment in RACFs, taking into account the perspectives of a broader range of stakeholders.

5.3 Method

5.3.1 Study design

The data presented here forms part of a larger study (described in Chapter 4), which aimed to complete a hearing-related communication needs assessment for adults living with dementia and hearing impairment who reside in RACFs. As part of this needs assessment, participants were asked to describe the impact of, and management for, hearing impairment for this population. However, during these interviews, participants also discussed barriers to, and facilitators of, optimal hearing impairment management. Thus, in the present study, interviews were further analysed to explore these underlying barriers and facilitators, against several potential target behaviours. It was envisaged that doing so would help to target priority areas for future interventions.

5.3.2 Participants and Sampling

Twenty-three participants took part in the larger needs analysis (see 4.3.2). However, data from two participants (both individuals living with dementia) were removed from this study as neither participant described barriers or facilitators

related to optimal hearing impairment management during their interviews. Table 5.1 presents the demographic information of the five audiologists, nine RACF staff and seven family caregivers of adults living with dementia and hearing impairment in RACFs in the present study.

Table 5-1 Stakeholder Demographic Information

	Audiologists (n = 5)	RACF Staff (n = 9)	Family caregivers (n = 7)
Age in years (number of participants)	20 – 30 (1) 30 – 40 (3) 40 – 50 (1)	20 – 30 (2) 30 – 40 (2) 40 – 50 (4) 50+ (1)	50 – 60 (1) 60 – 70 (1) 70 – 80 (4) 80+ (1)
Sex (number of participants)	Female (3) Male (2)	Female (7) Male (2)	Female (7)
Number of years working with people with dementia (number of participants)	< 1 year (1) 2-5 years (0) 6-10 years (4)	< 1 year (2) 2-5 years (2) 5-10 years (3) 10+ years (2)	
Employment position (number of participants)	Audiologist (3) Audiometrist (2)	Clinical Care Coordinator (2) Registered Nurse (1) Enrolled Nurse (1) Lifestyle Coordinator (2) Chaplain (1) Personal Care Worker (2)	
Relationship to person with dementia (number of participants)			Wife (4) Daughter (3)
Experience with hearing services of person with dementia family were discussing (number of participants)			No experience (3) Previous experience (2) Current experience (2)

Note. (n = X) represents the number of participants in each stakeholder group

5.3.3 Procedure

This research was approved by The University of Queensland Human Research Ethics Committee and Churches of Christ Ethics Committee and was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council & Australian Vice Chancellor's Committee, 2007).

Participant recruitment and sampling is detailed in section 4.3.2. An overview of participant recruitment is described below. Participants were recruited from three RACFs in the Darling Downs region of Queensland, Australia between July 2017 and March 2018. Potential participants from all groups were approached by the first author (AB, MAudSt, female) and were not known to her before taking part in the study. A database search of the Office of Hearing Services identified audiology clinics within the geographical region of the RACFs. The first author contacted all clinics, via cold-calling or face-to-face, to discuss participation in this project. RACF staff were approached face-to-face at the RACF by first author with information about the study; however, after several months, no RACF staff had taken part in this study as none were available to be interviewed outside of work hours. Accordingly, interviews were shortened so they could be conducted during staff work breaks. Family caregivers were identified and recruited face-to-face by the first author during a former study (presented in chapter 3) that had explored the feasibility of an AEP test for assessing hearing sensitivity with adults living with dementia in RACFs.

All interviews were conducted by the first author (AB) either over the phone ($n = 3$; an audiologist and two family caregivers) or face-to-face ($n = 18$) and ranged in duration between 10 and 72 minutes. The topic guide was originally developed to answer the primary questions of the overarching research project (see Chapter 4), but also probed factors that influenced hearing impairment management (see Appendix B). For example, participants were asked, "In your experience, how is hearing loss managed for residents living with dementia in care homes?" and a follow-up question of "what helps/hinders this?". Participants were also asked a final question of "In your opinion, how can hearing loss management be improved for residents living with dementia?" to which participants responded by further discussing factors for managing hearing impairment. All interviews were audio

recorded and transcribed verbatim by a professional transcription service and were checked for accuracy prior to data analysis.

5.3.4 Data analysis

The first step was to identify target behaviours that influence hearing impairment management. Based on a review of the transcripts and results in chapter 4, five potential target behaviours were chosen (1) recognition of hearing impairment, (2) assessment of hearing impairment, (3) referral to and provision of hearing services, (4) management of hearing aids, and (5) shared decision-making. Shared decision-making is a hallmark of person-centred care (Elwyn, Edwards, & Kinnersley, 1999). In the context of hearing healthcare, it is the process whereby audiologists work collaboratively and inclusively with clients (and families) to reach treatment decisions about managing hearing impairment that are evidence-based and align with the individual's values and needs (Stacey et al., 2017).

Subsequently, data were analysed using a deductive framework model of analysis as presented by Gale, Heath, Cameron, Rashid, and Redwood (2013), using Microsoft Excel™. A framework analysis was chosen as it is a form of thematic analysis (Ritchie & Lewis, 2003) that is considered useful when comparing multiple perspectives (Gale et al., 2013). Furthermore, a deductive, rather than inductive, approach was used as each factor was mapped to one of six pre-determined domains according to the Capability, Opportunity, Motivation - Behaviour (COM-B) model (Michie, Atkins, & West, 2014; Michie, van Stralen, & West, 2011) and then to one or more of the five target behaviours. The COM-B model is an interactive model designed to help guide behaviour change intervention using the behaviour change wheel (BCW; Michie, Atkins, & West, 2014; Michie, van Stralen, & West, 2011). The COM-B model proposes that, for someone to engage in a behaviour (B), they must have the physical and psychological capability (C); the social and physical opportunity (O); and want or need to do the behaviour (motivation), more than any other competing behaviour at that moment (M) (Michie, Atkins, & West, 2014; Michie, van Stralen, & West, 2011). Use of the COM-B model is increasing in audiology research because of its evidence-based development and positive implications for implementation science (Barker, Atkins, & de Lusignan, 2016; Coulson, Ferguson, Henshaw, & Heffernan, 2016; Maidment, Ali, & Ferguson, 2019;

van Leeuwen et al., 2018). The COM-B model has also been applied to describe behaviour changes required of RACFs in areas such as oral healthcare (Maramaldi et al., 2017). Therefore, we felt the COM-B would be a useful model for exploring the barriers and facilitators that influence key behaviours associated with optimising hearing impairment management for adults living with dementia in RACFs.

The six stages of the framework analysis, as described by Gale and colleagues (2013) (i.e., familiarisation, coding, developing the framework, applying the framework, charting data into the framework matrix, and interpreting the data) were applied to identify the barriers and facilitators underlying these behaviours. First, transcripts were read and re-read by the first author, during which reflective notes were documented. Next, transcripts were coded line-by-line using an iterative process to identify the barriers and facilitators that influenced one or more of the behaviours. Then, coded items were assigned to one of the six COM-B domains pertaining to: physical capability; psychological capability; physical opportunity; social opportunity; reflective motivation; and automatic motivation. Similar codes were then grouped together, creating a list of COM-B barriers and facilitators that became the framework. Transcripts were then checked against this framework and each factor was mapped to one or more of the behaviours. The first author completed the analysis for all 21 transcripts, with the first and second author (CM), regularly meeting to review all stages of the analysis. The third author (LH) resolved any disagreements between the first and second authors.

5.4 Results

Table 5.2 presents a summary of the COM-B barriers and facilitators for managing hearing impairment in residents with dementia, mapped against one or more of the five possible target behaviours for optimising hearing impairment management in this context.

Table 5-2 Summary of Target Behaviours for Managing Hearing Impairment of Residents with Dementia Identified by Stakeholders, and COM-B Barriers and Facilitators that influence each Behaviour

Behaviour	COM-B Domain	Barriers	Facilitators
1. Recognition of Hearing Impairment	Psychological Capability	RACF staff and family caregivers have difficulty differentiating hearing impairment from cognitive impairment	RACF staff and family caregivers' knowledge of residents
	Social Opportunity		RACF staff share information about residents suspected of having hearing impairment with one another
	Reflective motivation		RACF staff and family caregivers believe that hearing impairment should be better identified
	Automatic Motivation	RACF staff do not routinely look for hearing impairment	
2. Assessment of Hearing Impairment	Psychological Capability	PWD cannot following directions to complete pure-tone audiometry	Audiologists know that PWD have varied abilities to complete PTA and apply strategies to help PWD complete hearing pure-tone audiometry
	Physical Opportunity	Audiologists need more time to complete hearing assessments Completing hearing assessments without family or RACF staff is more difficult	Audiologists allow for more time when completing hearing assessments with PWD
	Reflective Motivation		Audiologists believe including RACF staff or family caregivers in appointments helps to assess hearing

3. Referral to and Provision of Hearing Services	Physical Opportunity	Audiologists have limited availability to provide timely hearing services within RACFs Not all audiology clinics provide hearing services for RACFs Not all residents have family who visit to facilitate referral to hearing services	Audiologists can provide timely hearing services within RACFs Family caregivers are available to arrange referral to hearing services Presence of a local audiology clinic has improved timeliness of hearing services
	Reflective Motivation		Audiologists and family caregivers believe that hearing services should be provided more frequently All stakeholders believe that hearing services should be provided in RACFs
	Automatic Motivation	RACF staff do not routinely refer residents to hearing services	
	Physical Capability	Vision and dexterity problems	
4. Management of Hearing Aids	Psychological Capability	RACF staff and family caregivers have limited knowledge of managing hearing aids PWD forget how to manage their hearing aids	RACF staff and family caregivers have a good understanding of managing hearing aids
	Physical Opportunity	RACF staff and family caregivers do not have the time to help PWD manage their hearing aids	Presence of a local audiology clinic
	Social Opportunity	RACFs have high staff turnover	

		RACF staff do not always support residents to manage their hearing aids	
	Reflective motivation		Audiologists believe it is beneficial to educate family caregivers and RACF staff about managing hearing aids
	Automatic Motivation	RACF staff do not routinely manage hearing aids	Audiologists put hearing aid management on resident care plan
5. Shared Decision-Making	Psychological Capability	RACF staff and family caregivers have limited knowledge of what hearing services offer other than hearing aids PWD cannot accurately describe their hearing-related needs Audiologists have difficulty making appropriate hearing-related decisions for PWD because of their limited knowledge	PWD can describe their needs to audiologists', RACF staff and family caregivers
	Physical Opportunity	RACF staff workload influences family caregivers' decision-making	Audiologists include a third party (family or RACF staff) during audiology assessments
	Reflective Motivation	RACF staff and family caregivers do not believe hearing aids are beneficial to PWD	RACF staff and family caregivers believe hearing aids are necessary Caregivers want information on all hearing impairment treatment options
	Automatic Motivation	Audiologists lead decision making processes Audiologists routinely recommend hearing aids	Audiologists routinely provide information to family caregivers to help them understand what

PWD is entitled to under hearing services scheme.

Audiologists routinely involve RACF staff and/or family caregivers during appointments

Note. PWD = person living with dementia; RACFs = residential aged care facilities; HA = Hearing Aid; PTA = pure-tone audiometry

5.4.1 Recognition of Hearing Impairment

For recognition of hearing impairment, two inter-related COM-B domains of psychological capability and automatic motivation were barriers to this behaviour. For example, most RACF staff reported having difficulty differentiating hearing impairment from cognitive impairment (psychological capability), with one RACF staff member explaining, *“It’s really hard because sometimes it’s just the natural progression that you don’t always see that it could be that [hearing loss], you just think it’s part of dementia so it’s probably skipped over quite a bit.”* Many RACF staff also reported that they do not routinely look for hearing impairment (automatic motivation). As one RACF staff member explained, *“I am not able to tell you actually about hearing loss, because rarely is it ever diagnosed or recognised when they come to nursing homes.... There’s not a lot of emphasis there. So, a lot of it is unrecognised.”*

Although most RACF staff acknowledged that hearing impairment was currently poorly recognised, importantly, they believed that there should be improved identification of it (reflective motivation). Many caregivers (RACF staff and family) reported that better recognition of hearing impairment was helpful for them. As one family member stated, *“Look, I think just having a better understanding of where she’s at [with her hearing]. That’s immensely helpful.”* Another facilitator that helped recognition of hearing impairment was RACF staff and family caregivers’ knowledge of residents (psychological capability). Family caregivers and RACF staff reported that knowing individuals helped them to distinguish whether communication breakdowns were from hearing impairment or cognitive impairment. Moreover, once RACF staff had this information, they could use strategies to improve hearing-related communication. For example, one caregiver explained speaking to the better hearing ear improved communication with a resident who had dementia and a single sided deafness, stating, *“I just found that was like opening a door.”*

5.4.2 Assessment of Hearing Impairment

In assessment of hearing impairment, psychological capability, physical opportunity and reflective motivation influenced this behaviour. For psychological capability, audiologists reported that some individuals living with dementia cannot follow the instructions to complete pure-tone audiometry. This led to some audiologists

questioning the accuracy of hearing test results. For example, one audiologist explained

Pure-tone audiometry can sometimes be a little bit tricky and that might not necessarily be a threshold when they're responding... And it's just keeping that in mind for some of the more advanced dementia sufferers and we might not get any responses at all.

To help in assessing hearing for adults living with dementia, audiologists allowed more time during appointments (physical opportunity) with one audiologist explaining *"We tend to allow more time in each appointment because everything is going to take a little bit longer."* All audiologists believed it was important to involve a family member or RACF staff during appointments to help facilitate assessments (reflective motivation). As one audiologist explained:

I always try to involve the partner or the family, or if none of them are available, the nurse. Because when I show up, I'm a stranger and that's not helpful, depending and [sic] where they are in the disease as well. For me to get any type of reliable and valid result, the environment has to be conducive for that.

