

# **THE EFFECTS OF HEARING LOSS ON PREFERENCES FOR SHARED DECISION MAKING IN RESIDENTIAL AGED CARE: A MIXED METHODS APPROACH**

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## **DECLARATION**

I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at Macquarie University or any other educational institution, except where due acknowledgement is made in this thesis. Any contribution made to the research by others, with whom I have worked with at Macquarie University or elsewhere, is explicitly acknowledged in the thesis.

I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that the assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.

Signed: 

Date: 07/10/16

## **ABSTRACT**

Hearing loss is associated with communication breakdown in residential aged care. A review of the literature found that the effects of hearing loss on residents' preferences for shared decision making remain unknown. The aim of the thesis is to assess how hearing loss affects residents' preferences for receiving information, and making decisions, in terms of their medical and everyday care. An exploratory mixed methods study was conducted, involving interviews and surveys, with 26 residents. Interviews covered five parts: demographic details; self-perceived hearing loss; and, preferences for receiving information and decision making about medical and everyday care. Statistical analysis, thematic analysis using the Framework Method, and inductive content analysis, were employed to analyse data. Participants demonstrated strong preferences for receiving information and involvement in decision making, in both medical and everyday contexts. Despite strong preferences for receiving information, some participants, including three with hearing loss, expressed dissatisfaction with the communication they received. Participants' with hearing loss reinforced the importance of family involvement in decision making processes. The findings offer direction for future research by emphasising the need to better understand the communication strategies employed by residents with hearing loss, and the role that family members play in shared decision making.

## **DEDICATION**

To my dad, for encouraging me to push myself to be better than my best. Without you, I would not have commenced my journey of higher degree research.

And to my mum, for providing me with emotional support from 26,800 kilometres across the world. Without you, I would not have made it this far.

## **PUBLICATIONS AND PRESENTATIONS ARISING FROM OR ACHIEVED DURING THE COURSE OF THIS CANDIDACY<sup>1</sup>**

### **Published papers in peer-reviewed journals**

Braithwaite J, Herkes J, **Ludlow K**, Lamprell G, Testa L. The association between organisational and workplace cultures, and patient outcomes: systematic review protocol. Submitted to *BMJ Open*. Accepted 6 October 2016.

Braithwaite J, Clay-Williams R, Vecellio E, Marks D, Hooper T, Westbrook M, Westbrook J, Blakely B, **Ludlow K**. The basis of clinical tribalism, hierarchy and stereotyping: a laboratory-controlled teamwork experiment. *BMJ Open*. 2016;6:e012467.

### **Papers submitted to peer-reviewed journals**

Clay-Williams R, Li Z, **Ludlow K**, Testa L, Braithwaite J. Medical leadership systematic review: do hospitals and healthcare organisations perform better when led by doctors? Submitted to *BMJ Open*; 22 September, 2016.

### **Chapters in books**

Braithwaite J, Mannion R, Matsuyama Y, Shekelle P, Whittaker S, Al-Adawi S, **Ludlow K**, James W. Introduction. In: Braithwaite J, Mannion R, Matsuyama Y, Shekelle P, Whittaker S, Al-Adawi S, eds. *Health Systems Improvement Across the Globe: Success Stories from 60 Countries*. Abingdon, UK: Taylor & Francis; Accepted 10 June 2015.

Braithwaite J, Mannion R, Matsuyama Y, Shekelle P, Whittaker S, Al-Adawi S, **Ludlow K**, James W. Discussion and Conclusion. In: Braithwaite J, Mannion R, Matsuyama Y, Shekelle P, Whittaker S, Al-Adawi S, eds. *Health Systems Improvement Across the Globe: Success Stories from 60 Countries*. Abingdon, UK: Taylor & Francis; Accepted 10 June 2015.

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<sup>1</sup> Not all publications and presentations are direct outputs of the research in this thesis, but are relevant to mixed methods study designs, or the overarching topic of health improvement.

**Seminar presentations**

**Ludlow K.** The effects of hearing loss on aged care residents' preferences for shared decision making: my MRes journey. *AIHI CHRIS Conversations*; 21 June, 2016; Sydney, Australia.

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## **LIST OF ABBREVIATIONS**

Auslan	Australian Sign Language
dB HL	Decibels Hearing Level
FY	Financial Year
RQ1	Research Question 1
RQ2	Research Question 2
SDM	Shared Decision Making

## CHAPTER 1. INTRODUCTION

### 1.1. Importance of the research project

Australia's ageing population is increasing the demands placed on health and aged care resources and services such as residential aged care facilities.<sup>1,2</sup> Australia's aged care sector is currently undergoing a major reform in order to enhance person-centred care and improve quality of care.<sup>3</sup> Person-centred care is an approach which encourages consumers to participate in their care and supports their involvement in the decision making process, termed *shared decision making*.<sup>3-5</sup> Effective communication and receptiveness of older consumers' preferences and needs is at the centre of quality care.<sup>6</sup> One of the barriers to communication faced by a large proportion of older Australians is hearing loss due to ageing processes, otherwise known as presbycusis.<sup>7,8</sup> Hearing loss can be a disabling condition, leading to miscommunication, confusion, frustration, and embarrassment,<sup>9</sup> as well as social isolation,<sup>10</sup> and poor health outcomes.<sup>11,12</sup>

The effects of hearing loss on communication are exacerbated in residential care settings due to environmental background noise,<sup>10</sup> and a lack of audiological resources.<sup>13</sup> Although residents report communication breakdown as a result of their hearing loss,<sup>10</sup> the effects of hearing loss on shared decision making in this setting remain unknown. This thesis aims to address this gap in the research by investigating how hearing loss in residential care impacts residents' preferences for shared decision making. To meet the needs of residents in aged care facilities, their preferences must first be understood. By assessing shared decision making preferences in terms of both *medical care* and *everyday care*, this study will provide a holistic account of residents' overall care experience.

#### 1.1.1. Aim and research questions

This thesis aims to assess how hearing loss affects aged care residents' preferences for involvement in shared decision making in regards to their medical care and everyday care. To achieve the study aim, two research questions were formulated:

Research Question 1 (RQ1): How does hearing loss affect aged care residents' preferences for receiving information, and decision making, in terms of their *medical care*?

Research Question 2 (RQ2): How does hearing loss affect aged care residents' preferences for receiving information, and decision making, in terms of their *everyday care*?



### 1.1.2. Thesis scope

The scope of this thesis was to assess how hearing loss affects aged care residents' preferences for shared decision making, conceptualised by two distinct phases: receiving information and making decisions. Preferences for shared decision making were assessed in terms of residents' medical care and everyday care. This thesis explored residents' preferences only and did not assess the actual care they received. In order to understand the experiences of residents and the effects of hearing loss, the term *hearing loss* encompassed hearing impairment, hearing disability, and hearing handicap. The term *Deaf* (uppercase 'D') was not included in this definition of hearing loss (see section 1.6). Hearing loss was measured by observable metrics (participant wore hearing aids or made reference to them, or participant requested that questionnaire item(s) be repeated), and a self-report instrument. This thesis does not intend to draw conclusions regarding residents' measured hearing function.

## 1.2. Person-centred care and shared decision making

Person-centred care results from reciprocal partnerships between health professionals, consumers, and families.<sup>14</sup> It is an approach which gives health consumers greater responsibility, accountability, and empowerment. This involves educating consumers, including them in the design, implementation, and evaluation of care plans, and respecting their preferences, values, and needs.<sup>3</sup> Person-centred care is also frequently referred to as: patient-centred care, patient-focused care, consumer-centred care, client-centred care, family-centred care, relationship-centred care, person-driven care, personalised care, or individualised care.<sup>3,15</sup> The term 'person-centred care' was selected for use throughout this thesis for three reasons: 1) 'Person-centred' is the term generally used in relation to the care provided to older consumers,<sup>3,15,16</sup> who are the focus of this research. 2) The use of *person* as opposed to *patient* takes the focus away from illness or disease and centres it on the individual.<sup>16</sup> This is especially important for residential aged care consumers who are *residents* and not always *patients*, as care involves more than just medical care. For example, socialisation and mealtimes are important features of the overall care experience.<sup>17-19</sup> 3) Person-centred care recognises the valuable contribution to decision making processes in health care of all parties, including consumers, families, carers, and medical professionals.<sup>3</sup>

One of the ways in which person-centred care is implemented in clinical practice is through shared decision making;<sup>5,20</sup> which is defined by Hoffmann (2014) as “a consultation process where a clinician and patient jointly participate in making a health decision, having discussed the options and their benefits and harms, and having considered the patient's values, preferences and circumstances”.<sup>20</sup>(page 1) Shared decision making involves three stages: information exchange, deliberation, and decision on the treatment to implement.<sup>21</sup> *Information exchange* is a two-way discussion process.<sup>21</sup> Health professionals provide consumers with information regarding medical conditions, treatment options and procedures, the risks and benefits of treatments, the effects of medication, and access to external support and resources.<sup>21</sup> Consumers are given the opportunity to discuss this information in light of their preferences, values, and needs. Consumers also divulge additional information such as their medical background and social context.<sup>21</sup> *Deliberation* involves an interactive discussion about potential treatments by weighing up the risks and benefits of each option.<sup>21</sup> It is common for third parties such family members or close friends to be consulted in the deliberation process.<sup>21</sup> *Decision on the treatment to implement* refers to an agreement between health professionals and consumers on the best course of action.<sup>21</sup> It is achieved through the deliberation process, and is supported by information exchange.

Shared decision making is achieved by *providing information* to health consumers and *supporting the decision making process*.<sup>5</sup> The provision of high quality information equips consumers with relevant knowledge, enabling them to make informed decisions.<sup>5</sup> Control over decision making can be conceptualised as a continuum, ranging from consumer-driven to clinician-driven, with shared decision making falling somewhere in between the two extremes.<sup>20</sup> Supporting consumers in decision making empowers them to make decisions without feeling overwhelmed by responsibility, abandoned, or excluded from the decision making process.<sup>22</sup>

### **1.3. Australia's aged care reform**

Governments, health care professionals, and health systems researchers worldwide have recognised the evidence-based benefits of person-centred care.<sup>23,24</sup> For example, interventions based on the principles of person-centred care have been found to reduce the length of hospital stay by 30% in patients with chronic heart failure,<sup>25</sup> and 50% in elderly patients with hip fractures,<sup>26</sup> compared to patients receiving ‘usual care’.

Internationally, health policy and legislation outlining various initiatives for the implementation of person-centred care and shared decision making are being developed.<sup>23</sup> For example, the Right Care Shared Decision Making Programme, as part of England's National Health Service, aims to develop tools to enhance and integrate shared decision making into clinical practice, and create a receptive culture for it.<sup>27</sup> Throughout Canada, shared decision making initiatives are under various stages of development.<sup>28</sup> In Ottawa, the Patient Decision Aids Research Group, a government funded research entity, provides decision support tools for patients, e.g., the Ottawa Personal Decision Guide<sup>29</sup> and the A to Z Inventory of Decision Aids,<sup>30</sup> and integrates decision aids in clinical practice through an Implementation Toolkit.<sup>31</sup>

Although person-centred care and shared decision making are endorsed by the Australian government, frameworks and resources to implement person-centred care and shared decision making in practice have previously been absent.<sup>23,32</sup> This is in part due to the divided responsibilities for government funding across states and territories,<sup>32</sup> and domains of care. In recent years however, the Australian government has recognised the need to transition from a traditional disease-control approach to health care delivery to one that is consumer-driven. Australia is currently undertaking a major health reform to improve quality of care, with recent recommendations from the Primary Health Care Advisory Group to the Department of Health promoting a transition to a more person-centred care approach.<sup>33</sup>

As part of Australia's health reform, the national government has proposed policy changes to achieve a sustainable and affordable aged care system by 2022.<sup>34</sup> These changes involve reviewing the current aged care standards, reducing regulations, and providing greater choice and flexibility to consumers in order to improve quality of care.<sup>6,34</sup> In 2014, individuals aged 65 years and older made up 14.75% of Australia's population.<sup>35</sup> This figure is expected to reach 20% in 2024,<sup>1</sup> increasing the demand for aged care services and resources. In the 2014 financial year (FY), 7.8% of Australians aged over 65, or 270,599 people, lived in residential aged care facilities.<sup>36</sup> The Australian government's recurrent expenditure on total aged care for 2013FY was AUD\$13.6 billion, including AUD\$9.4 billion spent on residential aged care.<sup>37</sup>

In order to meet the needs of Australia's ageing population, the Australian Aged Care Quality Agency held a series of discussion forums to obtain feedback from the aged care community regarding the quality of care delivered in the sector.<sup>6</sup> The Agency received

feedback from peak government bodies, health care providers, practitioners, carers, consumers, consumer advocate groups, and researchers. From this feedback, a discussion paper, “Let’s talk about quality – developing a shared understanding of quality in aged care services”,<sup>6</sup> was produced to inform the Agency’s work and the review of aged care standards. A key driver for the consultation process was the acknowledgement that Australia’s aged care sector needs a cultural shift away from a system that views health consumers as passive recipients of their care and towards one that is consumer-driven. This involves providing consumers with choice and autonomy, listening to the voices of consumers, providing timely, transparent information to promote informed decision making, and taking a holistic approach to care where interpersonal, social, and relational aspects of care are considered.<sup>6</sup> Achieving the cultural shift needed to support this change will require a synergy between policy and funding model reforms, and clinician behaviours. Policymakers and health professionals will be required to engage with consumers in open and ongoing discussions, and be responsive to their preferences and needs.<sup>6</sup>

#### **1.4. Older health consumers’ preferences for shared decision making**

The drive to understand the preferences and opinions of consumers, in Australia and internationally, has prompted research into the involvement of older individuals in person-centred care, with a focus on shared decision making. Family members play an integral role in the care provided to aged care residents, particularly in end-of-life care planning, and in regards to residents with advanced dementia.<sup>38-41</sup> Family members’ views and preferences are commonly emphasised in aged care research,<sup>42-44</sup> however little is known about aged care residents’ preferences for shared decision making. Some evidence suggests that residents want to be informed, but prefer minimal input in medical decision making.<sup>45</sup> To circumvent the lack of research on shared decision making in residential aged care, evidence from other health sectors can be examined. In primary and acute care, older patients are often perceived to play a passive role in their care, preferring clinicians to make final decisions.<sup>46-48</sup> This does not mean that older patients do not want to be involved in shared decision making, but that they focus on the information exchange. For older patients, involvement means receiving information about conditions, treatment options, and preventative measures,<sup>46,48</sup> with the opportunity to clarify details and ask questions. We know clinical practice in this area is not optimal: almost 40% of older patients want more information from

their clinicians without having to ask for it, and during hospital stays, about 45% receive less information than they would prefer.<sup>47</sup> Although acute and primary care settings provide valuable information about older patients' preferences for shared decision making,<sup>46-48</sup> testing the case in the residential aged care sector is necessary.

### **1.5. Residential aged care: a holistic approach to person-centred care and shared decision making**

Aged care facilities are a home for residents, a place for social interaction and for meaningful activity, and additionally, they coordinate medical care.<sup>49,50</sup> Hence, when exploring residents' preferences for shared decision making, a holistic approach needs to be taken to incorporate not only the medical side of care, but the 'everyday care'. Everyday care refers to non-medical aspects of care that residents encounter in their living environment such as active activities (e.g., outdoor tasks), socialisation, environment/rooms, food and dining, personal care (e.g., clothing), and independent pursuit activities (e.g., watching television).<sup>51</sup> Standardised routines, regulations, and environmental dynamics of aged care facilities can potentially restrict residents' choices in their day-to-day life, resulting in loss of autonomy, and reduced quality of life.<sup>52</sup> Allowing choice in relation to everyday matters such as food service, mealtimes, activities, and environmental surroundings is meaningful for residents.<sup>17,18,53,54</sup> Enabling residents to make decisions about their everyday care results in improved wellbeing and quality of life,<sup>18,55</sup> a sense of autonomy and dignity,<sup>56</sup> increased identification with others,<sup>55</sup> and better overall health.<sup>55</sup> In order to take a person-centred care approach, it is important when conducting research not to restrict the concept of care to medical intervention, but to also address residents' preferences for choice within, and about, their everyday living environment.

### **1.6. Defining hearing loss**

There are a number of terms use to describe hearing functioning that fall outside the normal range of hearing. Hearing impairment or hearing loss refers to "reduced sensitivity to pure tones, and tinnitus".<sup>57(page 1)</sup> The classification boundaries and labels assigned to degrees of hearing loss vary between organisations. Table 1.1 presents an overview of the classification system adopted by Cochlear.<sup>58</sup>

**Table 1.1: Classification of hearing loss severity**

Degree of hearing loss	Hearing loss range (dB HL)	Impact
Normal hearing	20+	Normal hearing
Mild hearing loss	25 to 39	Difficulty following speech in noisy situations
Moderate hearing loss	40 to 69	Difficulty following speech without a hearing aid
Severe hearing loss	70 to 89	Requires hearing aids or an implant
Profound hearing loss	90+	Reliance on lip-reading, sign language, or an implant

*Adapted from: Cochlear, 2016.<sup>58</sup>*

The experience or impact of hearing loss is often labelled as *hearing disability* or *hearing handicap*. Hearing disability refers to a decline in, or loss of, function such as speech perception and sound localisation.<sup>57,59</sup> Hearing handicap relates to the communicative, social, and emotional consequences of hearing loss.<sup>57,59</sup> In order to understand the experiences of consumers and gain a comprehensive account of the effects of hearing loss, this thesis does not distinguish between hearing impairment or degree of hearing loss, hearing disability, and hearing handicap. Instead, the term *hearing loss* is used throughout this thesis as an all-encompassing term.