5.4.3 Referral to and Provision of Hearing Services

For referral to and provision of hearing services, inter-related COM-B barriers existed in terms of automatic motivation and physical opportunity. RACF staff acknowledged that they do not routinely refer residents to hearing services (automatic motivation). As one RACF staff member explained *"I must admit, I've never seen that [referring resident with dementia to hearing services] happen."* Additionally, RACF staff also explained that if residents did not have a family caregiver to arrange for a referral to hearing services (physical opportunity), hearing impairment would remain unaddressed. One RACF staff member explained, *"Oh they didn't have family. Some people didn't have anyone, except elderly people to look after them, so yeah it [accessing hearing services] just didn't happen."*

In provision of hearing services, participants also often spoke about where hearing services were provided from (physical opportunity). Most participants believed that hearing services should be provided from within the RACF (reflective

motivation) and discussed the importance of having a local hearing services provider (physical opportunity). For example, one RACF staff member explained how hearing aid maintenance had improved since having a local hearing service provider, explaining,

It's been very hard in this community because we haven't had a hearing place, but there is one now, so now regular visits, which is fantastic. I have noticed the hearing aids are in much better condition than they were, and it's making our life easier.

Moreover, audiologists who did not provide hearing services within the RACF, acknowledged this as a limitation of their service (physical opportunity). For example, one audiologist stated

I think access is a big issue. There are a lot of other companies that head out to the nursing homes. We ourselves as a company don't. If they [people living with dementia] don't have somebody that can bring them in they're often missing out.

Audiologists also reported different opportunities to provide timely hearing services to residents within RACFs. For example, one audiologist explained how being able to provide a timely hearing services was advantageous for their practice stating:

I guess that's one advantage that we have, is that we ... particularly with [name of RACF], we visit there quite often. So, some of them with a problem, the nurse or family gives us a call, we can pop out there within a few days. And I guess being accessible is important for a lot of those people."

Conversely, audiologists who did not have the physical opportunity to provide more timely hearing services identified this as a limitation of their service, explaining that in some instances, residents would have to wait up to 3 months before being fitted with hearing aids.

In addition to the physical opportunity to provide timely hearing services, some participants expressed the belief that hearing services should be provided more frequently for this population (reflective motivation). For example, audiologists

and family caregivers who had experience with hearing services reported that review appointments should be provided every 3-months, rather than on a yearly basis.

5.4.4 Management of Hearing Aids

For management of hearing aids, participants described barriers and facilitators across all six COM-B domains. For physical capability, participants discussed how people with dementia have limited skills for managing their hearing aids. For example, participants described how residents' dexterity and/or vision affected whether they could manage their hearing aids. One family caregiver provided an example of how her father's visual impairment limited his ability to change his hearing aid batteries explaining that, *"He couldn't really see the positive and negative signs on the batteries"*.

Participants also described barriers and facilitators in terms of residents' and caregivers' (RACF staff and family) psychological capability for managing hearing aids, reporting varied levels of knowledge in both groups. For example, most participants explained that individuals with dementia can have difficulty remembering how to manage, insert or clean their hearing aid (psychological capability). As one audiologist explained, *"It's not that they can't get them in their ear, and things like that, it's that they would not remember."* Because of this, many residents with dementia rely on RACF staff and or family caregivers to help manage their hearing aids. However, caregivers (family and RACF staff) also often lacked knowledge about managing hearing aids. For example, one RACF staff member explained *"I have some difficulties to put them [hearing aids] on because not used to them. Also, not knowing about a hearing aid much at all. Also, how to change the batteries. Things like this."* Other RACF staff members described difficulty related to troubleshooting hearing aids. For example, one RACF staff member said,

Yeah, you know sometimes they can have a hearing aid in there. They still say they can't hear, eh? You don't know where to go sometimes because they have a hearing aid, there is no wax in their ears, they still can't...

Most participants also described physical and social opportunity barriers for managing hearing aids. These included RACF staff not having enough time to help residents, due to high workload pressure (physical opportunity). For example, one audiologist explained, *"They're [RACF staff] seeing fifteen different people a day. It's*

too hard to keep track of even putting the hearing aids on in the morning.” Social opportunity, in terms of RACF staff not helping residents to wear their hearing aids, also affected hearing aid management. For example, as one audiologist explained “It just comes down to management. The simple fact that it’s been done [hearing aid has been fitted] and it’s [hearing aid] not being worn, or the staff aren’t accessing it or doing it for them.”

Audiologists reported strategies and actions they took to ensure RACF staff managed hearing aids for residents with dementia. One strategy included ensuring hearing aid information was placed on residents’ care plans (automatic motivation). One audiologist explained that:

If it's on the care plan, they [RACF staff] kind of have to do it. If it's not on the care plan, I find that not even just dementia clients, anyone in a nursing home environment... they don't have the hearing aids in or it's a wrong sized battery, or the battery's dead in their ear.

Unanimously, audiologists believed in providing information to RACF staff and or family caregivers on managing hearing aids and involving them in appointments if possible (reflective motivation).

5.4.5 Shared decision-making

For shared decision-making, all COM-B domains, except for physical capability and social opportunity, influenced this behaviour. Regarding psychological capability, most caregivers (RACF staff and family) reported they lacked knowledge of hearing services and options for treating hearing impairment other than hearing aids. In reflective motivation, family caregivers and RACF staff reported incongruent beliefs toward the appropriateness of hearing aids for this population. For example, one RACF staff member described mostly negative beliefs about hearing aids, stating, “*If we give them hearing aids, what’s the point?*” Other caregivers (RACF staff and family) expressed positive beliefs. For example, one family caregiver stated, “*I think she needs them [hearing aids] ... necessary at this stage. It certainly helps her with communication and everything with the nurses. Otherwise, it’s like being in the dark.*” Caregivers’ (RACF staff and family) lack of knowledge of treatment options other than hearing aids, combined with some of their beliefs that

hearing aids are of little benefit to residents with dementia, may limit their ability to appropriately engage in decision-making conversations.

Importantly, most RACF staff and family caregivers expressed an interest in increasing their knowledge of hearing services and options for treating hearing impairment (reflective motivation). One RACF staff member said:

I think it would be really good to know what is available out there to assist with communicating with residents with dementia plus an added disability of the hearing loss. I think I would like to know what else is there that I could utilise.

Another barrier that influenced shared decision-making was the difficulty audiologists have in making treatment decisions for this population. All audiologists reported it is harder providing hearing services to this population, because of the residents' dementia (psychological capability). All audiologists reported inviting a family caregiver or RACF staff to attend the appointment (physical opportunity), thus creating an opportunity for shared decision-making to occur. For example, one audiologist said, *'If they [person living with dementia] have got family, I try and always get family to come into the appointment.'* However, although audiologists create this opportunity, decision-making processes appeared to be clinician led, rather than shared (automatic motivation). For example, one audiologist reported:

If they [person living with dementia] can take in a bit more, yeah, we'll go through the results and say, "This is what's happening." If they can't we just talk to the carer or the support person. We discuss the plan. We say, "Hey, this is what we're going to do next."

5.5 Discussion

This study investigated the underlying barriers and facilitators that influence target behaviours for managing hearing impairment for adults living with dementia and hearing impairment in RACFs, from the perspective of three stakeholder groups (audiologists, RACF staff and family caregivers). From the data, we initially identified five behaviours central to managing hearing impairment effectively: (1) recognition of hearing impairment; (2) assessment of hearing impairment; (3) referral to and provision of hearing services; (4) management of hearing aids; and (5) shared

decision-making. In the context of the COM-B model, inter-related barriers and facilitators were evident in terms of capability, opportunity and motivation. RACF staff not routinely looking for hearing impairment, referring to hearing services and managing hearing aids, indicates that hearing impairment is not currently a treatment priority for RACF staff (motivation). Moreover, RACF staff and family caregivers' limited knowledge on distinguishing hearing impairment from cognitive impairment, managing hearing aids, and on the options available for managing hearing impairment (capability) highlights potential areas for future research. Additionally, audiologists reported involving family members and/or RACF staff in all audiology appointments (opportunity), which were facilitators to shared decision-making and assessment of hearing impairment. Overall, these findings highlight that optimising the management of hearing impairment in residents with dementia is complex and multifaceted, and that capability, opportunity and motivation will need to be considered for improvements in target behaviours to occur.

RACF staff not prioritising hearing impairment (automatic motivation) was a barrier affecting three target behaviours in the present study: recognition of hearing impairment, referral to and provision of hearing services, and management of hearing aids. In previous research, this factor has been consistently reported to influence different aspects of managing hearing impairment for adults living with dementia in RACFs (Crosbie et al., 2019; Hopper & Hinton, 2012). For example, Hopper and Hinton (2012) describe that RACFs staff may place less importance on the management of hearing impairment compared to their management of other areas of residents' health, such as nutrition. Furthermore, Crosbie et al. (2019) argue that many of the systems and processes in RACFs are not designed to prioritise hearing impairment, and therefore the limitations of these systems and processes (e.g. limited time and resources available to staff) interfere with the practical aspects of staff managing hearing impairment, such as maintaining hearing aids. Moreover, an underlying theme described by Crosbie et al. (2019) that could improve all aspects of managing hearing impairment is that RACF staff are given permission to provide person-centred hearing care. We would argue that prioritising the management of hearing impairment would assist RACF staff being given permission to provide person-centred hearing care.

Another barrier that influenced multiple behaviours (recognition of hearing impairment, management of hearing aids, and shared decision-making) was stakeholders' knowledge of the behaviour (psychological capability). Family caregivers and RACF staff reported difficulty distinguishing hearing impairment from cognitive impairment, as well as having limited knowledge on the options for managing hearing impairment and disparate levels of knowledge on managing hearing aids. This is consistent with previous research in which the knowledge of RACF staff with regard to recognising hearing impairment and managing hearing aids has been identified as a barrier (Crosbie et al., 2019; Slaughter et al., 2014; Höbler et al., 2018). To our knowledge, this is the first time that family caregiver knowledge has been identified as a barrier too. Education and training is likely to improve RACF staff and family caregivers' knowledge on hearing impairment and many research groups have recommended such interventions for RACF staff (e.g. Cohen-Mansfield & Taylor, 2004b; Pryce & Gooberman-Hill, 2014). However, the benefits of training and education may be short lived because of the underlying cultural issues of RACF staff. For example, a systematic review including 63 intervention studies targeting RACF staff practice to improve resident outcomes – across a variety of health domains such as hygiene, nutrition, and falls prevention – found that a common barrier to the success of these studies related to high staff turnover, high workload and staff attitudes (Low et al., 2015). Therefore, future research may need to consider interventions that are broader than education and training alone.

Unique barriers that related to the specific behaviour of assessment of hearing impairment were also identified in this study. This behaviour was influenced by psychological capability, specifically whether residents knew how to complete hearing assessments. Audiologists reported people with dementia had varied abilities to complete PTA and questioned the accuracy of hearing thresholds for those able to complete it. Previous research discussed in chapters 2 and 3 of this thesis discussed the limitations of PTA as a means for assessing hearing sensitivity with this population and discussed the feasibility of cortical automatic threshold estimation (CATE), a fully automated late auditory-evoked potential (AEP) test, as an alternative to PTA. Thus, this barrier could potentially be overcome by the use of new objective assessments for adults with dementia and hearing impairment.

In relation to the target behaviour of access to and provision of hearing services, inter-related barriers linked to physical opportunity, automatic motivation and reflective motivation were identified. Most participants described the belief that hearing services should be delivered on-site, at the RACF. However, previous research groups have reported equivocal outcomes of providing on-site hearing services. For example, Lewsen and Cashman (1997) surveyed 115 residents of an RACF who owned hearing aids and found that 70% wore the device daily and 95% of hearing aids were in working order, attributing this positive finding to on-site hearing services (Lewsen & Cashman 1997). However, Linssen et al. (2013) evaluated the cost-effectiveness of providing an on-site hearing screening and rehabilitation program across eight Dutch RACFs and found this intervention was not cost effective as hearing aid use only increased from 28% to 33%. It could be that the lack of increase related to measuring outcomes in terms of hearing aid use only. Findings of the present study highlight the need to provide a range of interventions for managing hearing impairment.

In addition to discussing the need for on-site hearing services, participants in the present study described how referral to hearing services depended on whether family caregivers could arrange to take the person with hearing impairment and dementia to a clinic outside the RACF (physical opportunity). Families play an important role in hearing rehabilitation and are a known reason why adults seek out hearing services and become successful hearing aid users (Meyer et al., 2014, Hickson et al., 2014). However, to our knowledge, this is the first time families have been identified as being integral for helping their family member living with dementia in an RACF access hearing services.

Hearing aid management was influenced by motivation, capability and opportunity – demonstrating the complexity of this behaviour. This is also important since hearing aids are promoted as the first treatment choice for managing hearing impairment in the adult population. In the present study, RACF staff reported disparate levels of knowledge toward managing hearing aids (psychological capability). Some RACF staff were unaware of how to help residents to wear their hearing aids, others reported being unable to troubleshoot hearing aid problems. Hearing aid management was also influenced by time with many participants

reporting that RACF staff do not have the time to assist residents with their hearing aids (physical opportunity). Also, because RACF staff do not routinely manage hearing aids there was evidence that RACF staff do not prioritise managing hearing aids. Because of these barriers, multiple discrete behaviour change interventions or a complex intervention may be required to address RACF staff knowledge of, time for, and belief toward hearing aids.