Individuals with profound hearing loss are often labelled *deaf* (lowercase ‘d’), whereas the term *Deaf* (uppercase ‘D’) refers to individuals who culturally identify with the Deaf Community.<sup>60</sup> The Deaf Community primarily consists of individuals who were born not hearing or acquired hearing loss in their early life, and associated parties such as family members or interpreters.<sup>61</sup> Individuals who acquired hearing loss later in life, experience restricted hearing ability, differently compared to Deaf individuals, in terms of both identity and communication strategies. Members of the Deaf Community have a shared cultural identity and language.<sup>61</sup> In Australia, this language is known as Australian Sign Language (Auslan).<sup>62</sup> The concept of cultural Deafness lies outside the scope of this thesis and therefore it is not included in the definition of hearing loss.

### **1.7. The prevalence of hearing loss in Australia**

Around 13% of the Australian population, or three million people, have at least one long-term hearing disorder, such as complete or partial deafness or tinnitus.<sup>63</sup> A current figure for the Australian government's expenditure on hearing impairment could not be calculated due to lack of data. The most recent report identified from 2005 estimated that hearing loss at that time contributed to an economic burden of \$11.75 billion.<sup>64</sup> Hearing loss is associated with poor physical, social, and mental health outcomes, including increased risk of mortality,<sup>11</sup> incidence of hospitalisation,<sup>12</sup> social withdrawal,<sup>10</sup> depression,<sup>65,66</sup> and need for assistance.<sup>67</sup>

The prevalence of hearing loss increases with age, with 35% of Australians over the age of 65 experiencing complete or partial hearing loss.<sup>68</sup> Age-related hearing loss, termed presbycusis, is the most prevalent form of sensory decline in older adults.<sup>69</sup> It is characterised by a progressive degeneration of auditory functioning resulting in difficulties understanding speech, especially in the presence of background noise, reduced hearing sensitivity, and impaired localisation of sound.<sup>7</sup> In the majority of cases presbycusis initially affects high-frequency hearing, which is associated with consonant sounds.<sup>7,8</sup> This means that in the early stages of presbycusis, individuals often experience miscommunication and complain of not being able to understand information, as opposed to not being able to hear it.<sup>7,8</sup> As presbycusis progresses, mid and lower frequencies become harder to hear, exacerbating communication difficulties.<sup>7,8</sup>

### **1.8. The experience of hearing loss in residential aged care**

Quality communication is an integral part of person-centred care and shared decision making, particularly for older persons,<sup>6,70</sup> who value information exchange but often prefer to leave final decisions to health professionals.<sup>46,48</sup> Effective communication allows both consumers and health professionals to express their views and priorities in order to make informed decisions.<sup>5,20</sup> Hearing loss can dramatically reduce the quality of communication, with both consumers and professionals experiencing miscommunication, confusion, frustration, and embarrassment.<sup>9,71</sup>

Hearing loss is especially challenging for aged care residents, as they experience additional burdens such as complex medical problems, communication difficulties, or cognitive impairment.<sup>72</sup> For example, one study<sup>73</sup> found that individuals with hearing loss

had a 30-40% accelerated rate of cognitive decline, and a 24% increased risk for incident cognitive impairment, compared to individuals without hearing loss, over a six-year period. Hearing loss is also reported to be independently associated with lower scores on tests of memory and executive functioning.<sup>74</sup> The overlap between hearing loss and cognitive impairment increases communication difficulties, as mishearing speech is coupled with memory loss, confusion, and an inability to understand or process information.<sup>10,71</sup> Residential care staff can have difficulties distinguishing between communication problems due to the effects of hearing loss, and the effects of cognitive decline, which leads to uncertainty about how to best manage communication breakdown.<sup>71</sup> Communication problems are intensified in residential aged care facilities due to background noise from medical devices, television and radios, staff members, and other residents.<sup>10,75-78</sup> This problem is exacerbated in noisy communal areas such as dining rooms or activity rooms.<sup>10</sup> Aged care residents who have hearing loss demonstrate communication breakdown with other residents and members of staff, leading to social isolation and withdrawal.<sup>10</sup>

Hearing aids, assisted listening devices, cochlear implants, and active middle ear implants are some of the management strategies used to improve hearing function and provide communication support.<sup>79,80</sup> Access to audiological services is often limited in residential care facilities due to temporal and financial constraints, and feasibility issues.<sup>10,13</sup> Hearing aids are the primary management tool for improving hearing loss in older adults.<sup>81</sup> At a basic level, hearing aids improve recipients' hearing function by receiving sound waves through a microphone, converting the waves into electrical signals, and delivering amplified signals to the tympanic membrane.<sup>80</sup> Improvements in technology and the development of digital hearing aids have resulted in additional benefits such as improved sound quality, a range of programs for listening in different environments, and manipulation of frequency.<sup>81</sup> Despite these benefits, a large proportion of the adult population who experience hearing loss do not seek professional help, or do not use hearing aids.<sup>82,83</sup> Hartlet et al (2010) found that of 2,956 older Australian adult participants, 33% met the criteria for hearing loss, but only 11% of those participants owned a hearing aid. Furthermore, hearing aid non-usage rates were high, with 24% of hearing aid owners having never used their hearing aids.<sup>84</sup> Reasons for non-usage by those who require and own hearing aids include: lack of perceived benefits, poor sound quality, discomfort, background noise and feedback, financial burden, appearance, stigma associated with hearing aids/embarrassment, and inconvenience.<sup>81,82,84</sup>



Additional to negative attitudes towards the devices themselves, the need for help with care and maintenance of devices, such as requiring assistance with changing batteries, and limitations in manual dexterity, are also reported as a common reason for non-usage.<sup>81</sup> In residential settings, care staff members often lack formal training regarding the management of hearing devices, such as cleaning hearing aid moulds or changing the batteries of hearing devices, and have limited knowledge concerning the communication needs of residents with hearing loss.<sup>10,13,85</sup> The combination of a noisy environment, lack of access to audiological services, and limited formal staff training, creates a communication-poor environment for residents with hearing loss.

### **1.9. Research rationale**

One of the major aims of Australia's current health reform is to create a sustainable health system for Australia's ageing population by 2022, by providing high-quality person-centred care and empowering older consumers to participate in shared decision making.<sup>6,34</sup> Aged care research often relies on proxy views when residents are unable to provide informed consent, particularly regarding topics such as dementia, end-of-life decisions, and advanced care planning.<sup>42-44</sup> This means that unlike acute or primary care,<sup>46-48</sup> little is known about residents' involvement in their care, specifically their preferences for shared decision making.

Another area that requires more research attention is the relationship between hearing loss and person-centred care in residential settings. Hearing loss is the leading type of sensory decline in older adults,<sup>69</sup> causing disruption to information exchange, confusion, and miscommunication.<sup>9,10,71</sup> However, people who suffer from hearing loss are often excluded from research,<sup>47,86</sup> due to difficulties in communication and an inability to participate in data collection processes, such as telephone interviews. The limited literature that does exist on hearing impairment and shared decision making is restricted to decisions regarding the use of hearing devices or engagement in audiological rehabilitation, and the factors that influence these decisions.<sup>87-91</sup>

Communication breakdown as a result of hearing loss is especially relevant to residents of aged care facilities as they are exposed to environmental background noise,<sup>10</sup> and have difficulties accessing audiological services or receiving assistance with hearing devices from care staff.<sup>10,13</sup> Research has not yet addressed how hearing loss affects

residents' preferences for involvement in shared decision making. In order to improve the quality of care provided to aged care residents it is important to first understand residents' preferences for shared decision making and how hearing loss effects these preferences for medical and everyday care contexts. This gap is the focus of this research.

### 1.10. Organisation of thesis

The structure of the thesis is outlined in Table 1.2. Chapter 2 comprises a narrative literature review in the form of a draft paper (not yet submitted). The purpose of this chapter was to review and synthesise the evidence relating to the effects of hearing loss on person-centred care in residential aged care. The Methods chapter (Chapter 3) provides an overview of the study setting and participants, recruitment, the research procedure and study design, the selection and development of data gathering instruments, and data analysis. The thesis contains two findings chapters (Chapter 4 and Chapter 5). Findings: RQ1 Medical Care—Preferences for Information and Decision Making (Chapter 4) presents the results of statistical analysis, a tool validation, and thematic analysis using the Framework Method.<sup>92,93</sup> Findings: RQ2 Everyday Care—Preferences for Information and Decision Making (Chapter 5) contains the results from inductive content analysis.<sup>94,95</sup> The Discussion and Conclusion chapter (Chapter 6) outlines a summary of the findings, and discusses the unique contribution of the research, study challenges and lessons, directions for future research, and translation of the research. The conclusion section of Chapter 6 provides an overarching summary of the research project.

**Table 1.2: Summary of chapters, research questions, methods, and details**

Chapter	Research question	Methods	Details
<b>1. Introduction</b>	Research aim: to assess how hearing loss effects aged care residents' preferences for involvement in shared decision making in regards to their medical care, and everyday care		
		a) Literature search	Four online databases

Chapter	Research question	Methods	Details
<b>2. Narrative Literature Review</b>	How does hearing loss affect person-centred care in residential aged care?	b) Quality assessment	Mixed Methods Appraisal Tool <sup>96,97</sup>
		c) General inductive analysis and synthesis of results	Six papers Five factors
<b>3. Methods</b>	<p>Research Question 1 (RQ1): how does hearing loss affect residents' preferences for receiving information and decision making, in terms of their <i>medical care</i>?</p> <p>Research Question 2 (RQ2): how does hearing loss affect residents' preferences for receiving information and decision making, in terms of their <i>everyday care</i>?</p>	a) Focus group	Four health services researchers
		b) Selection and modification of questionnaires	Two health services researchers 1) Hearing Index <sup>98</sup> (RQ1 & RQ2) 2) Information-Seeking Scale <sup>99</sup> (RQ1) 3) Decision Making Preference Scale <sup>100</sup> (RQ1)
		c) Tool validation	1) Hearing Index 2) Two observable metrics
		d) Interview tool design and development	Two health services researchers Shared Decision Making (SDM) Interview Tool
		e) Recruitment	26/35 residents invited
		f) Interviews	26 participants
<b>4. Findings: RQ1 Medical Care—</b>	RQ1	a) Statistical analysis	1) Hearing Index 2) Information-Seeking Scale

Chapter	Research question	Methods	Details
<b>Preferences for Information and Decision Making</b>			3) Decision Making Preference Scale
		b) Tool validation	1) Hearing Index: 6/26 with hearing loss 2) Two observable metrics of hearing loss: 11/26 with hearing loss Hearing Loss Criterion = 11/26 with hearing loss
		c) Thematic analysis using the Framework Method <sup>92,93</sup>	1) Information-Seeking Scale 2) Decision Making Preference Scale 3) Hearing Index 4) Hearing Loss Criterion Three health researchers 28 codes, 13 categories, seven themes
<b>5. Findings: RQ2 Everyday Care—Preferences for Information and Decision Making</b>	RQ2	Inductive context analysis	1) Hearing Loss Criterion 2) SDM Interview Tool 47 codes, five main categories
<b>6. Discussion and Conclusion</b>	Summary of findings; research contribution; study challenges and lessons; future research; translation; and conclusion	a) Thank-you cards	28 hand written thank-you cards: 27 for participants and one for care staff
		b) Planned feedback sessions	Two invited feedback sessions: one for care staff and one for participants

## **CHAPTER 2. NARRATIVE LITERATURE REVIEW**

### **2.1. Overview of Chapter 2**

Chapter 2 presents a narrative review of the literature, addressing the research question: how does hearing loss affect person-centred care in residential aged care? The chapter is presented as a draft paper (not yet submitted). Data from six included studies was analysed using general inductive analysis.<sup>101</sup> The quality of each study was assessed using the *Mixed Methods Appraisal Tool*.<sup>96,97</sup>

## The effects of hearing loss on person-centred care in residential aged care: a narrative review of the literature

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### Authors' contributions:

KL conceptualised the study, carried out Stages 1 and 2 of the review, conducted the quality assessment and data analysis, and produced the initial draft of the manuscript. VM assisted with the study design including the generation of search terms, and was involved in the Stage 2 review. VM, DG, and MM provided critical revision of the manuscript for important intellectual content.

### Conflict of interest:

The authors declare no conflicts of interest.

## ABSTRACT

**Background:** Person-centred care empowers consumers to be active participants in their care by establishing mutual partnerships with health care professionals. Shared decision making is a key feature of person-centred care which encourages health professional, consumers, and family members to engage in quality communication and supports informed decision making. Hearing loss can reduce the quality of communication, especially in residential aged care where background noise intensifies communication breakdown and social isolation.

**Aim:** To review and synthesise relevant literature in order to address the research question: how does hearing loss affect person-centred care in residential aged care?

**Methods:** A two-stage narrative review was conducted between March-May 2016. Relevant search terms were entered into academic databases producing 635 results after removal of duplicates. A general inductive analysis was employed to identify recurring factors across included studies. The quality of each study was assessed using the *Mixed Methods Appraisal Tool*.

**Results:** Five common factors were identified across six included studies: communication breakdown, the overlap between hearing loss and cognitive impairment, social isolation and reduced social participation, lack of staff training and access to hearing services, and strategies to improve communication.

**Discussion and Conclusions:** Hearing loss contributes to communication breakdown in residential aged care and restricts residents' engagement and participation in social activities. Further investigation is needed to understand the impact of hearing loss on residents' autonomy and shared decision making. Future research should consider the perspectives of family members in conjunction with residents' and health professionals' views.

**Keywords:** person-centred care, shared decision making, hearing loss, communication, residential aged care, narrative review

## **The effects of hearing loss on person-centred care in residential aged care: a narrative review of the literature**

### **BACKGROUND**

The importance of person-centred care has been recognised internationally by government bodies, policymakers, health professionals, and researchers.<sup>1</sup> Person-centred care encourages mutual collaboration between health care professionals, consumers, and third parties such as family members or carers. This collaboration empowers consumers to be active participants in their care, and supports their autonomy.<sup>2,3</sup> A principal component of person-centred care is *shared decision making*, which refers to a consultation process aimed at supporting informed decision making, while taking into consideration consumers' preferences and values.<sup>4-6</sup> Shared decision making occurs through the exchange of information and supported decision making.<sup>4-6</sup>

Person-centred care is relevant to the residential aged care sector for two key reasons. First, ageing populations place demands on aged care services such as residential facilities.<sup>7</sup> In order to meet the needs of older consumers and improve the quality of their care, a consumer-driven approach is necessary.<sup>8</sup> Second, residents' autonomy and participation in their care is limited by mobility,<sup>9</sup> cognitive,<sup>10</sup> and sensory<sup>11</sup> impairments.

Person-centred care and shared decision making require effective communication, where consumers are encouraged to express their opinions and be active participants in their care.<sup>5,12</sup> One of the major barriers to communication in residential care is age-related hearing loss, termed presbycusis.<sup>13,14</sup> Presbycusis is a progressive degenerative condition affecting auditory functioning, speech comprehension, hearing sensitivity, and sound localisation.<sup>15</sup> The global rate of age-related hearing loss is high, with 33% of the world population over 65 years experiencing debilitating hearing loss.<sup>16</sup> The social and physical environments of residential aged care facilities further reduce the quality of communication as competing background noise from televisions, radios, announcement systems, and surrounding conversations lead to communication breakdown and social withdrawal in residents with hearing loss.<sup>14,17</sup>

In order to improve the quality of care provided to residents of aged care facilities, we need to understand how hearing loss affects person-centred care. Existing reviews have either focused on person-centred care in residential aged care,<sup>18,19</sup> or have addressed the issue

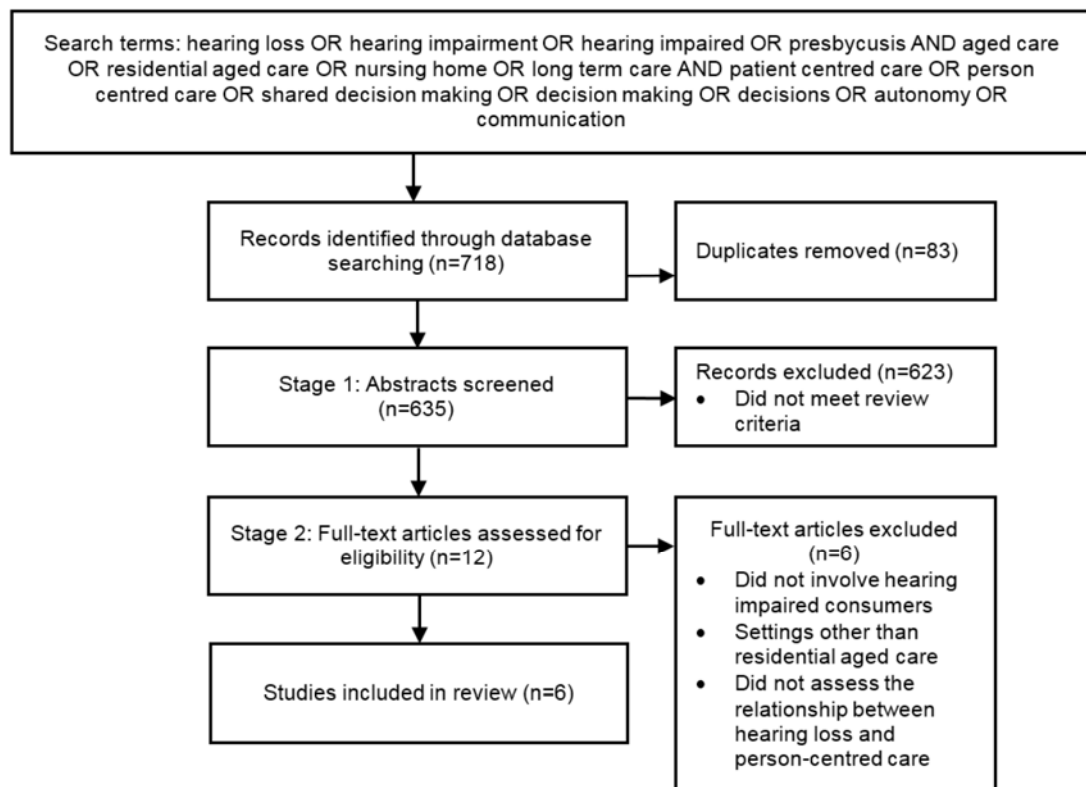


of hearing loss in older individuals.<sup>20,21</sup> This is, to the best of our knowledge, the first review attempting to link the two concepts together. The study aim is to review and synthesise the relevant literature, in order to address the following research question: how does hearing loss affect person-centred care in residential aged care?

## **METHODS**

A two-stage narrative review was conducted between March-May 2016, using a systematic approach. For the purpose of this review, person-centred care encompassed shared decision making, consumer-health professional interactions, communication, and autonomy. In Stage 1, article abstracts, titles, and topics were searched using bibliographic databases (Scopus, Web of Science, PubMed and Embase). The following search terms were entered into each database separately: “hearing loss” OR “hearing impaired” OR “hearing impairment” OR “presbycusis” AND “aged care” OR “residential aged care” OR “nursing home” OR “long term care” AND “shared decision making” OR “decision making” OR “decisions” OR “communication” OR “autonomy” OR “person centred care” OR “patient centred care.” The search was limited to peer-reviewed, English language articles, published between 2000-present. Terms were identified through an informal review of the literature and discussions with health care academics and aged care experts. The terms were selected to reflect the use of terminology across countries and care domains (e.g., person centred versus patient centred, and residential aged care versus nursing home versus long term care). The term “deaf” was not included in the search strategy as it primarily refers to individuals who were born hearing impaired, or acquired hearing impairment in early childhood.<sup>22</sup> Individuals who are Deaf (uppercase ‘D’) share a cultural identify as part of the Deaf Community and have different experiences of hearing impairment compared to individuals who acquired hearing loss later in life.<sup>22,23</sup>

The search identified 635 articles after removal of duplications (Figure 1). The abstracts of these publications were assessed against the following inclusion criteria: involves health consumers who acquired hearing loss in adult life; residential aged care setting; makes reference to person-centred care; peer-reviewed; English language; published between 2000-present; and involves empirical research. The Stage 1 review including the initial search was conducted by KL. The outcome of this process yielded 12 results.



**Figure 1: Flowchart diagram of search strategy and review process**

Stage 2 involved a full text review where the inclusion item “makes reference to person-centred care” was changed to “addresses the relationship between hearing loss and person-centred care.” Two reviewers, KL and VM, independently carried out the Stage 2 review with KL including 5/12 articles and VM including 9/12 articles, resulting in an agreement rate of 66.67%, and Cohen’s Kappa of .38.<sup>2</sup> After clarification of the research question and inclusion criteria, a consensus was reached between the two reviewers which lead to a final inclusion of six publications.<sup>14,24-28</sup> Of the six publications that were excluded, one publication involved settings other than residential aged care, four publications did not address the relationship between hearing loss and person-centred care, and one publication did not involve health consumers with hearing loss or address the relationship between hearing loss and person-centred care.

A statistical analysis was not appropriate for this review due to the limited number of included publications and their varied methodology. A narrative approach was therefore

<sup>2</sup> Although not essential due to the low number of included publications, Cohen’s Kappa was calculated for completeness.

taken to allow for descriptive presentation of data.<sup>29</sup> Data analysis was carried out by KL using a general inductive analysis.<sup>30</sup> Each publication was read until a general understanding of the context and patterns within and across the studies was gained. An open coding process consisted of applying descriptive labels to text in order to extract meaning.<sup>31</sup> Similar codes were grouped together to form categories, which represented recurring concepts. Categories were revised and refined into broader factors.

## RESULTS

### Study characteristics

For a summary of study characteristics see Table 1. Two publications employed a qualitative study design,<sup>14,28</sup> one study used a quantitative design,<sup>27</sup> and three studies involved mixed methodology.<sup>24-26</sup> Only one study recruited both residents and staff members as participants,<sup>14</sup> whereas two studies limited participants to care staff or aides,<sup>24,28</sup> and the remaining three studies involved only residents as participants.<sup>25-27</sup> The views of relatives were not assessed in any of the studies. In Aberdeen's (2014) study, family members were present during four of the 20 interviews, however, their views were not directly assessed.<sup>25</sup> Regarding person-centred care, consumers' autonomy was not assessed in any of the studies and only one study made reference to residents' decision making.<sup>26</sup> Looi et al (2004) reported that staff members "sometimes" encouraged patients to make decisions, however, the study did not assess the relationship between hearing loss and decision making.<sup>26</sup> All six publications evaluated the relationship between hearing loss and communication, and three of the studies reported on consumer-health professional interactions.<sup>14,24,28</sup>

**Table 1: Key properties of included publications after full text review<sup>3</sup>**

Publication	Country	Objectives	Participants	Methodology
Aberdeen (2014) <sup>25</sup>	Australia	1) To investigate the facilitation of communication through assistive listening devices	20 residents	Mixed methods: self-assessed questionnaire and interviews

<sup>3</sup> Tables in Chapter 2 are not included in the list of tables (page xii)

Publication	Country	Objectives	Participants	Methodology
Looi et al (2004) <sup>26</sup>	Australia	1) To investigate the prevalence of residents' hearing impairment, activity limitations, and participation restrictions in aged care residents. 2) To assess the communication environment in residential aged care. 3) To describe the implementation and outcomes of audiological rehabilitation interventions	15 residents	Mixed methods: self-assessed questionnaires and informal conversations
Pryce et al (2011) <sup>14</sup>	United Kingdom	To explore factors that affect the communication of aged care residents with hearing loss	18 residents and 7 care staff	Qualitative: observations, field notes and interviews
Pryce et al (2013) <sup>24</sup>	United Kingdom	1) To explore care staff views on hearing loss. 2) To identify the challenges associated with hearing loss in residential aged care. 3) To identify potential elements of interventions	10 care staff, including managers	Mixed methods: Observations, interviews, and surveys
Slaughter et al (2014) <sup>28</sup>	Canada	1) To explore health care aides' perception of hearing loss in aged care residents with dementia. 2) To assess how health care aides perceive the impact of residents' hearing loss on daily living and their participation in social activities	12 health care aides	Qualitative: semi-structured interviews, field notes, and reflective memos
Tsuruoka et al (2001) <sup>27</sup>	Japan	To explore the effects of hearing impairment on quality of life indicators for aged care residents	60 residents	Quantitative: self-assessed questionnaires

### Quality assessment

The quality of publications was assessed using the *Mixed Methods Appraisal Tool*<sup>32,33</sup> as it allowed for the evaluation of qualitative, quantitative, and mixed methods study designs. All

articles met the initial screening questions. Four of the six studies received quality scores between 75-100% (see Table 2). Quality scores of 25% were given to Aberdeen et al (2014)<sup>25</sup> and Looi et al (2004)<sup>26</sup> as the qualitative components of the research were poor or informal which subsequently affected the integration of qualitative and quantitative data. Both studies lacked an objective rationale for employing mixed methods, objective integration of qualitative and quantitative data, and a consideration for the limitations associated with this integration. Furthermore, neither study addressed how findings related to researchers' influence, or provided a detailed description of a qualitative analysis.

**Table 2: Quality assessment using the Mixed Methods Appraisal Tool**

<b>Publication</b>	<b>Mixed Methods Appraisal Tool Score<sup>32,33</sup> (%)</b>
Aberdeen (2014) <sup>25</sup>	25
Looi et al (2004) <sup>26</sup>	25
Pryce et al (2011) <sup>14</sup>	100
Pryce et al (2013) <sup>24</sup>	75
Slaughter et al (2014) <sup>28</sup>	75
Tsuruoka et al (2001) <sup>27</sup>	100

### **Data synthesis**

A general inductive analysis<sup>30</sup> revealed five factors informing the impact of hearing loss on person-centred care in residential aged care (Table 3). These were: communication breakdown, the overlap between hearing loss and cognitive impairment, social isolation and reduced social participation, lack of staff training and access to hearing services, and strategies to improve communication.

**Table 3: Factors informing the impact of hearing loss on person-centred care in residential aged care<sup>4</sup>**

<b>Factor</b>	<b>Description</b>	<b>References</b>
Communication breakdown	Difficulties in communication with other residents and care staff. Hearing loss and background noise were contributing factors.	14,24-28
The overlap between hearing loss and cognitive impairment	The combination of hearing loss and cognitive impairment resulted in increased communication difficulties.	14,26-28
Social isolation and reduced social participation	Residents withdrew from social activities due to hearing loss and problems communicating in group situations.	14,24-28
Lack of staff training and access to hearing services	Residential care facilities lacked access to audiological services and resources, as well as formal staff training relating to the communication needs of residents with hearing loss.	14,24-26
Strategies to improve communication	Approaches to improve communication were directed at staff behaviours, environmental modifications, and the provision audiological services and resources.	14,24-26,28

#### *Communication breakdown*

Communication breakdown as a result of hearing loss was reported in all six studies, with environmental factors such as background noise identified as exacerbating communication problems.<sup>14,24-27</sup> Residential care facilities were found to provide limited opportunities for communication,<sup>26</sup> where background noise from music, televisions, radios, announcement systems, and surrounding conversations reduced residents' abilities to hear others and engage in conversations.<sup>14,24,25,27</sup> Pryce et al (2011) and Pryce et al (2013) both highlighted the fact that residents were not provided with choice regarding modifiable background noise from sources such as televisions.<sup>14,24</sup> Care staff often turned on music or televisions as part of daily routines or to fill in time.<sup>24</sup> Not only were residents not asked if they wanted televisions turned on, but they did not notify care staff of their preferences.<sup>14,24</sup> Some residents found communication with other residents or care staff frustrating leading them to give up on attempts to compete with environmental noise.<sup>14</sup> Other residents were accepting

<sup>4</sup> Figures in Chapter 2 are not included in the list of tables (page xii)

of the limitations hearing loss placed on them, choosing to engage in more introverted-directed activities such as reading.<sup>25</sup>

### *The overlap between hearing loss and cognitive impairment*

In addition to environmental factors, the overlap between hearing loss and cognitive impairment also receives considerable attention in the literature. Cognitive impairment increased the likelihood of communication difficulties for residents with hearing loss as the effects of mishearing information were coupled with not being able to comprehend what was being said.<sup>14,28</sup> The ability of staff members to distinguish between residents' cognitive impairment and hearing loss enabled care staff to employ communication strategies targeted at the source of confusion.<sup>28</sup> This proved difficult for care staff who did not know the individual communication needs of residents.<sup>28</sup> Tsuruoka et al (2001) did not establish a relationship between dementia and hearing loss, yet they acknowledged a trend for rates of cognitive impairment to increase as hearing levels increased.<sup>27</sup> It is also important to note that cognitive impairment can adversely impact research, as cognitive impairment was recognised to potentially reduce the accuracy of participant responses, thus effecting implications of research findings.<sup>26</sup>

### *Social isolation and reduced social participation*

Hearing loss in residential aged care often resulted in social isolation and placed limits on residents' abilities to participate in social activities such as mealtime conversations or games.<sup>14,25,26,28</sup> Residents with hearing loss were often left out of conversations and experienced difficulties communicating in group situations.<sup>14,27,28</sup> As a result, residents experienced social isolation and withdrew to their rooms, or alienated themselves from social situations.<sup>14,25,28</sup> Staff members frequently found themselves responsible for providing social interactions and maintaining conversations with residents.<sup>24</sup> This communication was often brief, task-oriented, and based on residents' needs, as opposed to engagement in in-depth conversations.<sup>14,24,26</sup>

### *Lack of staff training and access to hearing services*

Communication between care staff and residents was facilitated by care staff knowledge of audiological services and resources.<sup>24</sup> Residential aged care facilities were reported to lack onsite services and resources, such as assisted listening devices, personal amplifiers, volume control telephones, or closed captions options on televisions,<sup>14,25,26</sup> which are designed to assist hearing function and communication. Access to hearing services required time and effort by care staff to organise appointments and transportation to offsite audiological services.<sup>14,24</sup>

Despite a desire to improve communication with hearing impaired residents,<sup>24,26</sup> little information or formal training was provided or offered to care staff.<sup>14,24,25</sup> Pryce et al (2013) reported that care staff did not know how to address the communication issues of residents, or how to manage hearing aid maintenance, e.g., fitting and cleaning devices.<sup>24</sup> Although some staff members recognised the limitations of hearing aids, others viewed hearing aids as a simple fix, indicating a need for more education surrounding hearing aids.<sup>24</sup> One study provided an intervention to care staff in the form of a training program.<sup>26</sup> This training led to individualised resident information sheets, informing staff members of hearing aid management, e.g., fitting devices, changing batteries, or turning hearing aids off and on.<sup>26</sup>

### *Strategies to improve communication*

Strategies to improve communication were directed at staff behaviours, environmental modifications, and audiological services and resources. At a behavioural level, care staff employed strategies to enhance communication including repetition, slowed speech, face-to-face conversations, clear pronunciation for residents who lip-read, writing information down, and using body language.<sup>24,28</sup> These strategies were learnt from experience and not through formal training.<sup>24</sup> Slaughter et al (2014) emphasised the need to adapt strategies dependent on the situation, e.g., talking in close proximity may assist communication, however, this could also put the safety of care staff at risk when talking to residents who have a tendency to lash out physically.<sup>28</sup> Forming close relationships with residents was reported by care staff to assist communication.<sup>24,28</sup> Familiarity with residents and knowledge of individual's communication needs enabled care staff to distinguish between confusion resulting from hearing loss and confusion resulting from cognitive impairment.<sup>24,28</sup>



The modification of contextual and environmental factors was also discussed in the literature as a means of improving communication.<sup>14,24,26</sup> A reduction of background noise could be achieved by eliminating unnecessary noise, e.g., turning off televisions or closing kitchen doors.<sup>14,24</sup> After an environmental assessment, Looi et al (2004) suggested that absorbent materials could be better incorporated into residential facilities.<sup>26</sup> Other strategies suggested to improve communication for residents with hearing loss included improved access to audiological services and resources such as assisted listening devices.<sup>24,26</sup> Aberdeen (2014) assessed residents' evaluation of assisted listening devices as a tool for communication facilitation.<sup>25</sup> The majority (90%) of participants in this study gave assisted listening devices high ratings in terms of improving their understanding of speech and enhancing the quality of sound.<sup>25</sup> Assisted listening devices were reported to assist conversation and communication, and provide greater clarity compared to standard hearing aids.<sup>25</sup>

## **DISCUSSION AND CONCLUSION**

Hearing loss and communication breakdown in residential aged care restricts residents' engagement and participation in the life of the facility. Four of the five factors identified, with the exception of strategies to improve communication, negatively reinforce each other, compromising the care of residents. The empirical research base from which this knowledge has been derived is very small: the insights were derived from only six studies. Not one study in this review directly assessed consumers' autonomy or shared decision making. Further research is needed to assess the effects of hearing loss across various domains of person-centred care, not just communication or interactions between residents and care staff. The review also failed to identify any studies directing assessing the opinions of family members despite the significant role they play in residents' care and the decision making process.<sup>34,35</sup>

Widening the scope of this review to included pre-2000 literature, non-English studies, and descriptive or theoretical publications may have provided additional knowledge, however, the search restrictions were implemented in order to identify current evidence-based information. The review focussed on residential aged care settings due to the global issue of ageing populations,<sup>7</sup> and the limitations that residential facilities place on consumers' autonomy.<sup>36</sup> Future research could explore how hearing loss affects person-centred care for older consumers across other settings, e.g., hospitals are environments also

subject to high levels of background noise.<sup>37</sup> Comparisons across different health settings would better inform the care provided to older consumers with hearing loss. An understanding of cognitive impairment and hearing loss, modification of environmental factors such as the reduction of background noise, formal staff training, and improved access to hearing services could facilitate communication opportunities and thus person-centred care for aged care residents with hearing loss.

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## CHAPTER 3. METHODS

### 3.1. Overview of Chapter 3

Chapter 3 provides an overview of the methods used in the study. There are six sections that follow: study setting and participants; recruitment; procedure; data gathering instruments; data analysis; and, summary and limitations.