In relation to shared decision-making, barriers were evident in psychological capability and both reflective and automatic motivation. RACF staff and family caregivers reported having limited knowledge of options available for managing hearing impairment, outside of hearing aids (psychological capability) and reported mismatching beliefs toward the appropriateness of hearing aids (reflective motivation). This may restrict their ability to participate in shared decision-making. Also, decision-making processes appeared to remain largely clinician-led with audiologists prioritising hearing aids over other intervention options (automatic motivation). Research has consistently identified that audiologists generally prioritise hearing aids in rehabilitative practice generally (Grenness, Hickson, Laplante-Lévesque, Meyer, & Davidson, 2015; Pryce, Hall, Laplante-Lévesque, & Clark, 2016); thus they do not routinely employ shared decision-making practices. Importantly, in the present study, facilitators to shared decision-making were identified in terms of physical opportunity and reflective motivation. Audiologists believed that a family caregiver or an RACF staff member should be included in all audiology appointments (reflective motivation), and reported inviting these individuals to attend appointments, thus creating an opportunity for shared decision-making to occur. Moreover, RACF staff and family caregivers reported being motivated to learn about options other than hearing aids.

5.5.1 Future Research and Limitations

For each of the target behaviours identified in this study, a unique combination of barriers related to that behaviour would need to be considered for a behaviour change intervention to be implemented successfully. For example, for recognition of hearing impairment – RACF staff knowledge of, and motivation toward, recognising hearing impairment could be targeted. A significant cultural change from RACF staff appears necessary for this behaviour change intervention to be successful. For

assessment of hearing impairment, audiologists could be provided with the physical opportunity to use alternative tests such as CATE. However, as identified in chapter 3 (see 3.5) significant reductions to the overall testing time is likely to be required first, before clinicians adopt this test into routine clinical practice. For referral to and provision of hearing services, RACF staff motivation toward referring residents to hearing services and or audiologists' provision of frequent on-site hearing services could be targeted. Significant cultural changes from both RACF staff and hearing services is likely to be required for this behaviour change intervention to be successful. Increasing RACF staff knowledge of, and motivation for managing hearing aids could result in improved hearing aid management. However, this may not result in residents increasing their use of hearing aids. Additionally, due to high staff turnover in RACFs, interventions may be short lived if they solely focus on educating and training staff (Low et al., 2015). Finally, for shared decision-making, interventions could target audiologists' habit of prioritising hearing aids (motivation) and instead provide information on the range of hearing interventions available for managing hearing impairment. This intervention could also potentially address caregivers' (family and RACF staff) knowledge of the options available for managing hearing impairment – an area that participants in the present study identified wanting information on.

As highlighted above, results of this study suggest that RACF staff culture and motivation toward managing hearing impairment may present a barrier to implementing behaviour change for a number of the target behaviours identified in the present study. This is complex to address, but vital to consider as RACF staff play a key role in optimising hearing services for adults living with dementia and hearing impairment in RACFs. Future research could explore designing an intervention that specifically focusses on this salient barrier. Using a theory-driven framework for designing interventions is recommended for designing complex interventions (Campbell et al., 2000). One theory-driven approach is the Behaviour Change Wheel (BCW), developed by Michie, van Stralen, and West (2011).

According to the BCW, future research could look to improve RACF staff ability to recognise hearing impairment (target behaviour) in residents with dementia by increasing their motivation for doing this (COM-B barrier). Targeted interventions

that may help to improve RACF staff motivation to recognise hearing impairment could include:

- (1) Persuading RACF managers and staff about the negative consequences that untreated hearing impairment has on caregiving (Ludlow, Mumford, Makeham, Braithwaite, & Greenfield, 2018) as well as the additional consequences it can have for residents living with dementia (Hopper & Hinton, 2012);
- (2) RACF staff receiving modelling on how recognising hearing impairment can help to reduce the negative psychosocial consequences of hearing impairment; and
- (3) Managers of staff in RACFs providing them with incentives, in terms of 'time dedicated to provide person-centred hearing care' (Crosbie et al., 2019), so that modelling and persuasion might be enhanced.

Limitations exist in the present study. Although using the COM-B model was a useful framework for identifying barriers and facilitators, this model was applied retrospectively to analyse the data. We acknowledge that integrating the COM-B model throughout the project design, including the design of the interview topic guides, would have provided opportunities to specifically probe participants' views regarding capability, opportunity and motivation. Future research could be designed to capitalise on these opportunities, and so identify further barriers and facilitators to implementation of behaviour change in this context. In addition, this research was conducted with a small sample of stakeholders from three RACFs in a regional area of Queensland, Australia. The findings therefore may not broadly represent other RACFs in Australia and internationally. In addition, the perspectives of residents with dementia and hearing impairment were not included and while it is acknowledged that participation in research is difficult for this population, future research could include perspectives from those with milder degrees of dementia.

5.6 Conclusion

Optimising hearing impairment management for adults living with dementia who reside in RACFs is complex, and for each target behaviour identified in this study, it

is clear that capability, opportunity and/or motivation need to be considered for behaviour change to occur. Using the COM-B model was helpful for identifying the underlying barriers and facilitators of the behaviours as well as highlighting realistic and appropriate future research avenues for recognition of hearing impairment, assessment of hearing impairment, referral to and provision of hearing services, management of hearing aids and shared decision-making. Although RACF staff priority for managing hearing impairment emerged as a salient barrier that influenced multiple behaviours, our evidence indicates that it may be more realistic to focus on interventions that target the specific behaviour of shared decision-making.

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Chapter 6 Development and Piloting of HEARMyChoice

In chapter 5, the barriers and facilitators underlying five central behaviours for managing hearing impairment for adults living with dementia in residential aged care facilities (RACFs) were identified. The five central behaviours were: (1) recognition of hearing impairment; (2) assessment of hearing impairment; (3) referral to and provision of hearing services; (4) management of hearing aids; and (5) shared decision-making. Having identified the barriers and facilitators against these five behaviours, the next step is to choose a behaviour to target a behaviour change intervention. Given the focus of this thesis is directed toward hearing services rather than RACF staff, two central behaviours are considered optimal for targeted intervention design, that of, assessment of hearing impairment and shared decision-making. Further research is needed to improve cortical automatic threshold estimation (CATE) before it is ready to be implemented in this population, thus it was not realistic to design an intervention study around assessment of hearing impairment. Thus, the final intervention study aimed to address the central behaviour of shared decision-making, that is, providing individuals with options for managing hearing impairment. Chapter 6 reports the development and piloting of a decision aid (HEARMyChoice®) aimed at helping people who live with dementia and a hearing impairment, and the accompanying caregiver, increase their knowledge of, and make a choice for, treating the hearing impairment.

This chapter is currently in preparation for review in the peer-reviewed journal *International Journal of Audiology*.

6.1 Abstract

Objective: Worldwide, person-centred care (PCC) is recognised as the gold-standard approach to healthcare. Shared decision-making – a collaborative process, whereby health care professionals and individuals work together to choose a treatment option that best aligns with the individual's values and goals – is a fundamental component of PCC. Moreover, decision aids are one tool that can facilitate shared decision-making. The aim of this study was to develop and examine the useability of a decision aid designed to help people living with dementia and hearing impairment in RACFs and for an accompanying caregiver to make a choice for treating the hearing impairment.

Design: Mixed-methods pre-test post-test design, consisting of self-report quantitative surveys and qualitative structured interviews.

Study Sample: Three dyads, consisting of an individual living with dementia and hearing impairment in a residential aged care facility (RACF) with a family caregiver, took part in the study. Descriptive statistics were used to analyse quantitative data and summative content analysis for qualitative data.

Results: The decision aid helped dyads choose a treatment option, reach agreement on treatment choice, improved knowledge of treatment options and reduced decisional conflict.

Conclusions: These findings highlight the potential utility of a decision aid for promoting shared decision-making. Further research should investigate feasibility of the decision aid from the perspective of clinicians and whether use of the decision aid helps to optimise hearing-related communication for adults living with dementia and hearing impairment in RACFs.

6.2 Introduction

Person-centred care (PCC) is widely considered the gold standard for healthcare (Härter, Moumjid, Cornuz, Elwyn, & van Der Weijden, 2017; Härter, van Der Weijden, & Elwyn, 2011). PCC shifts from a traditional biomedical, or clinician led, model of healthcare, toward embracing personal choice and considering individual values and goals (Kogan, Wilber, & Mosqueda, 2016). The process whereby healthcare professionals work collaboratively with individuals and third-parties – family members or RACF staff – is known as shared decision-making and is a fundamental component of PCC (Elwyn, Edwards, & Kinnersley, 1999), dementia care (Brooker, 2003; Kitwood, 1997; Livingston et al., 2010), and hearing healthcare (Laplante-Lévesque, Hickson, & Worrall, 2010b). Shared decision-making is a process that is used when multiple treatment options are available for managing a health condition (Stacey et al., 2017), such as the treatment options available for managing hearing impairment (Laplante-Lévesque, Hickson, & Worrall, 2010c).

Evidence indicates that although audiologists are cognizant of shared decision-making, their processes remain clinician led, with a bias towards hearing aid fitting (Grenness, Hickson, Laplante-Lévesque, Meyer, & Davidson, 2015; Pryce, Hall, Laplante-Lévesque, & Clark, 2016). For example, the qualitative needs analysis presented in chapters 4 and 5 of this thesis explored current management approaches for hearing impairment in RACFs and the barriers and facilitators underlying key behaviours that influence this. Twenty-three participants from four key stakeholder groups took part in semi-structured interviews and it was identified that audiologists prioritise hearing aids (chapter 4), decision making processes remain largely clinician led (chapter 5), and caregivers lacked knowledge of, but importantly expressed a desire to know all options available for managing hearing impairment for adults living with dementia in RACFs (chapter 5). Globally, other research groups have also confirmed that RACF staff are enthusiastic towards increasing their knowledge on managing hearing impairment for adults living with dementia in RACFs (Höbler et al., 2018; Pryce & Goberman-Hill, 2013). Thus, developing a resource that promotes shared decision-making practices and increases caregiver knowledge on the options available for treating hearing impairment may have benefits for implementation science.

Achieving shared decision-making for adults living with dementia in RACFs is complex. Professional and family caregivers must navigate the declining cognitive function of the individual with dementia, often over a long period (Livingston et al., 2010; Stans, Dalemans, de Witte, & Beurskens, 2013). During this time, the family's involvement and role in shared decision-making changes (Petriwskyj et al., 2014a, 2014b), and interactions between individuals, families, care staff and health professionals can be tense when preferences differ (Groen-van de Ven et al., 2016). For example, a qualitative study conducted in the Netherlands explored the perspectives of: adults living with dementia in RACFs ($n=23$); family or informal caregivers ($n=44$); and professional caregivers ($n=46$). This research identified that differing perspectives between formal and informal caregivers led to tension and problems with decision making with regard to the individual with dementia's healthcare (Groen-van de Ven et al., 2016). However, Einterz, Gilliam, Lin, McBride, and Hanson (2014) identified the role that decision aids can play in alleviating these challenges. They found that, using a decision aid, for conversations regarding advanced care planning, improved communication between formal and informal caregivers of 18 adults living with dementia in RACFs.

Decision aids are “tools that help people become involved in decision making by making explicit the decisions that need to be made, providing information about the options and outcomes, and by clarifying personal values.” (Ottawa Hospital Research Institute, 2015, p. 1). Thus, decision aids promote shared decision-making and PCC (Elwyn et al., 2006).

A growing body of research has highlighted the benefits of decision aids across diverse hearing healthcare situations including: bilateral sequential cochlear implantation (Johnston et al., 2009); adult hearing impairment (Laplante-Lévesque, Hickson, & Worrall, 2010a; Laplante-Lévesque et al., 2010b); and tinnitus management (Pryce et al., 2018). The benefits included: improved knowledge (Johnston et al., 2009), greater uptake of options other than hearing aids (Laplante-Lévesque et al., 2010a, 2010b); and useability of decision aids for achieving shared decision-making (Laplante-Lévesque et al., 2010b; Pryce et al., 2018). Decision aids have not yet been used with patients with hearing impairment and dementia living in RACFs.

The purpose of this project was to develop and pilot consumer useability of a decision aid, that may help people living with dementia and hearing impairment, and their caregivers, make decisions about treating the hearing impairment. Useability of the decision aid was determined by whether the decision aid helped consumers choose a treatment option, increased their knowledge of treating hearing impairment and reduced their decisional conflict. Clinician useability was not measured in the present study.

6.3 Method

The decision aid was developed systematically following guidelines from the International Patient Decision Aid Standards (IPDAS) Collaborative (Volk, Llewellyn-Thomas, Stacey, & Elwyn, 2013) and the Ottawa Hospital Research (OHR) Institute (Ottawa Hospital Research Institute, 2015). Due to time constraints, strict adherence to all IPDAS and OHR guidelines could not occur. As reported by Malloy-Weir and Kirk (2017), two years is required to complete all phases of decision aid development. A mixed-methods approach consisting of quantitative pre-exposure post-exposure self-report surveys and qualitative post-exposure, confirmatory structured interviews were used to assess useability of the decision aid. Figure 1 outlines the IPDAS phases of decision aid development (Volk et al., 2013). Phase 1 only of this protocol was completed in the present study.