#### 3.1.1. Highlights

- The study employed an exploratory mixed methods design, comprising interviews with participants recruited from a residential aged care facility in Sydney, Australia.
- Interviews consisted of a demographic questionnaire, three survey questionnaires, and semi-structured interview questions.
- Self-perceived hearing loss was assessed using the *Hearing Index*,<sup>98</sup> and observer-rated hearing loss was assessed through observable metrics.
- *Hearing Index* data and observer-rater data were combined to form the *Hearing Loss Criterion*.
- Participants' preferences for receiving medical information were assessed using the *Information-Seeking Preference Scale*.<sup>99</sup>
- Participants' preferences for decision making in regards to medical care were assessed using the *Decision Making Preference Scale*.<sup>100</sup>
- Participants' preferences for receiving information and decisions making in terms of everyday care were assessed using the *Preferences for Involvement in Shared Decision Making (SDM) Interview Tool*.
- Statistical analysis, and thematic analysis using the Framework Method,<sup>92,93</sup> were conducted to address RQ1.
- Inductive content analysis addressed RQ2.

### 3.2. Study setting and participants

The study was conducted at a not-for profit health and aged care provider located in Sydney, Australia. The facility comprised residential care, independent living units (self-care), respite care, a dementia unit, and a unit for residents with Huntington's disease. The residential care and self-care components of the facility offered similar access to medical and everyday care and therefore comprised the target population.

### 3.3. Recruitment

Senior care staff identified residents who met the inclusion criteria (Box 3.1). An on-site information session for residents was held at the care facility. Residents attending the information session, and who met the inclusion criteria, received an information sheet about the research and an invitation to participate. Residents unable to make the formal information session were invited through individual follow-up visits. Participants were recruited from both residential care (102) and self-care (27), giving a potential study population of 129.

#### Box 3.1. Inclusion criteria

##### Inclusion criteria

- Willingness and ability to provide informed consent
- Willingness to participate in and comply with the study
- Physically well enough to participate in the research, (i.e., the study places no additional physical burden on a participant)
- Ability to participate in an English language interview
- Age:  $\geq 65$  years\*

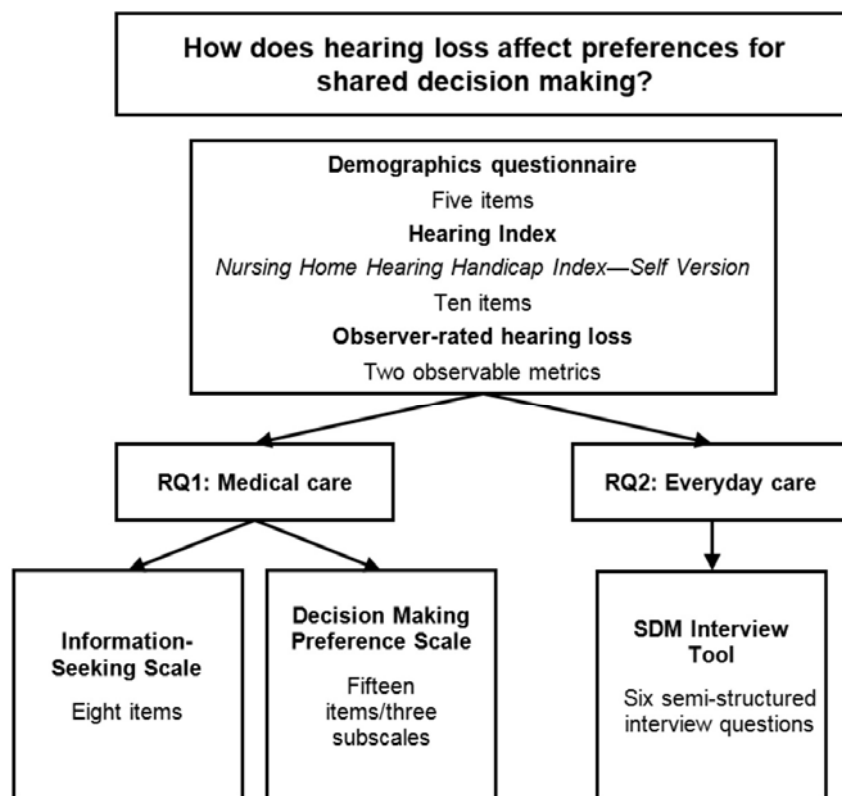
\* *The Australian government's definition of "older person", that is an individual 65 years or older, has been adopted for this study.*<sup>102,103</sup>

### 3.4. Procedure

Informed consent was obtained from each participant prior to commencement. Verbal process consent was also gained from participants, who were asked at various stages during the study if they were happy to continue. Process consent acknowledges that participants may vary in their competencies across domains and therefore the consent process needs to

be flexible and continuous.<sup>104</sup> This allows researchers to evaluate participants' consent throughout the research process as opposed to at a single time point.<sup>105</sup>

The study employed an exploratory mixed methods approach, and involved individual interviews consisting of a demographic questionnaire, three survey questionnaires, and semi-structured interview questions. Participants were administered a short demographic questionnaire, followed by the *Preferences for Involvement in Shared Decision Making Interview Tool (SDM Interview Tool)*, the *Nursing Home Hearing Handicap Index–Self Version (The Hearing Index)*,<sup>98</sup> and two preference scales: the *Information-Seeking Scale*,<sup>99</sup> and a modified version on the *Decision Making Preference Scale*<sup>100</sup> (Figure 3.1).



**Figure 3.1: Research design**

During the interviews, observer-rated hearing loss was also recorded using readily observable metrics (participant wore hearing aids or made reference to them, or participant requested that questionnaire item(s) be repeated). All measurement instruments were administered verbally in an interview format to accommodate participants with vision impairment and participants who experienced difficulties holding a pen. On-site interviews



also allowed for clarification of items as needed. When possible, interviews were conducted in private and quiet environments such as participants' rooms. Four interviews were conducted in a communal activity room due to individual needs, such as mobility limitations.

Each interview was taped via an audio recording device to ensure that participants' views were recorded and analysed accurately. In the event that a participant experienced confusion in response to interview questions, items were repeated or rephrased as necessary. Additional information provided to participants remained consistent across interviews, e.g., when referring to laboratory tests, "blood test" was used as an example, and when discussing everyday medical care, "colds" or "headaches" were given as examples.

### **3.5. Data gathering instruments**

#### *3.5.1. Demographic questionnaire*

A five-item demographic questionnaire (Appendix A) was administered to participants assessing age, gender, education, and, marital and health status.

#### *3.5.2. Measures of hearing loss*

Self-perceived hearing loss was assessed using the *Nursing Home Hearing Handicap Index–Self Version (Hearing Index)* (Appendix B).<sup>98</sup> The *Hearing Index* evaluates the impact of hearing ability on participants' daily functioning. This tool was selected as it is specifically designed for use in residential aged care. The *Hearing Index* has been previously validated when compared to audiological measures of hearing.<sup>57,106,107</sup> A scan of the literature suggests that this study represents the first application of the *Hearing Index* in the Australian context.

The index comprised 10 items, such as "How often are you embarrassed because you don't hear well?". The same rating scale was used as Strummer et al (1996), and Looi et al (2004), where each item was rated using a three-point Likert scale (1 = "no/almost never", 2 = "sometimes", 3 = "yes/very often"),<sup>57,106</sup> where higher scores indicated greater self-perceived hearing loss. In line with Schow and Nerbonne's (1977) criterion, participants who scored 40% or higher (a raw score of 18 or greater) were classified as having self-perceived hearing loss.<sup>98</sup> Participants were provided the option to answer items using the rating scale or to provide a verbal level of agreement. If participants chose the latter option, their answers were interpreted as numerical values on the rating scale, then clarified if

needed. With the exception of clarification, participants were not probed to expand on their answers during the interview, in order to maintain validity of the tool. Any additional responses to questionnaire items other than numerical ratings (e.g., explanations of answers, conversations, or anecdotes) were audio recorded.

In order to validate the *Hearing Index* in the study setting, participants' scores on the *Hearing Index* were compared with observer-rated hearing loss using two readily observable metrics: a) participant wore hearing aids during the interview or made reference to their hearing aids, and b) participant requested that questionnaire item(s) be repeated. Participants met the second condition when the request for repetition of items could not be attributed to background noise or the researcher's delivery of questions. Participants were deemed to have hearing loss if they scored 18 or higher on the *Hearing Index* (self-perceived hearing loss), or met the criterion for at least one of the observable metrics (observer-rated hearing loss). The grouping of self-perceived hearing loss and observer-rated hearing loss was labelled the *Hearing Loss Criterion*.

### 3.5.3. Medical care: Autonomy Preference Index

A review of the available tools in the literature indicated the *Autonomy Preference Index* as the most appropriate measure of shared medical decision making.<sup>99</sup> The *Autonomy Preference Index* has been applied in different countries, including Australia<sup>108,109</sup> and Germany,<sup>22</sup> and has been adapted for study in a diverse range of clinical contexts (i.e., mental health<sup>110</sup>), to investigate different clinical issues (i.e., pelvic floor disorder<sup>111</sup> and asthma<sup>108</sup>), and applied to specific subpopulations (i.e., older persons<sup>112</sup>). The *Autonomy Preference Index* evaluates shared decision making as two distinct constructs, measured by the *Information-Seeking Scale* and the *Decision Making Preference Scale*. Both scales have good internal consistency reliability, Cronbach's  $\alpha = .82$ .<sup>99</sup> Recent studies have found similar psychometric properties of the original and modified versions of the instrument.<sup>111,113</sup>

### 3.5.4. Medical care: Information-Seeking Scale

The *Information-Seeking Scale* (Appendix C) assesses consumers' preferences for receiving medical information. It has good test-retest reliability,  $r = .83$ . The scale comprised eight-items such as, "Information about your illness is as important to you as treatment", rated on

a five-point Likert scale (1 = “strongly disagree” to 5 = “strongly agree”), where higher scores indicated stronger preferences for receiving medical information. Participants were given the choice to answer items using numerical values, or to verbally state their level of agreement. If participants opted to give verbal explanations as opposed to numerical ratings, their responses were interpreted and assigned a numerical value on the rating scale, then clarified with participants as needed. Unless clarifying responses, participants were not probed for further explanations during the interviews to maintain validity of the tool. Verbal responses were captured using an audio recording device.

### 3.5.5. Medical care: Decision Making Preference Scale

The *Decision Making Preference Scale* (Appendix D) assesses consumers’ preferences for control over decision making. A modified version of the scale was employed in this study as, unlike the original version, it allows for a shared decision making option.<sup>100</sup> The modified scale has been administered to participants in Australia, the United Kingdom, and the United States of America.<sup>100</sup> The *Decision Making Preference Scale* consists of three independent subscales: *Doctor Preference*, *Patient Preference*, and *Joint Preference*.<sup>100</sup> The scale has good test-retest reliability,  $r = .87$  for *Doctor Preference*,  $r = .84$  for *Patient Preference*, and  $r = .91$  for *Joint Preference*.<sup>100</sup>

The terminology of the scale was slightly modified in this study for appropriate use in a residential aged care setting. Any item containing the term “doctor” was replaced with the terms “doctor/nurse/carer” as nurses and carers also provide considerable assistance to residents. The three subscales were therefore relabelled, “*Health Professional Preference*”, “*Resident Preference*”, and “*Shared Decision Making Preference*”, respectively. These subscales produced three mutually exclusive scores for each participant.

Each of the three subscale contained five items such as, “If you and your doctor disagree, you could talk it over and decide together” (*Shared Decision Making Preference*), rated on a five-point Likert scale (1 = “strongly disagree” to 5 = “strongly agree”), where higher scores indicated stronger preferences for either health professional control or resident control over decisions, or shared decision making. Certain items, which refer to frequency of check-ups, were omitted as they are less relevant to residential care. The *Decision Making Preference Scale* also contains nine additional items relating to vignettes, which assess how patients’ preferences are affected by the severity of disease. As this was not an objective of

the research, and a general measure of health was included in the demographic questionnaire, the vignette section of the scale was also omitted.

Similar to the administration of the *Information-Seeking Scale*, participants were given the choice to answer items using the numerical rating scale, or to provide their verbal level of agreement. The items on the three subscale of the *Decision Making Preference Scale* were worded similarly to each other. If participants were unable to understand the concept of the *Decision Making Preference Scale*, a simplified format of the tool was verbally administered so that participants were given a choice between health professional control, resident control, or shared decision making for each scenario. If participants answered questionnaire items using verbal levels of agreements, their responses were interpreted as a numerical value on rating scales. For participants answering the simplified version of the tool, a numerical value was assigned to the rating scales of each of the three subscales. Participants verbal responses were audio recorded, and numerical ratings were clarified with participants as necessary.

#### 3.5.6. *Everyday care: SDM Interview Tool*

The *Information-Seeking Scale* and the *Decision Making Preference Scale* both evaluate shared decision making in a medical context and do not reflect everyday care matters associated with residential care. Current survey tools that assess everyday care in a residential setting measure activity participation,<sup>53,54</sup> quality of life,<sup>18</sup> and attitudes towards residential facilities as a home.<sup>55</sup> A scan of the literature found no relevant questionnaires that evaluate residents' preferences for shared decision making in terms of everyday care. The *Preferences for Involvement in Shared Decision Making Interview Tool (SDM Interview Tool)* (Appendix E) was developed as a semi-structured interview tool in response to this limitation. Two issues were addressed by the interview tool: residents' preferences for receiving information about everyday care matters and preferences for involvement in everyday care decision making (Table 3.1). The tool was developed through an iterative process of literature review and discussion with research and aged care experts. Semi-structured interview items were verbally administered with examples and prompts provided to participants as necessary. Interviews were recorded using an audio recording device and accompanying field notes were generated during each interview.

**Table 3.1: Preferences for Involvement in SDM Interview Tool: target issues and guiding questions**

<b>Target issue</b>	<b>Guiding questions</b>
Preference for everyday care <b>information</b>	Do you receive as much information as you would like about your everyday care?  For example, what activities are on during the day, or what is served at mealtimes.
	When would you like to receive information about your everyday care?  For example, at the start of each day or when each activity is happening.
	How would you like to receive information about your everyday care?  For example, through conversations with staff, or from noticeboards.
Preference for everyday care <b>decision making</b>	Do you think you have enough control in making personal decisions?  For example, what clothing you wear, or what or when you eat.
	Do you think you have enough control in making social decisions?  For example, what activities you participate in, or who you sit next to at mealtimes.
	Do you think you have enough control in making decisions about your environment?  For example, the layout of your room, or communal furnishings such as plants.

### **3.6. Data analysis**

#### *3.6.1. Medical care*

RQ1, how does hearing loss affect aged care residents' preferences for receiving information, and decision making, in terms of their *medical care*? was addressed using mixed methods. Quantitative data consisted of participants' ratings on the *Hearing Index*, the *Information-Seeking Scale*, and the *Decision Making Preference Scale*. Qualitative data consisted of additional information provided by participants in response to questionnaire items, such as stories, anecdotes, and explanations of opinions. An integration of quantitative and qualitative data permitted a holistic understanding of the phenomenon of hearing loss in

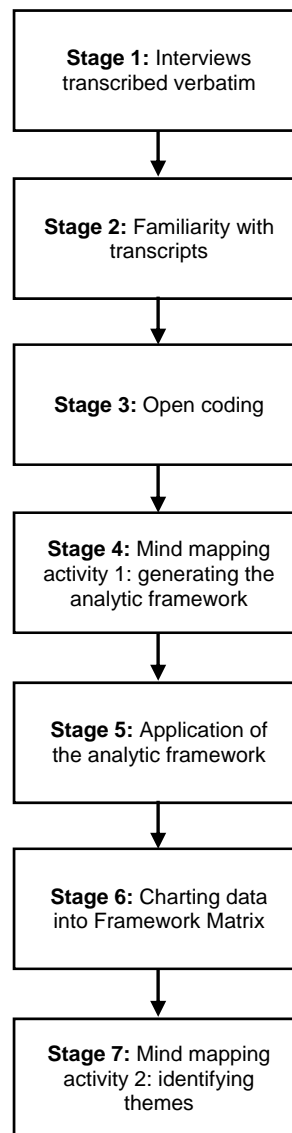
aged care.<sup>114</sup> Quantitative data were analysed using statistical methods to test for correlation between variables. Complimentary thematic analysis<sup>92,93</sup> of qualitative data provided a rich understanding of participants' experiences, opinions, and preferences. Data integration occurred via a process known as *merging*,<sup>114</sup> where quantitative and qualitative data were analysed separately and then brought together to present a comprehensive account of the research topic.

The statistical program SAS 9.4 ([http://www.sas.com/en\\_us/software/sas9.html](http://www.sas.com/en_us/software/sas9.html)) was used to produce descriptive statistics, and Spearman's Rank correlation compared *Hearing Index* scores and four preference variables: preference for receiving medical information (*Information-Seeking Scale*), preference for health professional control over medical decisions (*Health Professional Preference*), preference for resident control over medical decisions (*Resident Preference*), and preference for shared medical decision making (*Shared Decision Making Preference*). Qualitative data were thematically analysed using the Framework Method.<sup>92,93</sup> This method allows for the identification of reoccurring *themes* (Table 3.2) in individual participants' data while retaining original context, in addition to enabling comparisons to be made across the dataset as a whole.<sup>93</sup> The Framework Method has previously been used in residential aged care settings<sup>115,116</sup> and in research involving older consumers with hearing loss.<sup>117</sup> The method has also been applied in international contexts: in Europe,<sup>118,119</sup> the Americas,<sup>120,121</sup> Africa,<sup>122,123</sup> the Middle East,<sup>124,125</sup> Asia,<sup>126,127</sup> and Australasia,<sup>128,129</sup> as well as in cross-country research.<sup>130</sup>

**Table 3.2: Definition of codes, categories, and themes**

Unit of analysis	Definition
Code	A code is a descriptive label assigned to sections of raw data, <sup>93</sup> such as interview transcripts.
Category	Categories emerge from grouping similar codes. They provide a descriptive account of recurring concepts or ideas across data. <sup>93</sup>
Main category	Main Categories are a higher level grouping formed through an integration of similar categories. <sup>94</sup>
Theme	Themes emerge from an integration of categories. They explain data by commenting on central or recurring issues in the data. <sup>93</sup> Themes require abstract interpretation. <sup>131</sup>

Thematic analysis was conducted over seven stages (Figure 3.2). 1) Interviews were transcribed verbatim. 2) Familiarity with the data occurred through re-reads of transcripts and by listening back to the audio recordings. 3) Inductive open coding involved noting *codes* (Table 3.2) in the margins of transcripts in order to identify relevant concepts. Codes emerged from the data and were not pre-defined. 4) Similar codes were grouped together into *categories* (Table 3.2) through a mind mapping activity<sup>132</sup> in order to create a working analytic framework (Appendix F). 5) Two additional researchers coded the same initial three transcripts using the analytic framework. Any coding discrepancies were discussed in light of the research question and the framework was amended accordingly. All 26 transcripts were then manually indexed using the updated framework. 6) The resulting data were charted into a Framework Matrix. Data from the *Hearing Loss Criterion* was also charted into the Matrix to allow for comparison across categories between participants with and without hearing loss. 7) Categories were further reduced using a subsequent mind mapping activity,<sup>132</sup> where broader, overall themes were identified, interpreted, and labelled.



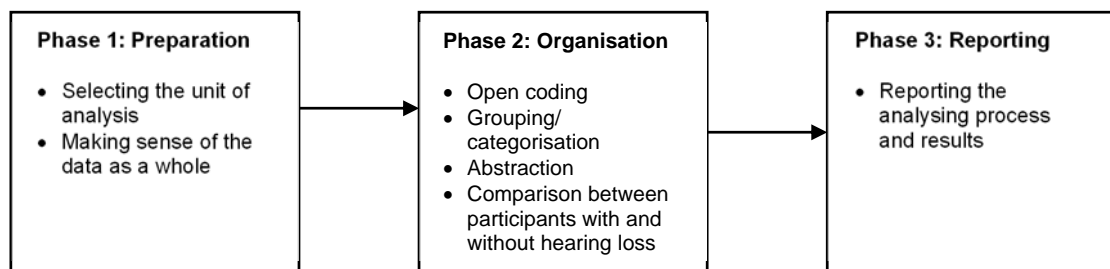
**Figure 3.2: Seven stags of thematic analysis using the Framework Method**

### *3.6.2. Everyday care*

RQ2, how does hearing loss affect aged care residents' preferences for receiving information, and decision making, in terms of their *everyday care*? was addressed using inductive content analysis.<sup>94,95</sup> Inductive content analysis is a descriptive qualitative approach which relies less on abstract interpretation compared to other thematic methods.<sup>95</sup> The analysis comprised three phases<sup>94</sup> (Figure 3.3): 1) The Preparation Phase involved listening back to the audio recorded interviews and re-reading transcripts with the aim of making sense of the data as a whole. 2) The Organisation Phase involved open coding, where



codes emerged from the data and were written in the margin of the transcripts. Similar codes were then grouped together under broader *categories*. This was followed by an abstraction process, where subcategories were reduced into *main categories* (Table 3.2). Data from the *Hearing Loss Criterion* was used to compare responses between participants with and without hearing loss. 3) The Reporting Phase involved reporting the analysing process and results.



**Figure 3.3: Inductive content analysis**

*Adapted from: Elo and Kyngäs, 2008.<sup>94</sup>*

### 3.7. Summary and limitations

Individual face-to-face interviews were conducted with participants residing in a residential aged care facility in Sydney, Australia. Each interview was verbally administered and audio-recorded. Hearing loss was assessed using the *Hearing Index* (self-perceived hearing loss) and observable metrics (observer-rated hearing loss) (Table 3.3). These two measures of hearing loss were later combined to form the *Hearing Loss Criterion*. Preferences for receiving medical information were assessed using the *Information-Seeking Scale*. Preferences for decision making were assessed using the *Decision Making Preference Scale*. The original version of the *Decision Making Preference Scale*<sup>99</sup> assesses preferences for doctors' control, and residents' control, over decision making. The tool does not consider preferences for shared decision making. To overcome this limitation, a modified version of the tool was employed in the study,<sup>100</sup> which assessed participants' preferences for decision using three mutually exclusive subscales: *Health Professional Preference*, *Resident Preference*, and *Shared Decision Making Preference*. Preferences for receiving information, and making decisions, in terms of everyday care, were assessed using the *SDM Interview Tool*.

**Table 3.3: Summary of data gathering instruments and constructs**

<b>Data gathering instrument</b>	<b>Construct</b>
Hearing Index	Self-perceived hearing loss
Observable metrics	Observer-rated hearing loss
Hearing Loss Criterion	Self-perceived hearing loss and observer-rated hearing loss
Information-Seeking Scale	Preferences for receiving medical information
Health Professional Preference subscale (Decision Making Preference Scale)	Preferences for health professionals' control over medical decision making
Resident Preference subscale (Decision Making Preference Scale)	Preferences for autonomy over medical decision making
Shared Decision Making Preference subscale (Decision Making Preference Scale)	Preferences for mutual discussion and decision making in terms of medical care
SDM Interview Tool	Preferences for receiving information and making decisions relating to everyday care

This study employed an exploratory mixed methods approach. RQ1, how does hearing loss affect aged care residents' preferences for receiving information, and decision making, in terms of their *medical care*? was addressed through statistical analysis, and thematic analysis using the Framework Method. RQ2, how does hearing loss affect aged care residents' preferences for receiving information, and decision making, in terms of their *everyday care*? was addressed via inductive content analysis. The results of the statistical analysis and thematic analysis using the Framework Method are presented in Chapter 4. The results of the inductive analysis are presented in Chapter 5.

## CHAPTER 4. FINDINGS: RQ1 MEDICAL CARE—PREFERENCES FOR INFORMATION AND DECISION MAKING

### 4.1. Overview of Chapter 4

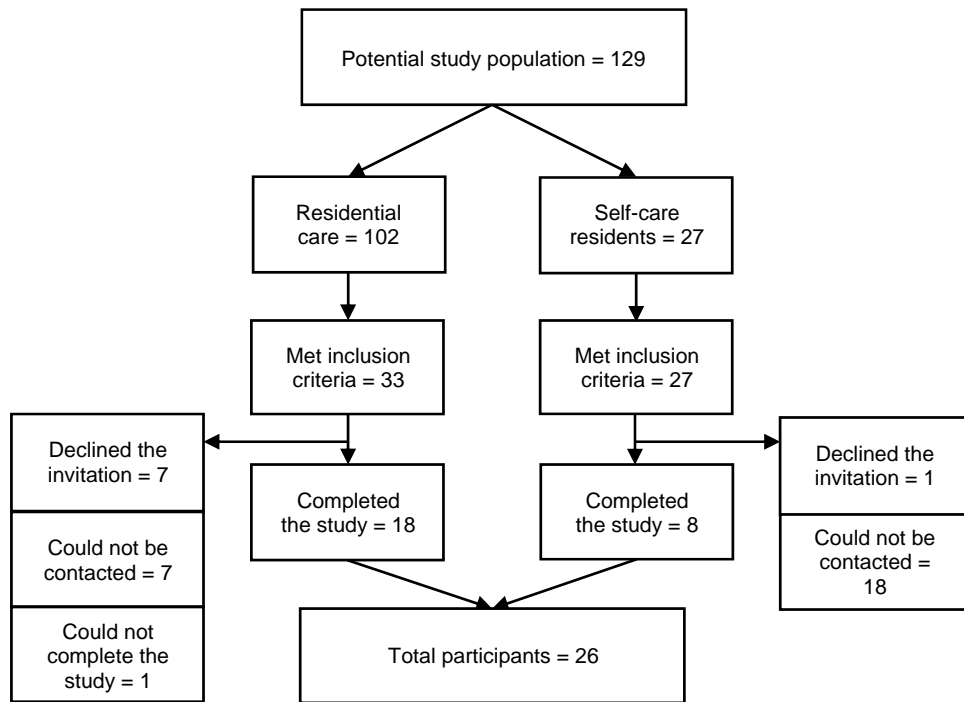
Chapter 4 presents findings from statistical and thematic analyses addressing RQ1: how does hearing loss affect aged care residents' preferences for receiving information, and decision making, in terms of their *medical care*? The statistical analysis comprised descriptive statistics and Spearman's Rank Correlation. Thematic analysis was conducted using the Framework Method.<sup>92,93</sup> The chapter also outlines the results of the *Hearing Index*<sup>98</sup> tool validation.

#### 4.1.1. Highlights

- At 5% significance level, there was no evidence of significant correlation between the *Hearing Index* and the preference variables: the *Information-Seeking Scale*,<sup>99</sup> and the *Health Professional Preference*, *Resident Preference*, and *Shared Decision Making Preference* subscales of the *Decision Making Preference Scale*.<sup>100</sup>
- Twenty-three percent of participants had self-perceived hearing loss based on *Hearing Index* scores, whereas 42% of participants met the criterion for hearing loss using the *Hearing Loss Criterion*.
- Thematic analysis identified seven recurring themes: 1) Preferences for receiving medical information, 2) Preferences for shared decision making, 3) Dependence on doctors as medical experts, 4) Resident autonomy, 5) Response to hearing loss, 6) Managing hearing loss, and 7) The impact of background noise.
- Both the statistical analysis and thematic analysis revealed that, overall, participants had strong preferences for receiving medical information and for mutual discussion and decision making with health professionals.
- Only participants with hearing loss discussed the importance placed on family member involvement in the decision making process.

## 4.2. Participants

From a potential study population of 129 (Figure 4.1), 33 participants from residential care met the inclusion criteria. Seven residents were unable to be contacted, seven residents declined the invitation, and 19 were recruited for the study. Reasons for non-participation included illness, unavailability, and a dis-interest in the study. One participant (Participant six) was excluded from the research due to an inability to complete the study requirements. All 27 residents in self-care met the inclusion criteria. Eighteen self-care residents were unable to be contacted, one resident was unavailable during the data collection period, and eight residents completed the study. The total study sample consisted of 26 participants.



**Figure 4.1: Recruitment of participants**

The study comprised interviews with 26 participants aged between 69-100 years ( $M = 83.8$ ,  $Mdn = 82.5$ ,  $SD = 8.36$ ). Participants' demographic information is presented in Table 4.1. Interview length ranged from 8.7 minutes to 44.2 minutes. The average interview length was 19.3 minutes ( $Mdn = 16.8$ ,  $SD = 10.41$ ).

**Table 4.1: Summary of participant demographic characteristics<sup>5</sup>**

Characteristic	Item	Frequency	Percentage (%)
Care type	Residential	18	69
	Self-care	8	31
Sex	Female	21	81
	Male	5	19
Age group	65-69	1	4
	70-79	8	31
	80-89	8	31
	90-99	8	31
	≥100	1	4
Highest level of study attained	<High school	18	69
	High school	2	8
	Some university	2	8
	Undergraduate	2	8
	Postgraduate	2	8
Marital status	Never married	9	35
	Married or common law	0	0
	Separated or divorced	2	8
	Widowed	15	58
Self-rated health	Poor	2	8
	Fair	7	27
	Good	11	42
	Very good	4	15
	Excellent	2	8

### 4.3. Overview of data analysis

RQ1 was addressed by comparing data from the *Hearing Index* and data from the preference variables: the *Information-Seeking Scale*, and the *Health Professional Preference*, *Resident Preference*, and *Shared Decision Making Preference* subscales of the *Decision Making*

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<sup>5</sup> Percentages may not add to 100% due to rounding.

*Preference Scale.* All 26 participants chose to respond to questionnaire items using verbal levels of agreements in the form of expressions of opinions and anecdotes. Participants responses were interpreted and assigned numerical values on the rating scales. Both statistical analysis and thematic analysis were employed to address RQ1. Quantitative ratings were analysed using SAS 9.4 and qualitative data were thematically analysed using the Framework Method.

#### 4.4. Statistical analysis

##### 4.4.1. Descriptive statistics

Participants answered all questions. There was no missing data. Six participants (23% of the sample) received a *Hearing Index* score of 18 or higher, meeting the criterion for self-perceived hearing loss.<sup>57,98</sup> Descriptive statistics for the *Hearing Index* and the preference variables are presented in Table 4.2.

**Table 4.2: Descriptive statistics for the Hearing Index and the preference variables**

<b>Variable</b>	<b>Mean</b>	<b>Median</b>	<b>Standard deviation</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Possible score range</b>
<b>Hearing Index</b>	14.7	12.5	5.42	10	26	10-30
<b>Information-Seeking Scale</b>	35.9	37.0	4.69	21	40	8-40
<b>Health Professional Preference subscale</b>	16.0	17.5	6.34	5	25	5-25
<b>Resident Preference subscale</b>	12.9	12.0	3.69	7	22	5-25
<b>Shared Decision Making Preference subscale</b>	22.1	23.5	3.48	14	25	5-25

Overall, participants reported high preference scores for receiving medical information with an average score of 35.9 out of a possible maximum score of 40 ( $Mdn = 37$ ,  $SD = 4.69$ ). The highest scores on the *Decision Making Preference* Scale corresponded to the *Shared Decision Making Preference* subscale ( $M = 22.1$ ,  $Mdn = 23.5$ ,  $SD = 3.48$ ).

#### 4.4.2. Spearman's Rank Correlation

The Spearman's Rank Correlation was chosen to test association between variables as it does not make any assumptions on data distribution, and is appropriate for scale ordinal variables.<sup>133</sup> There was no evidence of significant correlation between the *Hearing Index* and the preference variables at 5% significance level (Table 4.3). Due to the small sample size, estimates in this study are imprecise, as shown by the wide confidence intervals.

**Table 4.3: Spearman's correlation coefficient (rho) between the Hearing Index and the preference variables**

Scale or subscale	Spearman's rho	95% Confidence intervals	p-value (H0: rho=0)
Information-Seeking Scale	-0.30	(-0.62, 0.09)	0.1304
Health Professional Preference subscale	-0.26	(-0.59, 0.14)	0.2028
Resident Preference subscale	0.35	(-0.05, 0.65)	0.0814
Shared Decision Making Preference subscale	-0.14	(-0.50, 0.26)	0.5054

#### 4.5. Validation of the Hearing Index

In order to validate the *Hearing Index* in the study setting, participant scores were compared against two observable metrics recorded during the interviews: a) participant was wearing hearing aids or made reference to their hearing aids, or b) participant requested that questionnaire item(s) be repeated. Six participants scored 18 or higher on the *Hearing Index*, indicating self-perceived hearing loss.<sup>98</sup> Five additional participants met at least one of the criteria for observer-rated hearing loss based on the observable metrics.

There was no clear cut-off point in which self-perceived hearing loss matched observer-rated hearing loss. The difference in the total number of participants meeting the criterion for hearing loss based on self-perception and observers' ratings suggests that the *Hearing Index* has low sensitivity. To overcome this limitation, data from the *Hearing Index* and observable metrics were combined to create the *Hearing Loss Criterion*. Participants were deemed to have hearing loss if they scored 18 or higher on the *Hearing Index*, or met the criterion for at least one of the observable metrics. A total of 11 out of 26 participants, (42% of the sample) had hearing loss based on the *Hearing Loss Criterion* (Table 4.4).

**Table 4.4: Hearing Loss Criterion**

Hearing Loss Criterion	Participant number	Self-perceived hearing loss	Observer-rated hearing loss	
		Hearing Index score	Observable metrics	
			a) Participant was wearing hearing aids during interview or made reference to their hearing aids (Yes/No)	b) Participant requested that questionnaire item(s) be repeated (Yes/No)
Met	2	16	No	Yes
	4	12	Yes	Yes
	8	19*	Yes	Yes
	9	26*	Yes	Yes
	11	14	Yes	Yes
	14	26*	Yes	Yes
	17	10	Yes	No
	18	22*	No	Yes
	19	14	Yes	Yes
	23	26*	Yes	Yes
	24	22*	Yes	Yes
Did not meet	1	11	No	No
	3	10	No	No



Hearing Loss Criterion	Participant number	Self-perceived hearing loss	Observer-rated hearing loss	
		Hearing Index score	Observable metrics	
			a) Participant was wearing hearing aids during interview or made reference to their hearing aids (Yes/No)	b) Participant requested that questionnaire item(s) be repeated (Yes/No)
	5	13	No	No
	7	11	No	No
	10	15	No	No
	12	10	No	No
	13	10	No	No
	15	13	No	No
	16	10	No	No
	20	12	No	No
	21	11	No	No
	22	11	No	No
	25	10	No	No
	26	16	No	No
	27	11	No	No

\*A score of 18 or greater on the *Hearing Index* indicated self-perceived hearing loss.