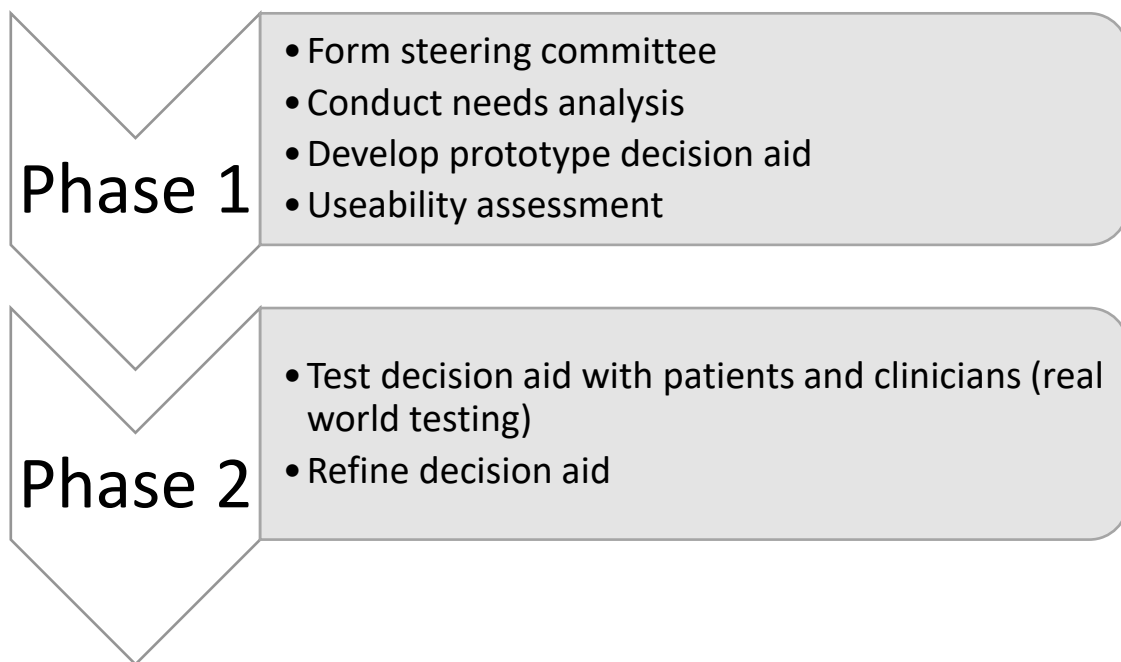


Figure 6-1 IPDAS Phases of HEARMyChoice® Development (Volk et al., 2013)

6.3.1 Phase 1: Decision Aid Development

Following the IPDAS and OHR guidelines, four initial stages were completed to develop and assess useability of the decision aid. First, the research team formed the steering committee, consisting of two audiologists, a psychologist and a speech pathologist. All members of this team had experience working with adults living with dementia and hearing impairment in RACFs and two committee members had previous experience developing decision aids in audiology.

Second, a literature review and needs analysis was conducted to explore the outcomes of hearing interventions for people living with dementia and hearing impairment in RACFs and to explore how hearing impairment is managed in this context. The literature review identified two recent systematic reviews that discussed the outcomes of treating hearing impairment for adults with dementia (Dawes, Wolski, Himmelsbach, Regan, & Leroi, 2019; Mamo et al., 2018). The needs analysis presented in chapter 5 of this thesis identified that, although clinicians commonly invite a caregiver (family or care staff) to attend audiology appointments, decision making processes remain clinician-led. Moreover, caregivers identified that they lacked knowledge of treatment options other than hearing aids and expressed an interest in knowing these.

Third, based on the literature review and needs analysis, a prototype decision aid was developed by the steering committee. To design the draft decision aid, previous audiology (Laplante-Lévesque et al., 2010a) and dementia (Carmody et al., 2014) decision aids, as well as person- and family-centred motivational tools from the Ida Institute (see <http://idainstitute.com>), were reviewed. Recommendations for developing hearing health literacy documents were also considered (Caposecco, Hickson, & Meyer, 2011). Three interventions were included in the decision aid: hearing aids, assistive listening devices, and communication education. Recently, two systematic reviews summarised the evidence of hearing interventions for adults living with dementia – including those living in RACFs (Dawes et al., 2019; Mamo et al., 2018). It should be noted that the level of evidence for these interventions for adults living with dementia and hearing impairment in RACFs were either low, or non-existent. To date, only one randomised controlled trial (published in two separate papers), has explored the outcomes of fitting hearing aids to community-dwelling adults living with dementia (Adrait et al., 2017; Nguyen et al., 2017). However, the studies investigated outcomes of hearing aids on cognition and quality of life and did not measure if hearing-related communication changed. The steering committee decided to exclude cochlear implants from the decision aid because there was no evidence to support the recommendation of this option for the target population (Dawes et al., 2019; Mamo et al., 2018). A consultative process, whereby four audiologists not involved in the original draft of the decision aid, was used to provide informal feedback on design and content. During this process, one audiologist suggested inclusion of information regarding managing and cleaning hearing aids. These processes resulted in the final prototype version of the decision aid, HEARMyChoice® (see Appendix C). Readability level was determined by placing the final written content into a word document. Flesh-Kincaid grade level was 6.7. This complied with the health literacy recommendation from Tasmanian Government of Australia who recommend consumer-based literacy is at a reading grade of 6 (Department of Health and Human Services, 2014).

Fourth, the prototype decision aid was assessed for consumer useability by adults living with dementia and hearing impairment who reside in RACFs, and their family caregivers. To determine if the decision aid was useable for this population, quantitative measures of treatment choice, knowledge of treatment options, and

decisional conflict were obtained as well as qualitative structured feedback on the decision aid design and content (comprehensibility). Details regarding participants, materials and procedures involved in the useability assessment are described below.

6.3.2 Participants

Consumers were dyads consisting of an individual living with dementia and hearing impairment who resided in an RACF and a family member/caregiver. Participants with dementia were included if they: (1) had a dementia diagnosis (any cause) as confirmed by the family caregiver; (2) lived permanently in an RACF; (3) had a hearing impairment greater than 25 dB HL in the better hearing ear (three frequency average 1000 Hz, 2000 Hz and 4000 Hz); and (4) had a family member/caregiver who could be present during the study. Family was broadly defined as “two or more individuals who depend on one another for emotional, physical and economical support”, with the members of the family being self-defined (Hanson, 2005, p. 7). The ability of the individual with dementia to communicate and read the information booklet was not a requirement for this study and no exclusion criterion regarding experience with hearing services was applied. Family caregivers were included in the study if they: (1) identified as being a family caregiver of the individual with dementia, and (2) were able to read and speak in English. Participants were recruited through multiple channels, including audiology clinics, word-of-mouth, and social media advertising. In total, six participants (three dyads), completed the useability assessment and their demographic information is presented in Table 6.1.

Table 6-1 Demographic Information of Dyads

Variable	Dyad 1		Dyad 2		Dyad 3	
	PWD	Fam	PWD	Fam	PWD	Fam
Age (years)	93	67	96	64	89	67
Gender	Female	Female	Male	Male	Female	Male
Highest level of education	Year 12	College	Unknown	Year 10	Year 10	Year 10
Relationship to PWD		Daughter		Friend		Son

Duration of dementia diagnosis	5 years	Unknown	1 year
Type of dementia	AD	Unspecified	AD
Length of time in RACF	2 months	2 months	3 months
3FA (dB HL)	38.33	45	41.67
Previously used hearing aids	No	Yes	Yes
Currently using hearing aids	NA	No	No

Note. PWD = person living with dementia; Fam = family member/caregiver; AD = Alzheimer’s disease; 3FA = three frequency average (1000, 2000, 4000 Hz) of the better hearing ear; RACF = residential aged care facility.

6.3.3 Assessment Materials

6.3.3.1 Demographic Questionnaire.

Background information regarding participants’ experience with hearing services, dementia history and socio-demographic information was collected.

6.3.3.2 Decisional Conflict Scale.

The decisional conflict scale used in the present study was based on the 10-item low literacy decisional conflict scale developed by O’Connor (1993) and is presented in Appendix D. The questionnaire contained two sections. In the first section participants were asked to identify their preferred treatment option. In the second section, participants’ decisional conflict was assessed based on responses to nine questions relating to making the treatment decision. For example, “Do you know which options are available to you?”. One question, which asked participants if they were clear about the risks associated with each treatment option, was removed as the decision aid developed in the present study did not contain information about risks. Participant response options to the second section included “Yes” (0), “Unsure” (2) and “No” (4). The decisional conflict scale contains four subscales:

- (1) uncertainty (how uncertain participants were about the best choice for them) (items 8, 9);
- (2) informed (how informed participants were about making their choice) (items 1, 2, 3);
- (3) values clarity (participants' clarity about the values and benefits of each option for them) (item 4); and
- (4) support (how supported participants felt in making their decision) (items 5, 6, 7)

The original decisional conflict scale has good internal consistency (alpha coefficient of 0.86)(O'Connor, 1995).

To obtain the overall decisional conflict score, scores for items 1 to 9 were summed, divided by 9 and then multiplied by 25 to give a score ranging from 0 (no decisional conflict) to 100 (extremely high decisional conflict). Scores on items from each subscale– were summed, and then divided by the number of items in the subscale. The results were then multiplied by 25, giving scores ranging from 0 (extremely certain/informed/clear about personal values and benefits/supported) to 100 (extremely uncertain/uninformed/unclear about personal values and benefits/unsupported) for each subscale.

6.3.3.3 Knowledge of Options for Treating Hearing Impairment Questionnaire.

This questionnaire was developed based on that developed by O'Connor (2000) and is presented in Appendix E. The questionnaire contained 14 statements, to which participants could respond with “Yes”, “No” or “Unsure”, and was used to measure participants' knowledge about treatment of hearing impairment. For example, participants were asked whether hearing aids were an option for treating hearing loss. Correct answers were scored “1” and incorrect or unsure answers were scored “0”; total scores were summed to give the final knowledge score (range = 0 to 14).

6.3.3.4 Interview Topic Guide

To obtain participant feedback regarding the usability and comprehensibility of the decision aid, a topic guide was developed based on the Ottawa Acceptability Questionnaire (O'Connor & Cranney, 1996) (see Appendix F). The guide covered the

following areas: initial impression; likes; improvements; design; length; content; wording; comprehensiveness; and a guided reflection on each step and section of the decision aid.

6.3.4 Procedure

This study was approved by The University of Queensland Human Research Ethics Committee. Written or verbal consent (or assent) was obtained from all participants prior to participation. Following consent, family members independently completed the demographic questionnaire, pre-exposure decisional conflict scale and knowledge of treatment options questionnaire. A member of the research team (AB) assisted individuals with dementia to complete the decisional conflict scale and knowledge of treatment options questionnaire by reading the questions to participants and recording their answers. Then, the individual with dementia underwent otoscopy and pure-tone audiometry (1000, 2000 and 4000 Hz). After the hearing assessment, the individual with dementia, family caregiver, and member of the research team (AB) completed the decision aid together. Directly after working through the decision aid, family members again completed the decisional conflict scale and knowledge of treatment options questionnaire and the research team member (AB) assisted individuals with dementia to complete these two post-exposure questionnaires. Dyads then provided feedback on the decision aid by taking part in confirmatory structured interviews that were also audio recorded. A confirmatory approach was considered optimal given that categories were already determined prior to data collection. A confirmatory rather than exploratory approach is recommended for researchers conducting studies where information is already known (Guest, MacQueen, & Namey, 2012). All audio recordings were transcribed by a professional transcription service prior to analysis. On average, use of the decision aid took 33 minutes (range 25 to 45 minutes) and structured interviews were 38 minutes (range 20 to 55 minutes).

6.3.5 Data Analysis

All data, quantitative and qualitative, was analysed using Microsoft Excel™. Given the small sample size, descriptive statistics were generated to report quantitative outcomes.

Structured interviews were analysed using summative content analysis (Hsieh & Shannon, 2005) which explores the number of times a word, or event occurs in the data, rather than interpreting meaning or themes from the data (Hsieh & Shannon, 2005). This was considered the most appropriate approach to determining whether changes to the decision aid were required. To complete the content analysis, the first author reviewed the transcripts of the dyads using the decision aid and of the structured interviews. When reviewing the transcripts of the dyads using the decision aid, the first author noted any difficulties with wording and suggestions made by dyads. Similarly, when reviewing the data from the structured interviews, the first author recorded all feedback (positive and negative) from each section of the interview guide, coding whether changes were required.

6.4 Results

6.4.1 Quantitative findings

Table 6.2 presents participants' preferred treatment choice for hearing impairment before and after using the decision aid. The preferred choice of each participant changed after using the decision aid. Four participants were unsure of which option to choose before using the decision aid and all four had made a decision after using it. Moreover, the individual with dementia and caregiver agreed on the treatment choice after using the decision aid. Suggesting useability of the decision aid for helping participants reach, and agree on, a treatment choice.

Table 6-2 Pre-Post Hearing Impairment Treatment Preferences

Dyad	PWD / FAM	Treatment Choice	
		Pre	Post
1	PWD	Unsure	Hearing aids & communication education
	FAM	Hearing aids	Hearing aids & communication education
2	PWD	Unsure	Hearing aids and assistive listening devices

	FAM	Unsure	Hearing aids, assistive listening devices, unsure
3	PWD	No treatment	Communication education
	FAM	Unsure	Communication education

Note. PWD = Person living with dementia and hearing impairment in a residential aged care facility; FAM = family caregiver. Options were (a) hearing aids; (b) assistive listening devices; (c) communication education; (d) a combination of a, b or c; (e) no treatment; (f) unsure.