#### 4.6. Thematic analysis

Qualitative data from the *Hearing Index*, the *Information-Seeking Scale* and the *Decision Making Preference Scale* were thematically analysed using the Framework Method.<sup>92,93</sup> An open coding process resulted in the identification of 28 initial codes. Similar codes were grouped into 13 broader categories using a mind mapping activity<sup>132</sup> to produce an analytic framework. The analytic framework was applied to the 26 transcripts and the data were charted into a Framework Matrix. Hearing loss was calculated using the *Hearing Loss Criterion*. Data from the *Hearing Loss Criterion* (Table 4.4) was charted into the Matrix to allow for comparisons between participants with and without hearing loss. Thematic analysis

identified seven themes: 1) Preferences for receiving medical information, 2) Preferences for shared decision making, 3) Dependence on doctors as medical experts, 4) Resident autonomy, 5) Response to hearing loss, 6) Managing hearing loss, and 7) The impact of background noise (Table 4.5). Sample quotes are used to highlight the themes. Quotes were de-identified and coded using participant numbers. The themes complement and expand on the findings from the statistical analysis by providing a deeper understanding of participants' preferences, values, and needs.

**Table 4.5: Summary of themes from thematic analysis**

Theme	Description
Preferences for receiving medical information	Overall, participants had a high desire for receiving information relating to medical conditions, treatment options, and side effects of medication
Preferences for shared decision making	Overall, participants had a strong desire for mutual discussion and decision making. For some residents, family members played an important role in shared decision making
Dependence on doctors as medical experts	Doctors were viewed as experts who should make important medical decisions
Resident autonomy	Participants wanted autonomy over end-of-life decisions and self-management of minor health issues as long as they were mentally alert
Response to hearing loss	Although the majority of participants with hearing loss accepted their condition, few either denied their hearing loss or tried to hide it from others
Managing hearing loss	Participants attempted to improve the reception of information through communication enhancing strategies, workarounds, and by wearing hearing aids
The impact of background noise	Background noise lead to communication breakdown for residents with and without hearing loss

## 4.7. Themes

### 4.7.1. Preferences for receiving medical information

Overall, participants had a strong desire for receiving medical information, including information about medical conditions, treatment options, and side effects of medication:

*“I think if you’ve got something wrong with yourself it’s better to know than sit and worry”* (Participant 1).

*“If you are not told, and it’s not explained to you, how are you going to cope with whatever the situation is?”* (Participant 10).

Every participant in the sample reported a preference for receiving information about their medical care, even if this was limited to certain situations, such as receiving new medication or during hospitalisation. A number of participants reported actively seeking information, and were confident asking health professionals questions to enhance their understanding of information provided to them.

Accompanying a desire for receiving medical information, was a dissatisfaction with the communication between residents and care staff or other health professionals. Some participants felt they did not receive as much information as they would like and recalled events where medication was prescribed, or blood tests were taken, without providing information about the purpose of the treatment or test: *“I want to know why I am taking it [medication], but I am never told and I think that is wrong because there is nothing wrong with my brain”* (Participant 14). Participants also expressed that doctors were often unavailable. These participants found that they were unable to talk to a doctor when they wanted to. Doctors were either too busy to see residents, or the time they spent talking to residents was limited: *“Now I assume the doctors are very busy and they just want to get away from you and they don’t want to give you information. You see, there is no use talking to the doctors”* (Participant 11). Due to this view, Participant 11 found it easier to accept doctors’ opinions and suppress his concerns, in order to avoid conflict: *“I don’t want to have an argument with him, because say for instance, if the doctor comes here and if I want to talk to him, I notice he doesn’t listen.”*

Some participants demonstrated minimal preference for receiving medical information. For example, Participant 21 was, in general, not concerned about receiving medical information but did reveal a desire to be informed about the side effects of new medication. One explanation for this view was that illness was inevitable at the later stage of life that participants were in, or due to an acceptance of their situation:

*“I don’t care what happens at this stage! ... I’m ready if the day comes, if the time is tonight”* (Participant 21).

*“I feel that, it’s [sickness] inevitable and, well, what’s the use in worrying!”*  
(Participant 18).

#### 4.7.2. Preferences for shared decision making

Overall, participants had a strong desire for mutual discussion and decision making with health professionals. Every participant expressed a desire for some form of shared decision making and used phrases such as “work together”, “talk it over”, “want some input”, “should be included”, “should be consulted”, “like a balance”, and “in conjunction with the doctor”. Some participants wanted shared decision making only in certain situations, e.g., when they became very sick: *“If it’s something, you know, really bad, I think you should talk it over with your doctor, otherwise how the heck would you know!”* (Participant 1).

Participants valued health professionals that would listen to them and whom they felt they could communicate with: *“I would love to find out the doctor, who, you know, who would really talk to me! Really understand me. So sometimes, my mind is not working, and he would take, or she would take, the time to explain it to me”* (Participant 11). When discussing shared decision making, participants often focused on information exchange and communication. In these instances, participants wanted to be included in the decision making process and noted the importance of being informed, but preferred to leave decisions to health professionals:

*“I wouldn’t want more control. I’d just want them [health professional] to discuss it with me and tell me what they feel”* (Participant 23).

*“I can’t make them [decisions] without the doctor’s information ... You’ve got to be informed, you can’t make decisions without information”* (Participant 10).

When discussing preferences for medical decision making, some participants broached the topic of family involvement in the decision making process. Interestingly, only participants with hearing loss discussed the role of family, expressing that involving family members in decision making was important to them: *“My family come into it. Everything, they come into it. Yes, I’m very important to them”* (Participant 8). Family involvement was not mentioned by participants without hearing loss.

#### 4.7.3. Dependence on doctors as medical experts

Although participants revealed a high preference for shared decision making, there were still strong views held by most participants that doctors should make important medical decisions: *“I do not worry; I leave it to the doctor ... I’d do what the doctor says. I have faith in him”* (Participant 5). Doctors were seen as experts who should be trusted. Participants often relied on doctors as a source of knowledge:

*“It’s not up to me. They are supposed to be doctors. Yes, they know everything”* (Participant 3).

*“Left to the doctors for God’s sake! ... I think I’ll leave it to the experts”* (Participant 22).

Dependence on doctors was especially relevant in more serious situations such as when participants were very sick or they were hospitalised. Participants did not feel that they had the medical training or expertise to make serious medical decisions: *“It’s different when you are in an emergency situation in a hospital”* (Participant 9).

The perception of doctors as all-knowing meant that participants trusted them and often took their advice, even when they disagreed with it. Participants emphasised the trust they had with doctors they were familiar with, and discussed the value they placed on the relationships they had formed with doctors over time: *“Well you put your trust in the doctor, if you know, you usually have an idea, if he’s been your doctor for a while, that you trust him”* (Participant 3).

#### 4.7.4. Resident autonomy

Although most participants preferred to leave decision making to health professionals, or to engage in shared decision making, a minority of participants expressed strong independence and autonomy. Examples included: refusal of medication, not taking health professionals’ advice, firing doctors, standing up to health professionals, and self-discharge from hospital: *“I went to hospital and I signed myself out because I don’t like the treatment”* (Participant 7).

Autonomy was desired for both major and minor health issues. Some participants held very strong views about autonomy in terms of end-of-life decisions, e.g., the right to resuscitate, transfusions, and life support: *“I refuse to be put on life support”* (Participant

15). It was also common for participants to want self-management and autonomy over smaller, everyday medical decisions such as treatment for headaches or colds:

*“I’m happy to deal with the small things if I understand myself what’s wrong”*  
(Participant 24).

*“You sort of know things don’t you? How to treat yourself”* (Participant 3).

A common topic that arose during interviews was the issue of body autonomy. Participants reported awareness of their “own body” and how they felt, or a knowledge of their medical conditions. This view meant that participants wanted to be informed and make decisions about their health: *“I’d still want to know, it’s my body ... My body, my life!”* (Participant 16).

Another common issue discussed by participants was an awareness of their cognitive capabilities. Participants wanted to be informed and involved in the decision making process while they were mentally alert:

*“Although my body is not the best, my mind is”* (Participant 14).

*“While I have mental faculties, I would want to be informed”* (Participant 18).

However, some participants were also aware of the limitations placed on them by cognitive impairment:

*“What happens if I’m not compos mentis enough to make decisions?”* (Participant 4).

*“Because maybe. I’m old now, so I may think the wrong way”* (Participant 8).

#### 4.7.5. Response to hearing loss

Most participants with hearing loss were accepting of their condition. These participants saw hearing loss as a part of the normal ageing processes. For example, when asked if she ever felt embarrassed because of her hearing loss, Participant 23 responded: *“No, because I know it’s normal.”* A small number of participants either denied that they had hearing loss, or acknowledged their hearing loss but attempted to hide it from others: *“No, I don’t feel embarrassed because I don’t ever let on that I have a hearing problem”* (Participant 14). Sometimes, external sources such as background noise or the quiet voices of other residents were blamed for communication breakdown: *“They whisper and I can’t hear. Or talk softly*

*and I can't hear. And sometimes I'm dying to!"* (Participant 14). Regardless of whether participants accepted or denied their hearing loss, the majority expressed some kind of emotional response such as frustration, sadness, embarrassment, or a desire to hear better.

#### 4.7.6. Managing hearing loss

Participants with hearing loss employed a number of strategies to improve communication and overcome the limitations placed on them by their sensory impairment. These strategies were classified into three groups: communication enhancing strategies, workarounds, and the use of hearing aids. Communication enhancing strategies involved lip-reading, informing others of hearing loss, asking people to repeat themselves, or asking people to speak louder. Communication was facilitated by face-to-face exchange and standing in close proximity to others:

*"They all just chat and I can't hear what they're saying. Sometimes the lady next to me will say, 'do you hear?' ... and then they say it clearly and if I can lip read as well then I can usually hear ... If I can see the lips and hear a bit, they're like facing you, then I can manage"* (Participant 23).

Workarounds refer to environmental manipulations to enhance the reception of information. The most common workarounds reported by participants were the use of closed-captions and turning up the volume on the television:

*"I do not listen to the TV at all, I just have captions. I can't hear the TV, just captions"* (Participant 23).

*"I put it on mute [the television]. Just read the writing"* (Participant 19).

Nine participants were either wearing hearing aids during their interview, or made reference to them. Only Participant 17 expressed a positive attitude towards her hearing aids, reporting that she wears them often and finds that they dramatically improve her hearing. The majority of participants with hearing loss wore their hearing aids only some of the time, or not at all, and commented on the barriers to hearing aid use. The most commonly reported barrier was the expense of hearing aids: *"Actually batteries are quite expensive for a hearing aid, so it's out"* (Participant 11). Participants 8 and 19 could not wear their hearing aids as they were broken, and Participant 23 found that hearing aids were not very effective against background noise. When asked if she has trouble hearing other people when a television or

radio was playing in the same room, Participant 23 replied: *“Terrible! Because of the background noise, even with the hearing aid, it is a lot louder than the person speaking.”*

#### *4.7.7. The impact of background noise*

Background noise was reported as one of the greatest contributors to communication breakdown. Participants explained that the care facility could be very noisy, especially in group situations where multiple voices were competing against each other. When asked if Participant 14 wished that she could hear better when she was with other people, she responded: *“One to one is alright, but one to two, three, four, five, hopeless! Hopeless! Hopeless! ... When I’m in a crowd, it’s hopeless and it’s been hopeless from the very beginning.”* Background noise was distracting and frustrating for participants who often misheard information, or could not keep up with conversations. This phenomenon was not restricted to participants with hearing loss. It was also common for participants without hearing loss to report an inability to hear in the presence of background noise. For example, Participant 21 explained: *“I don’t always hear correctly but that’s because something else is going on in the room.”*

### **4.8. Summary and limitations**

RQ1, how does hearing loss affect aged care residents’ preferences for receiving information, and decision making, in terms of their *medical care*? was addressed through statistical and thematic analyses. Descriptive statistics revealed that on average, participants had a strong preference for receiving medical information, and had higher scores on the *Shared Decision Making Preference* subscale, compared to the *Health Professional Preference* and *Resident Preference* subscales. There was no evidence of significant correlation between *Hearing Index* scores and scores on the preference variables at 5% significance level. The statistical analysis was limited by the small sample size. Validation of the *Hearing Index* against observable metrics resulted in 11 participants meeting the criterion for hearing loss, compared to six participants using the *Hearing Index* alone. This suggests that the *Hearing Index* has low sensitivity and used alone, may not be the most appropriate measure of self-perceived hearing loss.



Participants experienced difficulty when answering the *Hearing Index*, the *Information-Seeking Scale*, and the *Decision Making Preference Scale* using numerical rating scales and were offered the option to responding to items using verbal level of agreements. All 26 participants elected to respond to items using verbal levels of agreements, anecdotes and personal examples. This qualitative data was thematically analysed using the Framework Method.

Thematic analysis supported findings from the statistical analysis. Every participant discussed a preference for receiving medical information, even if they did not want to be informed in every scenario. Shared decision making was the most valued decision making option. Residents often conceptualised shared decision making to mean that they were kept informed and included in decision making, but they preferred to leave important decisions to doctors. Only participants with hearing loss emphasised the importance of family involvement in the decision making process. The involvement of family was not discussed by any of the participants without hearing loss. Most residents expressed a dependence on doctors as a source of knowledge and medical expertise. Some residents did reveal a preference for autonomy. This was most relevant when discussing self-management of everyday medical problems.

The themes *response to hearing loss* and *managing hearing loss* were only relevant to participants with hearing loss, however, the theme *the effects of background noise* related to both participants with and without hearing loss. Participants across the sample reported that background noise in the care facility lead to an inability to hear, miscommunication, and loss of information.

## **CHAPTER 5. FINDINGS: RQ2 EVERYDAY CARE—PREFERENCES FOR INFORMATION AND DECISION MAKING**

### **5.1. Overview of Chapter 5**

Chapter 5 presents findings from inductive content analysis addressing RQ2: how does hearing loss affect aged care residents' preferences for receiving information, and decision making, in terms of their *everyday care*?

#### *5.1.1. Highlights*

- Inductive content analysis resulted in the identification of five main categories: 1) Satisfaction with communication, 2) The effects of hearing loss on communication, 3) Preferred timing of information, 4) Autonomy and freedom, and 5) Mealtime-related decisions.
- Overall, participants reported being well informed about their everyday care.
- Twenty-three participants (88% of the sample) were satisfied with the amount of everyday care information they received. The three participants that expressed dissatisfaction all had hearing loss based on the *Hearing Loss Criterion*.
- Most participants wanted to receive information about everyday care activities in advance. Differences in preferences for the timing of information could not be attributed to hearing ability.
- Participants spoke about the importance of autonomy and freedom when it came to the control they had over personal, social, and environment decisions.
- Some participants felt restricted with their lack of control over mealtime-related decisions.

### **5.2. Preferences for shared everyday care decision making**

RQ2, how does hearing loss affect aged care residents' preferences for receiving information, and decision making, in terms of their *everyday care*? was addressed by comparing data from the *Hearing Loss Criterion* and data from the *SDM Interview Tool*. The interview tool comprised six semi-structured interview questions, assessing residents'

preferences for receiving information about everyday care matters and preferences for involvement in everyday care decision making. Participant responses were thematically analysed using inductive content analysis<sup>94</sup> to identify recurring patterns (main categories) in the data.

### 5.3. Inductive content analysis

Forty-seven codes emerged from the data, through an open coding process. Similar codes were then grouped together using a mind mapping activity<sup>132</sup> to form broader categories. Categories were repeatedly reduced until five main categories emerged: 1) Satisfaction with communication, 2) The effects of hearing loss on communication, 3) Preferred timing of information, 4) Autonomy and freedom, and 5) Mealtime-related decisions (Table 5.1). Eleven participants (42% of the sample) met the criteria for hearing loss using the *Hearing Loss Criterion* (see Chapter 4). Responses from these 11 participants were compared to the responses of the 15 participants without hearing loss, in order to identify difference across main categories between the two groups of participants. Sample quotes are used to highlight the main categories. Quotes were de-identified and coded using participant numbers.

**Table 5.1: Summary of main categories from semi-structured interviews**

Main category	Description
Satisfaction with communication	Effective communication resulted from the utilisation of a variety of information sources throughout the facility
The effects of hearing loss on communication	Hearing loss reduced the quality of the information exchange for some participants
Preferred timing of information	Participants varied in their preferences for the timing of everyday care information
Autonomy and freedom	Participants felt in control over personal, social, and environmental decisions
Mealtime-related decisions	Some participants were content with allocated seating and the provision of food during formal mealtimes, whereas other participants wished they made more choice over mealtime-related decisions

## 5.4. Main categories

### 5.4.1. Satisfaction with communication

Overall, participants communicated strong satisfaction with the amount of information they received regarding their everyday care. Some participants reported making an active effort to be informed: *“Every Friday there’s a weeks’ program put up on the boards in two or three places and I make it my business to have a look at that. I might check it a couple of times a week, just to refresh my memory as to what I am missing out on or what I should be paying attention to”* (Participant 10). Most participants attributed effective communication of everyday care matters to the variety of mediums by which information was provided (Box 5.1).

#### Box 5.1. Sources of everyday care information

##### Information sources

- Central white board in activity room
- Notice boards in various locations throughout the facility
- Information sheets about special events
- Records in personal diaries/written notes
- Other residents/friends
- Care staff
- Announcements over speakers

The information source most utilised by participants was a central whiteboard, located at the front of the activity room, which provided an hourly breakdown of the day’s activities such as quizzes and mealtimes: *“Everything’s written on the board, yoga, you know, we’re going to go to a picnic, or whatever party”* (Participant 3). Additional to the central board, were various notice boards placed throughout the facility. These boards presented information about daily, weekly, and monthly activities. Information sheets regarding special events such as holiday celebrations were posted on these boards. Participants also took it upon themselves to write important information down in diaries, notebooks, or pieces of loose paper: *“But I am getting to the stage where I need a pencil and paper to write it down, because by the time we’ve eaten our lunch and I’ve come up here, I’ve forgotten”* (Participant 21). In addition to written communications, participants frequently reported ‘word of mouth’ as an information source. Residents relied on other

residents to communicate everyday care information. This was especially true for Participant 1 who had severe vision impairment and was not able to read the central board: *“Well you see, I’ve got to rely on other people to tell me. I can’t see the board.”* Participants also received everyday care information from care staff in the form of direct conversation and announcements made over speakers.

#### *5.4.2. The effects of hearing loss on communication*

Three participants that met the criterion for hearing loss, based on the *Hearing Loss Criterion*, reported that they did not receive as much everyday care information as they would like. The other eight participants with hearing loss did not report difficulties with communication. The three participants that were affected all indicated that they experienced the impact in a significant way. Participant 8 felt that care staff did not provide enough information regarding everyday care, and when they did, she was unable to receive the information due to her hearing loss. When asked whether she was well informed about the activities in the facility, Participant 8 responded: *“No, no, no. They [care staff] don’t inform, that’s one thing. They write it on the board ... we should know! See, lunchtime, the lady will say what is happening today, that is all. And with me, no hearing aid, I cannot hear.”* Participant 23 thought that enough information was provided to her but she was unable to hear it. When asked if she received as much information as she would like about everyday care, Participant 23 responded: *“I do, except when they announce things at mealtimes. I can’t hear things of course.”* Participant 24 wanted to receive information from care staff but found that this did not happen: *“Well to be told by the staff would be nice, yes, yes.”* When asked if this happened, Participant 24 replied: *“No. You’ve got to, they say ‘oh it’s been on there, see, so you should know yourself, you can read.’”* Despite being dissatisfied with the quality of information they received, all three participants expressed a strong preference to be informed.

#### *5.4.3. Preferred timing of information*

Participants’ preferences for the timing of everyday care information varied considerably. Most participants wanted to receive information in advance, whether it be a day or a week beforehand. Residents in self-care were more likely to want information about activities at least a week in advance in order to accommodate their work commitments or social

engagements: *“Because I am not much around for what’s on, if I can be there, I’m happy to know about it and attend, but quite often I’m not able to attend”* (Participant 25). Some participants were content receiving information about activities as they occurred and did not express the need to be informed ahead of time. One of the explanations for this preference was that residents were often aware of what activities were on, or the timing of everyday events such as mealtimes. These events ran on a set schedule and participants had become accustomed to the routines in the facility: *“I mean we know, the mealtimes at the same every day”* (Participant 1). There were no differences between those with and without hearing loss regarding preferences for the timing of information.

#### 5.4.4. Autonomy and freedom

Overall, participants were highly satisfied with the level of control they felt they had over everyday care decisions, across personal, social, and environmental domains. Most participants expressed “complete freedom” or “total control” over personal decisions such as what clothing they wore: *“Oh yes! No one tells me what to wear!”* (Participant 3). Regarding social decisions, participants had the choice of participating in social activities or not. Participants who socially withdrew or decided to engage in more introvert-orientated activities, such as reading, did so by choice and therefore were still content with the level of control they had over social decisions: *“It’s [notice board] got a list of where you can put a tick and its N/A, not applicable, and that’s me. Like I say, I’m a bit of a lone wolf and I like, I’ve got a routine, know what I’m doing and I would prefer to do it my way”* (Participant 20). Only one participant spoke about the effects of hearing loss on social participation. Participant 14 said that her hearing loss was one of the reasons she avoided the activity room. She felt that she could not participate in activities as she was unable to hear: *“And I think that is one of the reasons why I don’t go to the activities room ... when they play bingo, I can’t hear because sometimes the girl that’s calling the numbers ... I can’t ... can’t understand what she’s saying.”*

Social activities were structured and these social routines provided participants with stability. Participants frequently demonstrated knowledge of what activities were held on each day and what time these activities occurred. This was comforting for most participants as routines provided structure to daily living. For example, participants could sit where they wanted in the activity room, however, they preferred to sit in the same spot each day and

socialise with the same group of people: *“Well we usually sit with the same people all the time. We can sit anywhere we like upstairs and in the activity room, but I always sit here, in this spot here”* (Participant 24).

Concerning environmental decisions, participants held the view that the facility was their home and their room was their personal space. When Participant 10 was asked if she was happy with the level of control she had over her environment, she said: *“Well you know, what’s here is what I wanted and that’s the way it stays.”* Participants reported that care staff respected residents’ privacy and did not place restrictions on them: *“There’s no restrictions, you can go out as long as you tell them ... there is no restriction and they are very good like that ... your privacy and your private life is your own”* (Participant 14). Participants experienced total control over their personal space; their rooms were filled with their own furniture, plants, photographs, and ornaments: *“What I’ve got in the room is all my stuff, you know”* (Participant 19). Participants also explained that they had some control over facility environment. For example, Participant 13 spoke about the communal plants in the facility which she cared for, and discussed the fish the facility acquired upon residents’ requests.

Self-care participants appeared to have a greater level of autonomy over their personal, social, and environmental decisions, compared to participants from residential care. Self-care participants had their own kitchens and did their own shopping, and some spoke about their places of employment: *“I pretty much do my own thing. I have my own car, so I do all my own shopping”* (Participant 10). Participants in residential care had most of their meals provided to them by the facility and some were unable to leave the facility without family assistance. Despite this apparent difference, participants were generally satisfied with their control over decision making regardless of care type. Although hearing loss did not impact participants’ autonomy, some participants expressed that mobility limitations and illness restricted residents’ freedom and their ability to participate in activities: *“For the residents that can move around, there is no restrictions”* (Participant 14).

#### *5.4.5. Mealtime-related decisions*

There was a divide between participants regarding their satisfaction with the level of control they had over mealtime-related decisions, such as food options and seating preferences. The facility had allocated seating for residents, and the same food was served to each resident

during formal mealtimes. The exception to this convention was for residents with dietary requirements, e.g., residents with allergies or diabetes: *“No, everyone gets the same that day, we all get the same meal. Oh, except some of them who are on a special diet”* (Participant 1). More choice was provided to residents outside formal meals; residents ate breakfast in their rooms, they could eat alone as opposed to in a large group, they had their own basic kitchenettes and access to communal kitchens, and they had options regarding the food they ate.

Concerning the topic of mealtime-related decisions, there were two groups of participants. One group did not feel restricted by the lack of choice provided to them. They were satisfied with the quality and amount of food served at formal mealtimes and were happy with the allocated seating system:

*“Well what I eat, they actually feed us very well in here, so I don’t have much choice about what I eat. But they do bring us breakfast, you know, corn flakes, coffee, because I can make it in my room. They bring us milk, you know, it’s all done very well for us”* (Participant 11).

*“In the dining room, we are allocated a table, but it doesn’t worry me. You get used to the people that are sitting round you and it would be funny to go to another table”* (Participant 3).

The other group of participants expressed a desire for more choice and control over mealtime-related decisions. This group of participants were not satisfied with the choices offered to them, they preferred the food they received at home, before they moved to the facility, or they were unhappy about sitting with people they would not normally sit with: *“The food isn’t always what I’d like, you know. I’m used to what you’re used to having at home”* (Participant 24). This difference was not attributable to participant characteristics, such as hearing loss or care type, but was related to personal preference, a desire for autonomy, and continued control over all aspects of their lives.

## **5.6. Summary and limitations**

RQ2, how does hearing loss affect aged care residents’ preferences for receiving information, and decision making, in terms of their *everyday care*? was addressed through inductive content analysis. Although some participants gave detailed answers to the *SDM*



*Interview Tool* questions, other participants gave minimal responses and did not feel the need to expand on their answers when prompted. Participant's responses were not detailed enough to permit the identification of abstract themes. The Framework Method<sup>92,93</sup> was not appropriate in this instance as a substantial number of cells would have been blank. Instead, a broader inductive content analysis provided a valuable descriptive account of the recurring patterns in data, in the form of main categories.

Comparing responses between participants with and without hearing loss revealed that although most participants expressed high satisfaction with the quality of information they received regarding everyday care, some participants with hearing loss did not feel that they received as much everyday care information as they would like, or could not hear the information provided to them. Furthermore, Participant 14 reported limitations to her participation in social activities as a consequence of her hearing loss.

Overall, participants felt they were autonomous in their personal, social, and environmental decisions. The only exception to this finding concerned mealtimes. There was a divide between participants, where some were satisfied with the allocated seating system and pre-determined food options, and the other group wished that they had more control over mealtime-related decisions. This difference was not attributed to differences in hearing ability.

## CHAPTER 6. DISCUSSION AND CONCLUSION

### 6.1. Overview of Chapter 6

Chapter 6 provides a summary of the study results and integrates findings in order to address the research aim: to assess how hearing loss affects aged care residents' preferences for involvement in shared decision making in regards to their medical care and everyday care. This is followed by a discussion of the original contribution of the research. The study challenges and lessons are presented, along with directions for future research. Recommendations for the translation of research findings into practice are then outlined. The conclusion section of this chapter provides an overarching summary of the research.

### 6.2. Summary of results

The narrative literature review, in Chapter 2, revealed that within residential aged care no study to date had assessed the effects of hearing loss on shared decision making. This research addressed this gap in knowledge by employing a mixed methods design assessing residents' preference for shared decision making, conceptualised by two phases: 1) receiving information, and 2) making decisions. In order to take a holistic view of the care provided to residents both medical care and everyday care contexts were considered in the study. To achieve the study aim, two research questions were generated:

RQ1: How does hearing loss affect aged care residents' preferences for receiving information, and decision making, in terms of their *medical care*?

RQ2: How does hearing loss affect aged care residents' preferences for receiving information, and decision making, in terms of their *everyday care*?

#### 6.2.1. Preferences for receiving medical information

Statistical analysis found no significant correlation between self-perceived hearing loss, assessed using the *Hearing Index*,<sup>98</sup> and preferences for receiving medical information, measured through the *Information-Seeking Scale*.<sup>99</sup> Similarly, thematic analysis revealed no difference in information-receiving preferences between participants with and without hearing loss, based on self-perceived hearing loss and measures of observer-rated hearing loss (*Hearing Loss Criterion*).

Descriptive statistics showed that, overall, participants provided high ratings on the *Information-Seeking Scale*. This finding was mirrored by the results of the thematic analysis, as every participant discussed a desire for receiving information about medical care, e.g., illnesses, treatment options, and side effects of medication. The study supports previous research,<sup>46,48</sup> which demonstrated that when older consumers define their involvement in care, they place greater value on good communication and information exchange.<sup>21</sup>

Associated with strong preferences for receiving information was dissatisfaction with health professionals' communication. Some participants expressed frustration with the lack of medical information they received. They felt that doctors were either unavailable, or did not listen to their concerns. Similar findings have been reported within acute care, where older consumers received less information from clinicians during their hospital stay than they preferred.<sup>47</sup>

#### 6.2.2. *Preferences for medical decision making*

Statistical analysis demonstrated no significant correlation between *Hearing Index* scores and preferences for medical decision making, assessed through the *Health Professional Preference*, *Resident Preference*, and *Shared Decision Making Preference* subscales of the *Decision Making Preference Scale*.<sup>100</sup> Thematic analysis, comparing responses from participants with and without hearing loss, based on the *Hearing Loss Criterion*, revealed that one difference between the two groups of participants, concerned family member involvement in the decision making process. An interesting finding was that only participants with hearing loss emphasised the role of family in decision making. The importance of family member involvement in the care provided to older consumers has been established in residential care, particularly in terms of dementia care and end-of-life care.<sup>38-41</sup> The study suggests that a desire for family involvement in medical-related decision making was more prominent for participants with hearing loss. A possible explanation for this finding is that family may provide a voice for residents with hearing loss, who experience communication breakdown in residential settings.<sup>10</sup>

Both statistical and thematic analyses revealed that, overall, participants demonstrated strong preferences for shared decision making. Each of the 26 participants spoke about their desire for discussion and mutual decision making with health professionals, and on average, participants scored higher on the *Shared Decision Making*

*Preference* subscale compared to the *Health Professional Preference* or *Resident Preference* subscales.

Participants frequently conceptualised involvement in decision making to entail the reception of medical information, with a lesser focus on making medical-related decisions. In line with previous evidence,<sup>46,48</sup> participants wanted to be informed about medical matters, but often preferred to leave final decisions to doctors. Participants viewed doctors as experts, relying on them to make important decisions, due to their medical knowledge and training. A minority of participants expressed preferences for autonomy and control over medical decisions, although this often related to the self-management of minor health problems.

#### *6.2.3. Preferences for receiving everyday care information*

Inductive content analysis revealed that hearing loss, assessed by the *Hearing Loss Criterion*, did not impact participants' preferences for receiving everyday care information, including the amount and timing of information. Similar to preferences for medical information, the majority of participants wanted to be informed about everyday care matters. Furthermore, most participants were highly satisfied with the amount and quality of information they received about daily activities, special events, and mealtimes. This satisfaction was largely attributed to the variety of information sources throughout the facility, such as notice boards, information sheets, conversations with other residents, and announcements from care staff. Only three participants expressed that they did not receive as much information about everyday care as they would like. These three participants all had hearing loss, based on the *Hearing Loss Criterion*. These participants reported that either care staff did not convey everyday care information, or if they did, the participants found that they were unable to hear it.

The study complements and extends existing knowledge regarding the association between hearing loss in residential care and communication breakdown,<sup>10</sup> by demonstrating that despite communication difficulties, participants still had strong preferences for receiving everyday care information. Although some participants with hearing loss experienced problems receiving information from care staff, they utilised other methods, such as the central white board, to remain informed about their everyday care.

#### 6.2.4. *Preferences for everyday care decision making*

Hearing loss, assessed by the *Hearing Loss Criterion*, did not affect participants' preferences for everyday care decision making, including personal, social, and environmental decisions. Participants were autonomous in their personal decisions, e.g., what clothes they chose to wear. Daily social activities were provided for residents including yoga, quizzes, and knitting groups. Hearing loss did not affect participants' preferences for the control they had over social decisions, however one participant found that her hearing loss limited her ability to join in on group activities such as bingo. Inability to participate in group activities has been previously reported by care staff as a consequence of hearing loss.<sup>71</sup> Contrary to the view that routines in residential care limit residents' autonomy,<sup>52</sup> scheduled activities and tacit knowledge about activities, such as what activities occur on what day and at what time, provided participants with structure to their daily lives. In terms of environmental decisions, the study revealed that in line with relevant literature,<sup>49</sup> the facility was viewed as a home by participants in addition to a care service. Participants had control over the furnishing and layout of their rooms, and to some extent they had input regarding the facility environment, including plants and fish.

The exception to the experience of freedom over everyday care decisions was mealtime-related choice. Meal enjoyment is a significant predictor of residents' overall satisfaction with care experience.<sup>18</sup> Providing food choice can support person-centred care in residential facilities,<sup>17</sup> however, residents are often provided minimal input in mealtime-related decisions or meal planning.<sup>54</sup> In the study setting, formal mealtimes were heavily structured in terms of assigned seating and set menus. Outside formal mealtimes, residents were provided with greater autonomy in terms of food-related options, the use of kitchenettes, and the opportunity to eat alone. Some participants were satisfied with mealtime conventions, whereas other participants wanted more control over mealtime-related decisions. These participants were either dissatisfied with the allocated seating system during formal mealtimes, or would have liked more choice regarding food that was served. The divide between participants' preferences for control over mealtime-related decisions was not associated with hearing ability.

#### 6.2.5. *Hearing Index tool validation*

Six out of 26 participants (23%) scored 18 or higher on the *Hearing Index*, meeting the criteria for self-perceived hearing loss. Previous use of the tool in residential care resulted in a similar rate of 29%.<sup>57</sup> Observer-rated hearing loss identified five additional participants who displayed signs of hearing loss (participant wore hearing aids or made reference to them, or participant requested that questionnaire item(s) be repeated). Mapping hearing loss into the Framework Matrix<sup>92,93</sup> using the *Hearing Index* criteria showed that the tool did not accurately represent participants' experiences of hearing loss. For the additional five participants who did not meet the *Hearing Index* cut-off, but were classified as having hearing loss based on observer-ratings, hearing loss had a negative impact on their daily function, e.g., problems understanding conversations, a desire to hear better, or difficulties hearing televisions and radio. To provide a more comprehensive account of hearing loss, self-perceived hearing loss and observer-rater hearing loss were combined to form the *Hearing Loss Criterion*. Mapping the *Hearing Loss Criterion* into Framework Matrix provided a more representative account of hearing loss, compared to the *Hearing Index* alone. This finding suggests that the *Hearing Index* may have low sensitivity, and emphasises the need to employ a variety of measures when assessing hearing loss in research and in practice.

#### 6.2.6. *Communication breakdown in residential care*

Hearing loss proved to be a burden for participants, negatively impacting their communication, and ability to participate in social activities or group conversations. Participants with hearing loss reported a desire for better hearing, and reported common emotions in response to their hearing loss, such as sadness, frustration, and embarrassment.<sup>9</sup>

The effects of hearing loss on communication were exacerbated in the presence of background noise, or during group conversations where multiple voices were present. Although research determining the noise levels present in Australian residential care homes has yet to be conducted, international evidence depicts that levels are higher than recommended.<sup>75,77,78</sup> Furthermore, background noise in residential care homes has been reported to lead to communication breakdown for residents with hearing loss.<sup>10</sup> Interestingly, the effects of background noise did not discriminate against hearing ability. Participants with

and without hearing loss expressed frustration with the noise levels in the facility and experienced communication difficulties when competing against background noise.