Table 6.3 presents the overall pre-post decisional conflict scores and subscale scores for each participant. There was a general trend for participants' decisional conflict scores and subscale scores to reduce (improve) after using the decision aid. Five participants' overall decisional conflict reduced after using the decision aid and one participant's scores remained unchanged. It should be noted that for this one participant, their pre-post decisional conflict scores were low. For the 'values clarity' and 'uncertainty' subscales, all participant scores remained the same or improved after using the decision aid. For the 'informed' subscale, most participant scores remained the same or improved. However, one participant's scores were worse after using the decision aid. For the 'support' subscale, two participants scores improved after using the decision aid, two remained the same (both participants had a pre-post score of 0, demonstrating they felt highly supported) and two scores, both in dyad 2, were worse after using the decision aid.

Table 6-3 Pre-Post Overall and Subscale Decisional Conflict Scores

Dyad	PWD /FAM	Overall decisional conflict		Informed		Values Clarity		Support		Uncertainty	
		Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post
1	PWD	72.11	11.11	100	33.33	0	0	50	0	100	0
	FAM	11.11	11.11	33.33	33.33	0	0	0	0	0	0
2	PWD	55.56	44.44	83.33	100	50	0	16.67	33.33	75	0
	FAM	66.67	61.11	100	100	100	0	33.33	66.67	50	25
3	PWD	38.89	22.22	66.67	50	50	0	0	0	50	25
	FAM	33.33	0	33.33	0	0	0	33.33	0	50	0

Note: PWD = person living with dementia; FAM = family caregiver

Pre-post quantitative knowledge scores are depicted in Figure 6-2. Participant scores remained the same (n = 2) or improved (n = 4) after using the information booklet.

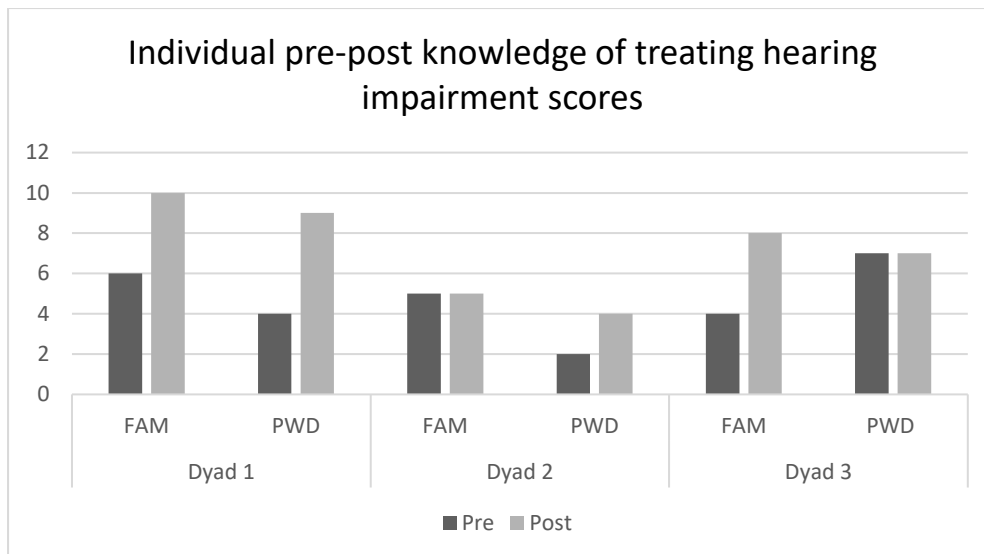


Figure 6-2 Pre-Post Knowledge of Treating Hearing Impairment Scores.

Higher scores reflect greater knowledge.

6.4.2 Qualitative Findings

Table 6-4 summarises participants overall impression of the decision aid and Table 6-5 summarises their suggestions for improving the decision aid. Overall, both adults living with dementia and their family caregivers perceived the decision aid favourably, reporting it was interesting and informative. One individual living with dementia reported that the decision aid could be improved by ensuring it was accessible to the target population and stated, "Put it on the market.". Other suggestions for improving the decision aid included increasing the font size and including more images. Increasing the font size was emphasized by one individual living with dementia, who also had a visual impairment and commented that the decision aid might be easier for him to read if the print were larger. Two participants reported no additional topics should be included in the decision aid.

Although most participants felt that the decision aid was long enough and contained adequate information, one family caregiver reported that there could be

more information, particularly in step 2, regarding what is involved in each treatment option. This suggestion appears consistent with the quantitative findings, where only half of the participants' scores on the "informed" subscale improved after using the decision aid, demonstrating that they still did not feel informed about their decision. All participants were indifferent regarding the section containing further resources. For example, family caregivers commented, "I haven't really gone into all of this" and "Probably not right now." In addition, one family caregiver questioned the relevance of including references in the decision aid, asking if this was included for legal reasons. Most participants liked the inclusion of the section relating to hearing aid management, even if they were not pursuing this option.

Table 6-4 Interview Feedback on the Decision Aid (*n* = 6)

Section of the decision aid	Example quotes
Initial response (first impression)	"Pretty good. Very good actually." PWD 2
Initial response (liked)	"It's very informative. It helps you. Yeah, I think it certainly shows you how you can go about getting help to communicate and in a better way." FAM 1
General Length and Content	"Thought there was plenty of information." PWD 3
Wording	"I thought it was quite well done. You want it to be simple." FAM 1
Step 2 – Hearing aids / assistive listening devices / communication education	"I like the idea of pictures. I think it makes things a little bit easier. You associate straight away with what they're talking about." FAM 2
Further resources	Participants reported ambiguity around additional resources "Probably not right now at this stage" FAM 2 – indicating this information was not relevant to them at this point in time.

Note. ALD = Assistive Listening Device; PWD = individual living with dementia; FAM = family caregiver;

Table 6-5 Participants' Feedback on Changes to the Decision Aid (*n=6*)

Section of the decision aid	Number of participants who suggested a change	Suggested change
Initial response (improvements)	3	<p>"Maybe for elderly people, maybe the printing could be a little bit bigger." FAM 2</p> <p>"Maybe a bit more details, on the communication side." FAM 3</p>
Design	1	"Well, very basic point of view. Maybe some more pictures." FAM 3
Introduction and instructions	1	"Not sure about the second paragraph there." FAM 3
Step 2 – Read about my options	1	<p>"Well, maybe some sort of rating as to useability." FAM 3</p> <p>"It's not actually guiding you. In a way it's saying you make the choice. And whether that's good or bad it's saying well, we recommend that you should go for A rather than option B. Option A is not practical, for whatever reason. B is the next best, let's say." FAM 3</p>
Step 2 – Hearing aids / assistive listening devices / communication education	2	<p>"I like the idea of pictures. I think it makes things a little bit easier. You associate straight away with what they're talking about." FAM 2</p> <p>"Because if you're gonna make a choice you need to, between I don't need a hearing aid maybe I need an assistive device. But, could I get away with communication education. Maybe a bit more information [on communication education] before enrolling in one or the other." FAM 3</p>
Step 3	2	RA: "I wonder if, because I've used the booklet with you and, of course, you have [name of daughter] as well, but I wonder if in this section, what is the next step? Is it important to know how to contact someone to get

		it?" FAM 2: "Yeah, you are right. That's not ... A lot of people wouldn't know, would they?"
Further resources	3	Participants reported ambiguity around additional resources "Probably not right now at this stage" FAM 2 – indicating this information was not relevant to them at this point in time.

Note. ALD = Assistive Listening Device; PWD = individual living with dementia; FAM = family caregiver;

6.5 Discussion

This project aimed to develop and assess consumer useability of a decision aid designed to assist people living with dementia and hearing impairment who reside in RACFs make decisions regarding treatment of their hearing impairment. Following the guidelines presented by IPDAS and OHR for decision aid development, we used a systematic approach to design, review and assess useability of the decision aid, HEARMyChoice®. Findings from this study showed that the decision aid helped participants: make decisions regarding treatment of their hearing impairment; reach agreement on treatment choice; and to some extent it reduced decisional conflict and improved knowledge of the options available for treating hearing impairment. These preliminary findings support the use of a decision aid with this population. However, the sample size was very small and further testing is required to explore whether this tool is acceptable to clinicians and the broader population of people living with dementia who reside in RACFs.

The decision aid helped all three dyads choose an option for treating hearing impairment. Interestingly, after using the decision aid, all participants' preferred treatment choice had changed – with two of the three dyads choosing multiple treatment options, for example, hearing aids and communication training (see Table 2). This finding aligns with the recommendations from chapter 4 of this thesis, that, audiologists implement person-centred care by recommending more than hearing aids for managing hearing impairment. It also aligns with previous audiology decision aid findings that adults with a hearing impairment do not ubiquitously choose hearing aids when offered evidence-based choices (Laplante-Lévesque et al., 2010a).

In this present study, the decision aid also helped all three dyads reach agreement on treatment choice. Before using the decision aid, members of two dyads reported disparate preferences, and both members of the third dyad were unsure of their preference. The findings here are consistent with those of Einterz et al. (2014) who identified that decision aids can help improve agreement between shared decision-making stakeholders of people living with dementia in RACFs. Given the tensions that can arise between formal and informal caregivers of adults living with dementia in RACFs when treatment preferences differ (Groen-van de Ven

et al., 2016), this finding suggests that the decision aid might also be useful for reducing any tension between caregivers regarding managing hearing impairment.

In addition to helping dyads reach agreement and choose an option for treating hearing impairment, overall decisional conflict was either unchanged or reduced after using the decision aid. This finding is consistent with that of Carmody et al. (2014), who found that use of a decision aid to help decide whether to stop or continue driving improved decisional conflict for 12 adults living with dementia. Interestingly, when considering subscale scores in the present study, there were three instances where individual decisional conflict scores were worse after using the decision aid. The reasons for this were unclear and suggest the need for further evaluation of the decision aid with additional participants.

Use of the decision aid improved knowledge of treating hearing impairment for four of the six participants in the present study. This finding is similar to that of Carmody et al. (2014) and Johnston et al. (2009) both of whom report improved knowledge in adults with dementia (Carmody et al., 2014) and caregivers (Johnston et al., 2009) after using a decision aid. A motivation that was highlighted by caregivers (RACF staff and family caregivers) in chapter 5 of this thesis was that they were interested in increasing their knowledge on the options available for treating hearing impairment. Thus, these preliminary findings suggest that the decision aid, HEARMyChoice®, is useful in addressing this need.

6.5.1 Future Research and Limitations

Given the promising findings of this pilot study, future research should be conducted to explore the acceptability of the decision aid to clinicians as well as a broader range of consumers. Future research should also explore how the decision aid influences choice in real-life settings, and the impact this has on clients' hearing-related communication and quality of life.

The small sample of participants is the major limitation of the present study. Communication and cognition of people living with dementia varies (Caramelli, Mansur, & Nitrini, 1998), and all three individuals with dementia who took part in this study were able to effectively communicate, understand the decision aid and provide feedback on it. Although no formal rating of dementia severity was completed, participants' ability to complete these tasks indicates that their dementia was likely

mild. It remains unknown whether HEARMyChoice® is useful for individuals and caregivers of individuals with more severe or later-stage dementia, including those who may be unable to verbally express their needs.

Another limitation was the use of the same individual to collect pre-post data and to present the decision aid. This may have biased the findings and in future studies it would be most appropriate for a different individual to apply the decision aid and for post assessments to be conducted by an individual blind to pre-assessment scores.

6.6 Conclusion

Decision aids are one resource that has been promoted to aid clinicians in employing shared decision-making practices in audiology (e.g., Johnston et al., 2009, Laplante-Levésque, Hickson, & Worrall, 2010a; Pryce et al., 2018). The present study involved developing and piloting a decision aid in accordance with the IPDAS collaboration guidelines (Volk et al., 2013). Furthermore, the study demonstrated that, in a small sample of adults with dementia living in an RACF, the decision aid, HEARMyChoice®, helped participants and family caregivers choose an option for treating hearing impairment and, in most instances, improved their knowledge of treating hearing impairment and reduced overall decisional conflict. Future research is needed to explore the useability and acceptability of the decision aid with a wider range of consumers and with clinicians who would be the ultimate users of such an aid.

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Chapter 7 Conclusion

There is a paucity of research related to optimising hearing services for adults living with dementia and hearing impairment in residential aged care facilities (RACFs). The body of research presented in this thesis contributes to this under-researched area by advancing knowledge in diagnostic audiology, rehabilitative audiology; and by developing a decision aid that that may improve the management of hearing impairment in the future. A systematic review and three original research studies were completed to address the four central aims (see section 1.3) and findings are discussed in this chapter in relation to these aims.

7.1 Summary of the Key Findings

7.1.1 Diagnostic Audiology

The first aim of this thesis was to identify the proportion of adults living with dementia who could complete pure-tone audiometry (PTA). A fundamental step for improving hearing-related communication for any individual is an accurate hearing assessment. In chapter 2, a systematic review was completed to address the first aim of this thesis and the term of “complete PTA” referred to the person’s ability to cooperate to at least establish his or her hearing threshold at a minimum of three frequencies in both ears as assessed by the audiologist. Electronic searching from four databases initially yielded 1,237 eligible studies. After full-text review, only three studies met all inclusion criteria, highlighting the dearth of research in this area. Moreover, of these three studies, none had a primary aim that considered the ability of adults living with dementia to complete PTA. The systematic review found that between 56% and 59% of people living with dementia could complete PTA.

Furthermore, there was a difference in the proportion of participants reported as completing PTA according to dementia severity. Overall, people with milder degrees of dementia were more likely to be able to complete PTA (Hopper, Slaughter, Hodgetts, Ostevik, & Ickert, 2016; Quaranta et al., 2014; Villeneuve et al., 2017). As the systematic review identified that a significant proportion of adults living with dementia are unable to have their hearing thresholds determined by PTA (at

least 40%), the feasibility of an alternative, non-behavioural diagnostic test, was explored (chapter 3).

The second aim of this thesis was to explore the feasibility of Cortical Automatic Threshold Estimation (CATE), an automated auditory-evoked potential (AEP) test, as an alternative to PTA for hearing threshold estimation with adults living with dementia in RACFs. In chapter 3, 16 people living with dementia in RACFs, including five individuals with severe dementia, had their hearing sensitivity assessed across the four speech frequencies (500, 1000, 2000 and 4000 Hz) via PTA and CATE. Dementia severity was determined using the Clinical Dementia Rating Scale – Chronic Care Version (CDR, Marin et al., 2001). To our knowledge, this was the first study that has conducted hearing threshold estimation for adults living with dementia in RACFs, which specifically explored the feasibility of a late AEP test. Moreover, it is the first AEP study to include adults with severe dementia in the participant sample, in the context of estimating hearing thresholds.

Of the 16 participants, all of whom were asked to complete both hearing tests, 11 completed CATE and nine completed PTA (see Figure 3-2). Overall, using both PTA and CATE resulted in 14 out of 16 participants (87.5%) having their hearing thresholds estimated. This is a considerable improvement on previous studies where it has been identified that fewer than 32% of people living in RACFs can have their hearing sensitivity determined via PTA (Burkhalter, Allen, Skaar, Crittenden, & Burgio, 2009; Hedner, Broms, Harris, & Steen, 1987). There was also a high correlation between PTA and CATE at 1000, 2000 and 4000 Hz and a moderate correlation for 500 Hz. Moreover, family member presence was also highlighted as a variable that may have contributed to participants' ability to complete either test.

A considerable limitation of CATE for audiologists was that it took, on average, five times longer to estimate hearing thresholds compared to PTA. Importantly though, for the five adults assessed with severe dementia, four completed CATE and none completed PTA. In contrast, for the nine adults with moderate dementia, seven completed PTA and five completed CATE; suggesting that PTA is more appropriate for estimating hearing thresholds with adults with moderate dementia.

Overall, the results demonstrated that for diagnostic audiology, PTA should remain as the most commonly used test for hearing threshold estimation, but that CATE was a feasible alternative, for adults assessed with moderate and severe dementia, when PTA is not possible. Moreover, presence of family members may contribute to the ability of adults living with dementia completing any hearing assessment.

7.1.2 Rehabilitative Audiology

To address the third aim of this thesis – to understand the hearing-related communication needs of residents with hearing impairment and dementia – 23 participants from four stakeholder groups took part in semi-structured interviews. The four stakeholder groups were audiologists, RACF staff, individuals living with dementia and hearing impairment in RACFs and family caregivers. Three research questions were investigated as part of the needs assessment: (1) what is the impact of hearing impairment for adults living with dementia in RACFs; (2) how is hearing impairment currently managed; and (3) what barriers and facilitators underlie key behaviours that influence hearing impairment management with this population.

In chapter 4, results for the first two research questions were presented. Thematic analysis revealed three central themes of (1) far-reaching consequences of hearing impairment, (2) appropriately managing hearing impairment is beneficial and important, and (3) different stakeholder priorities for managing hearing impairment. All stakeholder groups described the negative impacts of hearing impairment on residents' psychosocial wellbeing and resident-caregiver communication. They also acknowledged that appropriately managing hearing impairment was beneficial for residents living with dementia in RACFs. However, the third theme (i.e. different stakeholder priorities for managing hearing impairment) highlighted that different priorities for managing hearing impairment existed between audiologists and RACF staff. That is, audiologists prioritised hearing aids, expressing somewhat negative perspectives about assistive listening devices (ALDs); whereas RACF staff prioritised communication strategies and acknowledged that they do not routinely refer residents with dementia and hearing concerns to hearing services. Moreover, family caregivers reported mixed views on the appropriateness of hearing aids and commonly used communication strategies irrespective of their views toward hearing

aids. This finding suggested that family caregiver management priorities were in-between those reported by audiologists and staff in RACFs. Thus, because of the mis-match in treatment priorities reported by stakeholders, hearing impairment remains sub-optimally managed.

In chapter 5, interviews were further analysed using The Framework Method (Ritchie & Lewis, 2003) to investigate the underlying barriers and facilitators that influenced hearing impairment management. First, five central behaviours for effectively managing hearing impairment were identified based on the findings presented in chapter 4. These were: (1) recognition of hearing impairment; (2) assessment of hearing impairment; (3) referral to and provision of hearing services; (4) management of hearing aids; and (5) shared decision-making. Then, data were analysed using a deductive framework analysis to map underlying barriers and facilitators according to the Capability, Opportunity, Motivation – Behaviour (COM-B) model from the Behaviour Change Wheel (BCW; Michie, Atkins, & West, 2014; Michie, van Stralen, & West, 2011). Inter-related barriers and facilitators emerged with respect to stakeholders' capability, opportunity and motivation.

Two barriers influenced multiple behaviours. Firstly, it was found that RACF staff did not routinely refer residents to hearing services, manage hearing aids nor look for hearing impairment; the corollary of this was that RACF staff did not prioritise hearing impairment. Secondly, RACF staff and family caregivers lacked knowledge of hearing impairment, affecting their ability to: recognise hearing impairment; manage hearing aids; and, participate in shared decision-making. Unique barriers and facilitators that related to each target behaviour were also identified (see Table 5.2).

Chapter 5 also considered which of these five behaviours were reasonable to address in the final intervention study of this thesis. Due to the barriers referenced above, it was found that interventions targeting assessment of hearing impairment, recognition of hearing impairment and referral to and provision of hearing services were outside the scope of this PhD. It was also not considered appropriate to design an intervention to address the behaviour of management of hearing aids, due to the multiple barriers that existed for this behaviour regarding stakeholder groups capability, opportunity and motivation and that the focus of the work in this thesis

was toward audiologists. Therefore, it was felt that a more considered approach would be to acknowledge the limitations of hearing aids and focus on offering other options, that is, shared decision-making. The first step toward designing an intervention that targets shared decision-making, was to develop a resource that could be used to facilitate this.

7.1.3 Decision Aid Development

The final aim of this thesis was to develop and pilot consumer useability of a decision aid designed to help residents with hearing impairment and dementia, and a family caregiver, manage the hearing impairment. In chapter 6, the development of a dementia friendly decision aid was reported along with a pilot study on consumer useability. The decision aid, HEARMyChoice®, was developed following the guidelines of the International Patient Decision Aid Standards (IPDAS; Volk et al., 2013). Importantly, interdisciplinary stakeholders were consulted to assist with the design of the decision aid including: audiologists, a speech pathologist and a psychologist. It was then also piloted with three consumer dyads. The dyads consisted of an individual living with dementia and hearing impairment in an RACF as well as a family caregiver. Preliminary findings were promising, demonstrating that the decision aid helped dyads to reach agreement on treatment choice and in most instances, increased their knowledge of treatment options. Moreover, the study described in chapter 6 showed that most participants chose a range of interventions to address their hearing-related communication needs.

Overall, findings from the final aim of this thesis appear to align with those of hearing-related needs analysis, in that: (1) audiologists should be mindful not to prioritise hearing aids and ensure they routinely recommend all options for managing hearing impairment (chapter 4); and (2) a decision aid is one resource that could be developed to increase knowledge of the options for managing hearing impairment.

7.2 Clinical Implications for Hearing Services

The research presented in this thesis has three key implications for hearing services. In relation to diagnostic audiology, audiologists should continue to attempt to establish hearing thresholds via PTA first for adults living with dementia. It was

found to be five times faster than CATE as used in the study described in this thesis and approximately 60% of adults living with dementia could have their hearing thresholds estimated using this test. However, CATE has potential as an alternative for those adults living with severe dementia, who are unable to have their hearing thresholds estimated using PTA. More work is needed to shorten the testing time of CATE so that hearing services could more easily use this test in routine clinical practice.

In relation to rehabilitative audiology, shared decision-making was identified as the key clinical implication in the context of service provision of adults living with dementia in RACFs. Shared decision-making promotes that a collaborative and inclusive approach between patients-practitioners and caregivers occurs to reach treatment decisions that are evidence-based and align with the individual's values and beliefs (Elwyn, Edwards, & Kinnersley, 1999). The hearing-related needs analysis conducted in this thesis as well as the development and piloting of the decision aid highlighted the clinical importance of shared decision-making in several ways. Firstly, disparate priorities for managing hearing impairment were reported across all stakeholders and audiologists must consider these priorities. There was evidence that audiologists prioritise hearing aids, yet, research consistently describes problems associated with managing hearing aids. Secondly, RACF staff and family caregivers reported wanting to know what options – other than hearing aids – were available for managing hearing impairment. Thirdly, a resource was developed that could be used by clinicians to promote shared decision-making and when piloting this resource, all three dyads chose different options for managing hearing impairment – further highlighting the importance of providing choices for managing hearing impairment.

The responsibility of optimising hearing-related communication for adults living with dementia and hearing impairment in RACFs is shared between RACF staff and audiologists. Therefore, in addition to the clinical implications for audiologists related to diagnostic and rehabilitative audiology, RACF staff prioritising hearing impairment management is also key to any optimisation of hearing services for adults living with dementia and hearing impairment in RACFs. Aligning with the recommendation by Crosbie et al. (2019), RACF staff must be given permission to

provide person-centred care, in the context of optimising hearing-related communication for residents living with hearing impairment and dementia. Therefore, increasing RACF staff priority for managing hearing impairment, may translate to improved person-centred hearing care and in doing so, improve the overall wellbeing of adults living with dementia and hearing impairment in RACFs.

Finally, the research in this thesis highlighted the key role of family caregivers in all aspects of the management of hearing impairment for residents with dementia in RACFs. This was first highlighted in chapter 3, where family member presence was highlighted as a potential variable that influenced the ability of people with dementia to complete hearing tests. Moreover, in chapter 5, family caregivers were identified as being key contributors to accessing hearing services for people living with dementia in RACFs. Audiologists who provide hearing services to this population, should consider involving family members in all appointments with this population – aligning their practice with other research groups that have highlighted the important role family members have in managing hearing impairment (Ekberg, Meyer, Scarinci, Grenness, & Hickson, 2015; Hickson, Meyer, Lovelock, Lampert, & Khan, 2014; Meyer et al., 2014).

7.3 Strengths and Limitations

7.3.1 Strengths

The research presented in this thesis has several strengths. Firstly, the systematic review (chapter 2) adhered to internationally recommended guidelines for conducting and registering a systematic review. Secondly, the study of CATE, a novel late AEP test, was the first of its kind to use objective, electrophysiological measures to determine hearing sensitivity with adults with dementia living in RACFs, including adults with severe dementia (chapter 3). Thirdly, to our knowledge, the qualitative needs analysis (chapters 4 and 5) was the first to combine and present multiple stakeholder perspectives together, an approach that allowed for the identification of incongruent practices across hearing services and RACF staff. Finally, this thesis developed a dementia-friendly decision aid, following internationally recommended guidelines for the development of decision aids (IPDAS; Volk et al. 2013). Decision aids have been used previously to present

treatment options for adults with hearing impairment (e.g. Laplante-Lévesque, Hickson, & Worrall, 2010b) but not for adults with dementia and hearing impairment in RACFs and their family caregivers.

7.3.2 Limitations

Alongside the strengths of this research, several methodological limitations should also be acknowledged that relate to generalisability of the findings. Firstly, this research was conducted in a specific geographical region, that is, within three RACFs in the Darling Downs region of Queensland, Australia. Findings cannot be generalised to other geographical locations and to community-dwelling adults living with dementia. Secondly, the sample size was very small in both the CATE study (chapter 3) and piloting of the decision aid (chapter 6), limiting how results may translate to the wider population of adults living with dementia in RACFs as well as the ability to complete statistical tests. Moreover, in the study that piloted the decision aid (chapter 6), it was planned that audiologists would pilot the decision aid with the desired consumer. Seven audiologists had consented to pilot with this. However, after 6 months of attempting recruitment, no clinician had the opportunity to use the decision aid with the desired consumers. Given the time constraints of this final thesis project, the thesis candidate, instead piloted the decision aid with the three dyads. Therefore, it is currently unknown if the decision aid is acceptable for audiologists to use in their clinical practice.

In addition to the limitations on the generalisability of the findings, a number of limitations relate specifically to the qualitative research presented in chapters 4 and 5. Firstly, due to competing demands of the research team, strict adherence to the EQUATOR network guidelines for conducting qualitative research – specifically, having two members of the research team complete each stage of qualitative analysis, allowing for triangulation of findings – was not feasible (O'Brien, Harris, Beckman, Reed, & Cook, 2014). Nevertheless, throughout all stages of thematic and framework analysis, regular meetings between the thesis candidate (primary coder) and second and third authors (CM and LH) occurred, to ensure, as much as possible that findings were impartial, unbiased and reflective of the entire dataset. Secondly, hearing screening of family caregivers and RACF staff was not conducted as part of the research. Given that six family caregivers and one RACF staff member

were over the age of 50, it is possible that these participants also had hearing impairment (Access Economics, 2006), which may have influenced their responses to questions raised during the qualitative interviews. Third, in chapter 5, data was analysed retrospectively using the COM-B model and hence, some factors may have been missed. It may have been more appropriate to have designed the topic guide based on the COM-B model and then conduct the analysis. Such an approach has been more commonly applied in audiology (Barker, Atikins, & de Lusignan, 2016; Maidment, Ali, & Ferguson, 2019) and in RACFs (Hartmann et al., 2018).

7.4 Future Research

The research described in this thesis provides a foundation for future diagnostic and rehabilitative audiology research. For diagnostic audiology, CATE needs modifications for this clinical population. Further research is required to reduce the time taken to establish hearing thresholds with adults living with dementia in RACFs. Furthermore, because CATE is a novel late AEP test, it may be beneficial to compare it to other, more established AEP tests, such as the auditory steady-state response.

The exploratory research presented in chapter 5 identified two key future research opportunities: (1) increasing RACF staff motivation for prioritising hearing impairment; and (2) increasing audiologists' habit for providing options for managing hearing impairment. An intervention that aimed to increase RACF staff motivation for prioritising hearing impairment was not undertaken in the current thesis, because the focus of the research presented in this thesis was on optimising hearing services and also it was not feasible to conduct such an intervention study in the timeframe. However, future research should investigate options for increasing RACF staff motivation for prioritising hearing impairment as RACF staff have a fundamental role in supporting residents living with dementia to manage their hearing-related needs.

In the present thesis, the first steps for designing an intervention aimed at promoting shared decision-making and audiologists' habit of providing options for managing hearing impairment was to develop a resource for clinical use. As described by Bowen et al. (2009), the next stage of intervention design would be to

complete a three-phase feasibility study exploring the acceptability of the decision aid. First, focus groups with audiologists could explore the feasibility of the decision aid. Second, a randomized controlled trial could compare if the decision aid is efficacious in reaching a treatment decision, knowledge of treatment options, and decisional conflict as compared to decision making without using a decision aid. Third, a population-based survey could determine effectiveness of the decision aid in the real-world before, during and after implementing the decision aid into routine clinical audiology practice.

In addition to future feasibility studies, the introduction of a decision aid into clinical practice likely requires significant behaviour change by audiologists. Changing audiologists' behaviour and RACF staff behaviour towards better managing hearing impairment is difficult. Researchers are encouraged to use a theory-driven approach when designing complex behaviour change interventions (Michie, Atkins, & West, 2014). Thus, the decision aid, developed and presented in chapter 6, could be integrated into future behaviour change interventions aimed at increasing shared decision-making between audiologists and adults living with dementia and hearing impairment in RACFs and their families.

In the context of managing hearing impairment, a fundamental component of shared decision-making is that evidence-based outcomes are discussed with consumers to assist in making a decision (Elwyn, Edwards, & Kinnersley, 1999). A limitation that was first highlighted in the introductory chapter to this thesis (chapter 1) and again in the study that described developing the decision aid (chapter 6) was the lack of high-quality evidence of any hearing intervention for adults living with dementia which included those living in RACFs (Mamo et al., 2018). Therefore, consistent with the recommendation by Mamo et al. (2018) and to help audiologists with shared decision-making, future research, namely, randomised controlled trials, are warranted to investigate the outcomes of treatment options for adults living with dementia and hearing impairment in RACFs.

Finally, a novel approach for future research with this population would be to investigate the application of eHealth solutions. Electronic based decision aids have previously been shown to be acceptable for adults living with dementia (Span et al., 2013; Span et al., 2015). Therefore, in Australia where geography may limit access

to resources, eHealth solutions are an option to help overcome this limitation and moreover increase uptake from an international perspective.

7.5 Overall Conclusions

In 1982, after conducting a mostly failed study aimed at increasing hearing aid uptake among adults living in RACFs, Schow concluded that “... *hearing professionals may be well advised to devote the majority of their efforts in attempts to help the large number of hearing-impaired persons who are not residing in nursing homes.*” (Schow, 1982 p173). More than 35 years later, hearing impairment remains sub-optimally managed in RACFs, including among residents living with dementia.

The body of research in this thesis has provided the foundation for future research aimed at improving the overall wellbeing of adults living with dementia and hearing impairment in RACFs, by appropriately managing their hearing-related communication needs. It has highlighted the feasibility of a novel, fully automated late AEP test, reinforced that current hearing impairment management is sub-optimal, and developed a shared decision-making resource that has potential for improving hearing services in the long term. Moreover, the research identified that a number of inter-related barriers exist in the domains of capability, opportunity and motivation providing a catalyst for future research. The most pressing of which, are: (1) increasing RACF staff motivation for prioritising hearing impairment; and (2), increasing audiologists' habit of providing choice for treating hearing impairment. It is hoped that over the next 35 years, hearing professionals do not abandon adults living with dementia in RACFs. Instead, a movement toward holistic interventions and a shift away from solely focussing on hearing aids is considered key for optimising hearing services for adults living with dementia and hearing impairment who reside in RACFs.

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Appendix A: Ethical Approval Letters



THE UNIVERSITY OF QUEENSLAND
Institutional Human Research Ethics Approval

Project Title: Is cortical automatic threshold estimation a feasible means of assessing hearing of people with dementia who reside in an aged care home?

Chief Investigator: Ms Anthea Bott

Supervisor: Dr Carly Meyer, Prof Louise Hickson, Prof Nancy Pachana

Co-Investigator(s): Dr Carly Meyer, Prof Louise Hickson, Prof Nancy Pachana, Dr Bram Van Dun, Dr Fabrice Bardy

School(s): School of Health and Rehabilitation Sciences

Approval Number: 2017000355

Granting Agency/Degree: PhD; HEARing CRC

Duration: 31st March 2020

Comments/Conditions:

- HREA Application Form, 14/03/2017
- Project Description, 14/03/2017
- Letter of Support - Dr Carly Meyer, 14/03/2017
- Letter of Support - Prof Louise Hickson, 14/03/2017
- CDR Scale, 14/03/2017
- Consent Form_CATE, 14/03/2017
- Information Sheet_CATE, 14/03/2017
- Medical Data Record Sheet, 14/03/2017

Note: if this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:

University of Queensland Human Research Ethics Committee A

This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:

Professor Emerita Gina Geffen

Chairperson

University of Queensland Human Research Ethics Committee A

Registration: EC00456

Signature

Date

21/04/2017



THE UNIVERSITY OF QUEENSLAND

Institutional Human Research Ethics Approval

Project Title: Evaluating the communication needs of people living in aged care homes with dementia and hearing impairment

Chief Investigator: Ms Anthea Bott

Supervisor: Dr Carly Meyer, Prof Louise Hickson, Prof Nancy Pachana

Co-Investigator(s): Dr Carly Meyer, Prof Louise Hickson, Prof Nancy Pachana

School(s): School of Health and Rehabilitation Sciences,

Approval Number: 2017000356

Granting Agency/Degree: PhD; HEARing CRC

Duration: 31st March 2019

Comments/Conditions:

- HREA Application Form, 14/03/2017
- Letter of Support - Dr Carly Meyer, 14/03/2017
- Letter of Support - Prof Louise Hickson, 14/03/2017
- Letter of Support - Prof Nancy Pachana, 14/03/2017
- Topic Guide_Aged Care Staff example, 14/03/2017
- Topic Guide_Audiologist example, 14/03/2017
- Topic Guide_Client family example, 14/03/2017
- Aged Care Staff Information Sheet, 14/03/2017
- Aged Care Staff Consent, 14/03/2017
- Audiologist Information Sheet, 14/03/2017
- Audiologist Consent Form, 14/03/2017
- Family Information Sheet, 14/03/2017
- Family Consent Form, 14/03/2017
- Individual Information Sheet, 14/03/2017
- Individual Consent Form, 14/03/2017
- PDF Audiologist, 14/03/2017
- Project Description CNA, 14/03/2017
- Background Questionnaire - Aged Care Staff, 14/03/2017
- Background Questionnaire - Family / Caregiver, 14/03/2017

Note: If this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:

University of Queensland Human Research Ethics Committee A

This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:

Professor Emerita Gina Geffen

Chairperson

University of Queensland Human Research Ethics Committee A

Registration: EC00456

Signature

Date

21/04/2017



THE UNIVERSITY OF QUEENSLAND
Institutional Human Research Ethics Approval

Project Title: HEARMyChoice: a decision aid for adults with dementia and hearing impairment living in aged care.

Chief Investigator: Prof Louise Hickson

Supervisor: Prof Louise Hickson, Dr Carly Meyer, Prof Nancy Pachana

Co-Investigator(s): Ms Anthea Bott, Dr Carly Meyer, Prof Nancy Pachana

School(s): School of Health and Rehabilitation Sciences

Approval Number: 2018001379

Granting Agency/Degree: the HEARing Cooperative Research Centre

Duration: 3rd September 2020

Comments/Conditions:

- HREA Application AB03420, 03/07/2018
- Responses to committee, 03/09/2018
- Project Description, 03/07/2018
- PIS – Audiologist v2, 03/09/2018
- PIS – Family caregiver v2, 03/09/2018
- PIS – Person responsible v2, 03/09/2018
- CF – Audiologist, 03/07/2018
- CF – Family caregiver, 03/07/2018
- CF – Individuals, 03/07/2018
- CF – Person Responsible, 03/07/2018
- Decisional Conflict Scale draft, 03/07/2018
- HEARMyChoice Audiologist acceptability draft, 03/07/2018
- Patient demographic form – audiologist, 03/07/2018
- Patient demographic form – ind-fam, 03/07/2018
- Interview Guide family, 05/07/2018
- Interview Guide Individual with dementia, 05/07/2018
- Social media advertising transcripts, 05/07/2018

Note: If this approval is for amendments to an already approved protocol for which a UQ Clinical Trials Protection/Insurance Form was originally submitted, then the researchers must directly notify the UQ Insurance Office of any changes to that Form and Participant Information Sheets & Consent Forms as a result of the amendments, before action.

Name of responsible Committee:

University of Queensland Human Research Ethics Committee A

This project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research* and complies with the regulations governing experimentation on humans.

Name of Ethics Committee representative:

Professor Emerita Gina Geffen

Chairperson

University of Queensland Human Research Ethics Committee A

Registration: EC00456

Signature _____

Date _____

03/09/2020



Research Ethics Clearance

Churches of Christ in Queensland

31 May 2017

Anthea Bott
School of Health and Rehabilitation Sciences,
University of Queensland, St Lucia Q 4072

Dear Anthea,

I am pleased to advise that your research titled *"Is cortical threshold estimation a feasible means of assessing hearing of people with dementia who reside in an aged care home?"* and *"Evaluating the communication needs of people living in an aged care home with dementia and hearing impairment"* have been granted ethical clearance by the Research Ethics Group of Churches of Christ in Queensland. The projects may be conducted in the following facilities:

Toowoomba Aged Care Services, and
Carramar and Villa Carramar (Stanthorpe)

Please note that this clearance is conditional upon the research being carried out as described in the application and that Churches of Christ in Queensland retains the right to withdraw from this research at any time. A brief project report summarising your findings is also required at the conclusion of the project.

We wish you all the best with your research endeavours and look forward to a summary of your results upon completion of this project. For any questions, please email the Research Ethics Group at research.ethics@cofcqld.com.au or call Ph. 07 3363 1743.

Yours sincerely,

Signature

Tracey Hurst
Chair, Research Ethics Group
Churches of Christ in Queensland
41 Brookfield Road Kenmore QLD 4069
P.O. Box 508 Kenmore QLD 4069
P 07 3363 1791 M 0412 449 031

Bringing the light of Christ into communities

Appendix B: Interview Topic Guide (family version)

INTERVIEW TOPIC GUIDE (Family)

Dementia, hearing loss and RACFs

- 1. Tell me how you find talking with your (family member) since he/she has moved into x?**
 - a. What has changed?
 - b. How does this make you feel?
 - c. Is there anything that you need to help communicate and interact with x?
 - d. Can you tell me about the onset of your (family members) dementia/hearing loss/moving into aged care?

- 2. Tell me about the activities that your family member participates in here?**
 - a. How does your (family member) communicate during these activities?
 - b. What opportunities does your family member have to talk and communicate here?
 - c. How is this different to when he/she was living at home?

- 3. In your experience, how does your family members' hearing loss impact his/her interactions at the aged care home?**
 - a. How do you tell the difference between communication problems due to dementia or due to hearing loss?

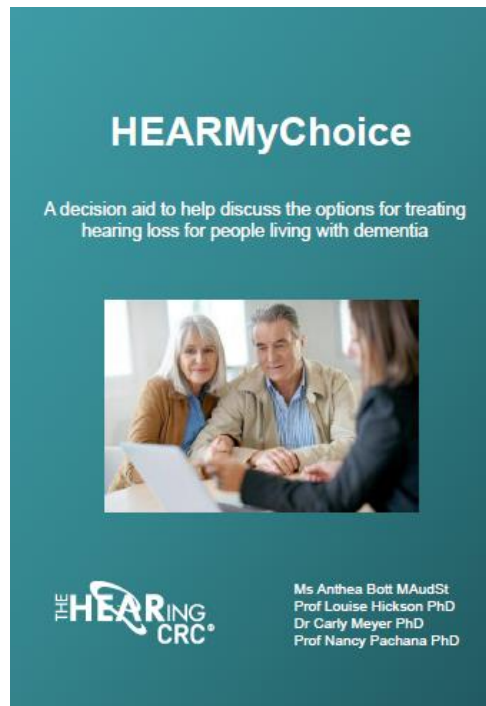
- 4. How is your (family members') hearing loss managed here?**
 - a. What differs between managing your (family members) hearing loss here, compared to when your (he/she) lived at home?
 - b. How do you feel about this?
 - c. Who is involved in managing your (family members) hearing loss?

- 5. How could hearing services be improved for your family member?**
 - Is there anything either of you would like to add?
 - Are there other things that you expected me to ask you that I have not?

Is there anything that you would like to ask me about this study?

Thank you.

Appendix C: HEARMyChoice pilot version



Contents

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2

Introduction and Instructions

Introduction

Most older adults who have dementia will also have a hearing loss. A hearing loss can make communication difficult for a person living with dementia. There are options to treat your hearing loss.

Research tells us that people want to know more information about what these options are. The information used to develop this booklet is based on research conducted in Australia and overseas.

Use this booklet if you are an individual living with dementia and hearing loss in aged care. Work through the booklet together with your audiologist and a caregiver to find the right option for you.

Instructions

- Please read through this booklet with your audiologist and a caregiver
- You will be guided through 3 steps
- You may reuse this booklet as often as you wish

This information is not intended to replace the advice of a health care provider.

3

Step 1

Do I want to treat my hearing loss?

It is okay to do nothing. You do not have to treat your hearing loss. If you choose not to treat your hearing loss you should continue to have your hearing evaluated yearly. Please read the statements below and think about how important it is for you to treat your hearing loss right now.

- My hearing loss affects my ability to hear nurses or my family.

Yes No

- My main difficulty with communicating relates to my ability to hear.

Yes No

4

How important is it for me to improve my hearing right now?

On the line below, please indicate how important it is for you to improve your hearing right now.

0 = not at all; 10 = very much

0 _____ 10

How important is it to my family for me to improve my hearing right now?

On the line below, please indicate how important it is for your family to improve your hearing right now.

0 = not at all; 10 = very much

0 _____ 10

I would like to...

- Treat my hearing loss (turn to page 6)
- Not treat my hearing loss (stop here)

If you do not want to treat your hearing loss right now, you do not need to continue with the steps of this booklet. Contact your audiologist if you notice a change in your hearing and continue to have your hearing evaluated yearly.

5

Step 2

Read about my options

Below is a summary of the 3 options available to treat your hearing loss. Please check any options you would like to know more about. You can choose more than 1 option.

	Hearing aids
What do I have to do?	<ul style="list-style-type: none"> • Attend 3 or 4 sessions to be fitted with hearing aids • Wear the hearing aids
What are the positives?	<ul style="list-style-type: none"> • My hearing will improve in most situations
What are the negatives?	<ul style="list-style-type: none"> • I might not be able to manage my hearing aids without help
Options I want to know more about.	<input type="checkbox"/> (see page 8 – 9)

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Assistive listening devices	Communication education
<ul style="list-style-type: none"> • Choose a device to improve my hearing in a specific situation (e.g. watching TV, talking on the phone, talking to someone) • Wear the device 	<ul style="list-style-type: none"> • Attend at least 2 sessions to learn strategies to help me hear better (e.g. turning down background noise) • Use the strategies in everyday life
<ul style="list-style-type: none"> • My hearing will improve in a specific situation 	<ul style="list-style-type: none"> • I will learn about ways to help me hear better
<ul style="list-style-type: none"> • I might not be able to manage my device without help 	<ul style="list-style-type: none"> • I will need others to use the strategies when talking with me
<input type="checkbox"/> (see page 10 – 11)	<input type="checkbox"/> (see page 12 – 13)

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Hearing aids

Hearing aids are the most common option for treating hearing loss. They will help you hear in most situations. Some people with dementia may not be able to manage their hearing aids on their own. To help you decide if you want to choose this option, please answer the statements below.

- It is very important for me to improve my hearing in most situations.
 Yes No
- I think I can manage my hearing aids on my own.
 Yes No – see page 16 for information on managing and cleaning your hearing aid
- I do not have problems with my hands or vision that will impact how I manage my hearing aids.
 Yes No
- There is someone else who can help me manage my hearing aids (e.g. family member, nursing staff).
 Yes No

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Assistive listening devices

Assistive listening devices are used to help you hear in a specific situation. For example, talking on the phone, watching TV or talking to another person. They can be easier to manage than hearing aids. To help you decide if you want to choose this option, please answer the statements below.

- It is very important for me to improve my hearing in a specific situation, e.g. when watching TV.
 Yes No
- I think I can manage the device on my own.
 Yes No
- I do not have problems with my hands or vision that will impact how I manage my device.
 Yes No
- I have someone who will help me to manage the device (e.g. family member, nursing staff).
 Yes No
- All of my questions about assistive listening devices have been answered.
 Yes No – What questions do you have?

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- I can regularly have my ears checked for wax.
 Yes No
- The aged care home is not very noisy and will not impact how well my hearing aids assist me.
 Yes No
- All of my questions about hearing aids have been answered.
 Yes No – What questions do you have?

If you answered yes to most questions, hearing aids are likely to be suitable for you.

I would like to...

- Try hearing aids (turn to page 14)
- Not try hearing aids
- Look at another option (turn to page 6 and 7)

9

If you answered yes to most questions, assistive listening devices are likely to be suitable for you.

I would like to...

- Try an assistive listening device (turn to page 14)
- Not try an assistive listening device
- Look at another option (turn to page 6 and 7)

Images of assistive listening devices



Telephone amplifier



Pocket talker



Wireless TV headphone



Bellman Maxi-Pro: Speech amplifier; TV amplifier; and TV streamer

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Communication education

Attending a communication education program will help you to learn strategies to help you hear better. You can also take a family member with you. To help you decide if you want to choose this option, please answer the statements below.

- It is very important for me to learn strategies to help me hear better.
 - Yes No
- It is very important for my family to learn strategies to help me hear better.
 - Yes No
- I can learn and remember new things easily.
 - Yes No
- I have someone who will help me to use these strategies (e.g. family member, nursing staff).
 - Yes No
- All of my questions about communication education have been answered.
 - Yes No – What questions do you have?

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If you answered yes to most questions, communication education is likely to be suitable for you.

I would like to...

- Try communication education (turn to page 14)
- Not try communication education
- Look at another option (turn to page 6 and 7)

Two key communication strategies

1. Turn down background noise
2. Speak face-to-face



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Step 3

What is the next step?

I have decided to try...

	Hearing aids
The next step is to...	• Choose a hearing aid style to try.

Hearing aid styles



Behind the ear (BTE)

Receiver in canal (RIC)

In the ear (ITE)

Completely in canal (CIC)

14

Assistive listening devices	Communication education
• Choose a device to try (see page 11 for examples)	• Book a time to start the communication education program

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How to manage and clean my hearing aid

How do I turn hearing aids on and off?



To turn a hearing aid on, close the battery door.

To turn a hearing aid off, open the battery door.

How do I tell right from left?



Hearing aids have a colour marking.

Red is for right.
Blue is for left.

16

How do I change the battery?



Step 1: Open the battery door and remove the old battery.



Step 2: Take a new battery from the battery pack. If there is a coloured sticker on the battery, take it off.



Flat side
↑

Step 3: Place the new battery in the hearing aid and close the battery door. Make sure the flat side of the battery faces up.

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How do I insert a hearing aid?



Step 1: Place the hearing aid body behind your ear



Step 2: Put the dome or mould in your ear

How do I look after my hearing aids



Everybody's ears produce wax. Each day, wipe over the hearing aid with a soft cloth. Once a week, use a brush to remove any wax around the hearing aid dome and tube.

18

What should I do if my hearing aid isn't working?



Step 1: Check that the hearing aid dome is fully in your ear. The tube should be flat against the side of your face. Make sure the battery door is completely closed.



Step 2: To check if your hearing aid is working, cup the hearing aid in your hand. If you hear a whistling sound, your hearing aid is working.

If your hearing aid doesn't whistle, try the following:

1. Replace the battery.
2. Inspect and clean the hearing aid for wax. Remove any wax from the dome or tube.
3. Check the tubing for any kinks or cracks. Call your audiologist to replace broken tubing.
4. Contact your audiologist if you have tried these steps and your hearing aids aren't working.

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Further resources

Websites about hearing loss and hearing devices

- www.hearinet.org.au
- www.audiology.asn.au
- www.independentaudiologists.net.au
- www.forum.hearingtracker.com
- www.hear-it.org
- www.consumeraffairs.com/health/hearing/#

Videos about managing hearing aids

- <https://vimeo.com/120444588> (How to manage and clean your hearing aid)

Support for dementia care and advocacy

- <https://www.dementia.org.au/>
- <http://www.who.int/news-room/fact-sheets/detail/dementia>
- <https://www.alz.co.uk/research/world-report>

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Miscellaneous

Conflict of interest

Financial support was provided by The HEARing Cooperative Research Centre. Neither the authors nor their affiliated organisations stand to gain financially from the use of this booklet.

Adapted from

The Ottawa Personal Decision Guide © 2006, O'Connor, Jacobsen & Stacey, Ottawa Hospital Research Institute, Ottawa, Canada.

Version 1

Last updated 12 November 2018.

Disclaimer

This booklet is not intended to replace the advice of your health professional or doctor. All efforts have been taken to ensure the content of this booklet is accurate at the time of publication.

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Appendix D: Decisional Conflict Scale

Pre- Appointment: Making a choice on treating my/my family members' hearing loss

A. Which hearing treatment option do you prefer? Please check ✓ one.

- a. Hearing aids
- b. Assistive listening devices
- c. Communication education
- d. A combination of A, B or C
- e. No treatment option
- f. Unsure

B. Considering the option you prefer, please answer the following questions:

	Yes	Unsure	No
Do you know which options are available to you/your family member?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know the benefits of each option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you know the amount of time required for each option?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are you clear about which benefits matter most to you/your family member?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have enough support from others to make a choice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are you choosing without pressure from others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you have enough advice to make a choice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are you clear about the best choice for your family member?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel sure about what to choose?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix E: Knowledge of hearing treatment options pre-exposure questionnaire

Pre-Appointment: What I know about treating hearing loss for people with dementia now

Here are some questions about treating hearing loss. We would like to know how familiar you are with the options before you go through the information booklet. We will ask you these questions again after you have used the information booklet 'HEARMyChoice'.

Below are listed some statements about treating hearing loss. Please show whether you think they are true, false, or you are not sure by *circling* the word beside each statement.

1. Options for treating hearing loss include...

Hearing aids	True	False	Unsure
Assistive listening devices	True	False	Unsure
Communication education	True	False	Unsure
No intervention	True	False	Unsure
Taking Panadol	True	False	Unsure
Ginko Biloba	True	False	Unsure

2. Hearing aids...

Improve hearing in a specific situation	True	False	Unsure
Can be hard for people with dementia to manage	True	False	Unsure
I may have to attend up to 4 appointments if I choose this option	True	False	Unsure

3. Assistive listening devices...

Improve hearing in most situations	True	False	Unsure
I may have to attend up to 4 appointments if I choose this option.	True	False	Unsure

Don't require someone else to help you manage them	True	False	Unsure
--	------	-------	--------

4. Communication education...

I may have to attend up to 4 appointments if I choose this option	True	False	Unsure
---	------	-------	--------

A caregiver will learn strategies too	True	False	Unsure
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Appendix F: Topic Guide HEARMyChoice

Topic Guide

Thank you for your time and for agreeing to take part in this project. The project is developing a booklet to help you make a choice about treating your hearing loss. I would now like to get your thoughts on the booklet. Before I start do you have any questions?

Initial Response

- a) In your own words what do you think is the **purpose** of this booklet?
- b) What were your **first impressions** of this booklet?
- c) What did you **like** about the booklet?
- d) How can we **improve** the booklet?
- e) Would you like to see this booklet used during audiology appointments in the future? Why/Why not?
- f) Overall, how helpful was this booklet for assisting you to choose an option for treating your / your family members hearing loss?

Design

What do you think about the overall design of the booklet (colour, images, size of writing; anything about the way the booklet was presented?)

General Length and content

How did you find the length of the decision aid?

(e.g. too long, too short, the right length?)

What did you think about the amount of information in the booklet?

(e.g. too much, too little, the right amount)

Wording

Which sentences or sections in the booklet could be clearer?

Comprehensiveness

a) Are there any topics or questions that you feel were not covered in this booklet that should be included? YES (if yes, please tell us what you think should be added)
NO

Now we will go through the specific sections of the booklet that you looked at during or after the appointment. Please turn to page 3 (introduction & Instructions):

- What was your overall impression about this page?
- What was useful and why?
- What wasn't useful and why?

Please turn to page 4-5 (step 1) do I want to treat my hearing loss:

- What was your overall impression about this step?
- What was useful and why?
- What wasn't useful and why?

Please turn to page 6-7 (step 2) Read about my options:

- What was your overall impression about this step?
- What was useful and why?
- What wasn't useful and why?
- What else would you have liked to have seen in this section?

Hearing aids (if applicable):

- What was your overall impression about this section?
- What was useful and why?
- What was not useful and why?

ALD (if applicable):

- What was your overall impression about this section?
- What was useful and why?
- What was not useful and why?

Communication education (if applicable):

- What was your overall impression about this section?
- What was useful and why?
- What was not useful and why?

Please turn to page 14-15 (Step 3) what is the next step:

- What was your overall impression about this section?
- What was useful and why?
- What was not useful and why?
- What else would you have like to have seen in this section?

Did you look through the information on pages 16-19 (How to manage and clean my hearing aids?)

If yes:

- What was your overall impression about this section?
- What was useful and why?
- What was not useful and why?

Please turn to pages 20 – 24 (further resources etc)

- What was your overall impression about this section?
- What was useful and why?
- What was not useful and why?

Other factors

Today I wanted to gather your thoughts on the booklet that we went through together about treating your hearing loss? Is there anything else you would like to add about this?

Thank you