#### *6.2.7. Overcoming the challenges associated with hearing loss*

Most participants with hearing loss accepted their sensory decline as a normal consequence of ageing, however a few participants either denied their hearing loss or spoke about trying to hide it. Participants' denial may explain why there was a mismatch between self-perceived and observer-rated hearing loss. For example, Participant 4 owned hearing aids and asked for repetition of questions during his interview, yet he stated that he rarely wore his hearing aids, and he scored a 1 ("no") on *Hearing Index* item 10, which asked about the need for people to repeat themselves. Participant 4 met both criterion items for observer-rated hearing loss, yet only scored 12 on the *Hearing Index* (out of a possible score of 10-30), where a higher score indicated greater self-perceived hearing loss.

Participants' use of communication enhancing strategies and workarounds may also account for the difference between self-perceived hearing loss and observer-rated hearing loss. Participants used strategies to improve information exchange with other residents and care staff. These strategies included lip-reading, informing others of their hearing loss, asking people to repeat themselves, asking people to speak louder, engaging in face-to-face communication, and speaking with others in close proximity. Workarounds, which refer to environmental manipulations, were employed to either enhance the reception of information, or to avoid situations in which hearing loss might be problematic. Workarounds discussed by participants included the use of closed captions, turning up the television, or avoiding television shows with a lot of dialogue. For example, Participant 23 initially declared that she did not have trouble hearing the television or radio, but upon reflection, said that she actually had so much trouble hearing the devices that she never listened to them, thus eliminating the problem.

Hearing aids are a management tool designed to improve recipients' hearing function,<sup>80</sup> potentially reducing the impact of hearing loss on day-to-day life. For example, Participant 17 suffered from tinnitus and spoke about her poor hearing, however, as she wore hearing aids consistently, she found that her hearing loss did not affect her daily functioning. Participant 17 met the criterion for observer-rated hearing loss, yet she scored a ten on the *Hearing Index*—the lowest possible score, where a higher score indicates greater hearing

loss. Although hearing aids can be beneficial for some individuals, most participants cited common barriers to hearing aid usage,<sup>81,82,84</sup> and found that their hearing aids were not very effective when competing against background noise.

Participant engagement in communication strategies and workarounds, and their use of hearing aids, meant that some participants did not view their hearing loss as problematic as they discovered ways to overcome the challenges associated with it.

### **6.3. Original research contribution**

The study is, as best as can be determined, the first of its kind to explore the effects of hearing loss on shared decision making in residential aged care. Related research has either focused on residents' decision making preferences,<sup>45</sup> older consumers' decision making preferences,<sup>46-48</sup> issues associated with older consumers' experience of hearing loss,<sup>81,91</sup> or hearing loss in residential aged care,<sup>10,13,71,79,134</sup> yet no study to date has brought these concepts together. The study also makes a unique contribution to aged care research by approaching care through a holistic lens and incorporating both medical and everyday contexts into the definition of care.

The Australian government is currently reviewing its aged care standards in an attempt to achieve a sustainable and affordable aged care system by 2022.<sup>6</sup> One of the key objectives of this reform is a cultural shift away from a system that views older consumers as passive recipients of care, to one that is consumer-driven.<sup>6</sup> The Australian Aged Care Quality Agency has published a discussion paper addressing this cultural shift, "Let's talk about quality – developing a shared understanding of quality in aged care services."<sup>6</sup> This paper described the following key initiatives to achieving consumer-driven care: providing consumers with choice and autonomy, listening to the voices of consumers, providing timely, transparent information to promote informed decision making, and taking a holistic approach to care where interpersonal, social, and relational aspects of care are considered.<sup>6</sup> The research findings supported the Australian Aged Care Quality Agency's initiatives by demonstrating that participants had strong preferences for information, involvement in decision making, and autonomy, in medical, personal, social and environmental care domains. The study provided a platform for aged care residents to voice their opinions and could be used to inform the review of aged care standards by providing an insight into residents' preferences for involvement in their care.



Consumers with hearing loss are sometimes excluded from research,<sup>47,86</sup> due to communication problems. The study highlights the capabilities of consumers with hearing loss to engage in research processes and converse with researchers. The study shapes future research by identifying challenges to conducting research with the study population, as well as strategies to overcome these issues.

## **6.4. Study challenges and lessons**

### *6.4.1. Conducting research in residential aged care*

One of the major limitations of the study concerned the small sample size. Due to cognitive impairments and physical limitations, only 60 of 129 residents met the study inclusion criteria. Twenty-five of these residents were unable to be contacted. This meant that 35 residents were invited to participate. The study was completed by 26 participants. The small sample size proved to be problematic in terms of the statistical analysis of data. The wide confidence-intervals resulting from the small sample size meant that correlation estimates between variables were imprecise.

One of the most pervasive challenges for research in the aged care sector is the mental capacity of participants. A large proportion of residents exhibit some degree of cognitive impairment, with approximately 52% of permanent residents having dementia.<sup>135</sup> The high prevalence of cognitive impairment presents ethical implications in regards to informed consent. Obtaining informed consent requires participants to understand information provided to them, including potential risks and benefits of research, confidentiality matters, and what is expected of them as participants.<sup>136</sup> The design of the study addressed the research challenge associated with cognitive impairment in two ways. First, senior care staff used the inclusion criteria to select residents who were willing and able to provide informed consent. Second, participants were asked at various stages during their interview if they were happy to continue with the study, a practice termed process consent.<sup>104,105</sup>

In addition to cognitive competencies, physical limitations can restrict residents' ability to participate in research.<sup>137</sup> Residential aged care is provided to persons who can no longer be supported at home or in the community, due to frailty, complex medical needs, or disability.<sup>2</sup> Even seemingly simple tasks, such as filling out questionnaires or holding a pen, can be problematic for some potential participants. The study involved face-to-face, verbally administered questionnaires to accommodate the functional needs of participants, such as

vision impairment or difficulties providing written answers. The majority of interviews were administered in quiet environment to assist communication. Four of the 26 interviews were conducted in communal rooms to meet the needs of participants with restricted mobility.

Participants often experienced difficulties associated with the concept of rating scales and the format of questionnaires (*Hearing Index*, *Information-Seeking Scale*, and *Decision Making Preference Scale*). To overcome this limitation, participants were given the opportunity to respond to items by providing a verbal level of agreement. Participant responses were interpreted and assigned a numerical rating. It is important to recognise that the process of interpreting participants' answers and converting them to numerical values has the potential to create bias in data collection. In an attempt to counteract possible bias, participant's opinions were clarified as necessary.

Another important consideration when conducting research with consumers who have hearing loss is the use of hearing devices during data collection. Hearing aids are designed to enhance the reception of sound for individuals with hearing loss.<sup>80</sup> Whether hearing aids owners were wearing their devices or not during their interviews had the potential to influence their answers on the *Hearing Index*. Although hearing aid-related observations were recorded, participants were not directly asked about their hearing aid usage. Future research should consider the influence of hearing aids on participant responses.

#### *6.4.2. Lessons learned from implementation challenges*

Two main lessons were gained from this research. First, research in residential aged care needs to be flexible in its approach and implementation. Participants' cognitive abilities and physical needs need to be accommodated for through the delivery of questions, the time allocated to administer data gathering tools, and the environment in which the research takes place, e.g., quiet rooms for participants with hearing loss, or common rooms for participants with mobility limitations. Second, simplified versions of tools, in regards to language and components, need to be considered. The language used in tools should be concise and clear. Participants occasionally had difficulty relating to questions. Examples and prompts tailored to individual circumstances, e.g., medical conditions, should be provided to participants when necessary. In this study, participants experienced difficulties responding to questionnaire items using quantitative rating scales. It was evident that open-ended

interviews, as opposed to survey questionnaires, may have been a more appropriate method in which to gauge participants' opinions.

## **6.5. Future research**

The study emphasised the need to assess hearing loss using a variety of tools. Measures of self-perceived hearing loss are essential to the understanding of the effects that hearing loss has on residents' daily functioning. However, using self-assessed measures alone did not provide an accurate representation of hearing loss. One explanation for the lower rate of self-perceived hearing loss compared to observer-rated hearing loss was participants' use of communication enhancing strategies and workarounds. Participants employed strategies to improve information exchange, or manipulate their environment in attempts to reduce the problems associated with hearing loss. It would be valuable to better understand these strategies and how they operate in residential care, as well as the effectiveness of each approach. Future research conducting in the area of hearing loss should also reflect on the effects of hearing aid usage on participant responses, either by controlling for the effects of hearing aids, or by asking participants to respond to questions as if they were not using their devices.

A demographic characteristic shown to somewhat impact participants' preferences was care type. Participants in self-care were observed to be more autonomous in their daily living compared to participants from residential care, e.g., self-care participants had self-sustained units and did their own shopping. Both self-care participants and residential care participants had strong preferences for information, however, self-care participants preferred to receive everyday care information in advance so that they could work facility activities and events into their schedules. The influences of employment and care type were not within the scope of the study, however, these findings do provide direction for future research.

The study assessed residents' *preferences* for receiving information and for involvement in decision making. The next logical step in understanding the effects of hearing loss on shared decision making in residential aged care would be to measure the *actual* involvement of residents in their care and the effects that hearing loss has on communication and decision making. This would enable comparisons between residents' preferred and actual involvement in shared decision making processes. Research of this type would inform

person-centred care interventions aimed at aligning the care provided to residents with their preferences.

Residential aged care depends on a network of stakeholders such as family, care staff, doctors, nurses, speech pathologists, and physiotherapists. In order to gain a comprehensive account of the care provided to aged care residents with hearing loss, future research should not only evaluate the preferences and involvement of residents, but should also aim to understand these with respect to other care parties. The narrative review, Chapter 2, revealed that participants in person-centred care-focused research involving aged care residents with hearing loss were restricted to residents and care staff.<sup>10,13,71,79,134</sup> Research in this area neglects to address family experiences. The study found that the involvement of family in the decision making process may be more relevant to residents with hearing loss. Research is needed to explore this finding further and to understand the importance of family for residents with hearing loss.

## **6.6. Translation**

In order to translate the knowledge gained from this research into practice, two invited feedback sessions have been planned: one for care staff and one for residents. The feedback session for staff will provide an opportunity to inform facility management and care staff of residents' strong preferences for involvement in their care, in terms of receiving information, and making decisions. Older consumers are often viewed as passive recipients of their care, so this information may encourage care staff to actively involve residents in decision making processes. This session will also provide feedback on the strengths of the facility, such as the range of information sources, the provision of social opportunities, and residents' autonomy over everyday care decisions. Additionally, the session will inform facility staff of areas that participants' thought could be improved, such as high noise levels, the restrictions placed on mealtime-related decisions, and residents' dissatisfaction with the amount of medical information conveyed by health professionals and care staff.

Upon completion of the study, facility management were given a thank-you letter to deliver to participants, in addition to individualised hand written thank-you cards. The feedback session for residents will provide an opportunity for the researcher to personally thank participants for taking time to complete the study. This session has three other purposes. First, the findings of the study will be explained, allowing participants to

understand their contribution to the overall research project. Second, participants can see that their preferences and needs are recognised and valued. Third, it will enable participants to appreciate the importance of person-centred care research, and encourage them to be active players in changing the way older consumers' role in decision making is viewed.

## **6.7. Conclusion**

Hearing loss is the most prevalent form of sensory decline in individuals over the age of 65,<sup>69</sup> impairing auditory functioning, speech comprehension, hearing sensitivity, and sound localisation.<sup>7</sup> Although evidence shows that hearing loss in residential aged care contributes to communication breakdown,<sup>10</sup> the narrative review in Chapter 2 demonstrated that no study to date has assessed how residents' hearing loss impacts their preferences for involvement in shared decision making. The research addressed the knowledge gap by employing a mixed methods design to explore the effects of hearing loss on residents' preferences for receiving information, and making decisions, in terms of medical and everyday care. This study employed a holistic approach to aged care research by acknowledging the everyday care needs of residents, as well as their medical needs.

Quantitative analysis assessed the association between self-perceived hearing loss and preferences for receiving information, and for control over decision-making. A complementary qualitative analysis provided a deeper understanding of residents' preferences and the impact of hearing loss using measures of self-perceived and observer-rated hearing loss. Qualitative interviews provided insight into residents' preferences for receiving information and their level of control over personal, social, and environmental decisions. A comparison of responses between participants with and without hearing loss was conducted in order to assess the impact of hearing loss on residents' preferences for everyday care.

Hearing loss did not impact participants' preferences for receiving medical information, and had minimal effects on their preferences for medical decision making. The only difference in medical-related preferences was the importance placed on the involvement of family in the decision making process by participants with hearing loss. In terms of everyday care, hearing loss did not affect participants' preferences for receiving information or making decisions. However, hearing loss did reduce the quality of communication for

three participants with hearing loss, where they did not receive as much everyday care information as they would have liked.

By highlighting the challenges and lessons learned from conducting research in residential aged care, this study provides assistance for future studies in this field. The findings of this study offer direction for future research by emphasising the need to better understand the role that family members play in the care provided to residents with hearing loss. The study also has practical implications for facilitating a person-centred care approach in residential aged care. The feedback provided to the study facility will inform care staff of residents' preferences for involvement in their care, as well as the communication needs of residents with hearing loss. The feedback provided to participants will encourage them to take an active role in their care, helping to align their care with their preferences.

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## APPENDICES

### Appendix A: Demographic questionnaire

<b>Demographic information</b>	
<b>Age:</b>	
<b>Gender:</b>	
<b>Highest level of study attained</b> <i>(please circle one)</i>	<input type="radio"/> < High school <input type="radio"/> High school <input type="radio"/> Some university <input type="radio"/> Undergraduate university degree <input type="radio"/> Postgraduate <input type="radio"/> Doctorate
<b>Marital status</b> <i>(please circle one)</i>	<input type="radio"/> Never married <input type="radio"/> Married or common law <input type="radio"/> Separated or divorced <input type="radio"/> Widowed
<b>Self-rated health status</b> <i>(please circle one)</i>	<input type="radio"/> Poor <input type="radio"/> Fair <input type="radio"/> Good <input type="radio"/> Very good <input type="radio"/> Excellent

## Appendix B: Nursing Home Hearing Handicap Index—Self Version (Hearing Index)

For each statement, please rate each item from 1-3, where 1 = “no/almost never”, 2 = “sometimes,” and 3 = “yes/very often”

1. When you are with other people do you wish you could hear better?

*Please circle a number.*

1	2	3
_____		
No	Sometimes	Yes

2. Do other people feel you have a hearing problem when they try to talk to you?

*Please circle a number.*

1	2	3
_____		
No	Sometimes	Yes

3. Do you have trouble hearing another person if there is a radio or TV playing in the same room?

*Please circle a number.*

1	2	3
_____		
No/Almost never	Sometimes	Yes/very often

4. Do you have trouble hearing the radio or TV?

*Please circle a number.*

1	2	3
_____		
No	Sometimes	Yes

5. How often do you feel life would be better if you could hear better?

*Please circle a number.*

1	2	3
_____		
Almost never	Sometimes	Very often

6. How often are you embarrassed because you don't hear well?

*Please circle a number.*

1	2	3
_____	_____	_____
Almost never	Sometimes	Very often

7. When you are alone do you wish you could hear better?

*Please circle a number.*

1	2	3
_____	_____	_____
No/Almost never	Sometimes	Yes/very often

8. Do people tend to leave you out of conversations because you don't hear well?

*Please circle a number.*

1	2	3
_____	_____	_____
No	Sometimes	Yes

9. How often do you withdraw from social activities in which you ought to participate because you don't hear well?

*Please circle a number.*

1	2	3
_____	_____	_____
Almost never	Sometimes	Very often

10. Do you say "what?" or "pardon me?" when people first speak to you?

*Please circle a number.*

1	2	3
_____	_____	_____
No	Sometimes	Yes

## Appendix C: Information Seeking-Scale

*For each statement, please indicate your level of agreement using a scale from 1-5, where 1 is “strongly disagree” and 5 is “strongly agree”.*

1. As you become sicker you should be told more and more about your illness.  
*Please circle a number.*

1 2 3 4 5

Strongly disagree Strongly agree

2. You should understand completely what is happening inside your body as a result of your illness.  
*Please circle a number.*

1 2 3 4 5

Strongly disagree Strongly agree

3. Even if the news is bad, you should be well informed.  
*Please circle a number.*

1 2 3 4 5

Strongly disagree Strongly agree

4. Your doctor/nurse/carer should explain the purpose of your laboratory tests.  
*Please circle a number.*

1 2 3 4 5

Strongly disagree Strongly agree

5. You should be given information only when asked for.  
*Please circle a number.*

1 2 3 4 5

Strongly disagree Strongly agree

6. It is important for you to know all the side effects of your medication.  
*Please circle a number.*

1 2 3 4 5

Strongly disagree Strongly agree

7. Information about your illness is as important to you as your treatments.  
*Please circle a number.*

1 2 3 4 5

Strongly disagree Strongly agree

8. When there is more than one method to treat a problem, you should be told about each one.  
*Please circle a number.*

1 2 3 4 5

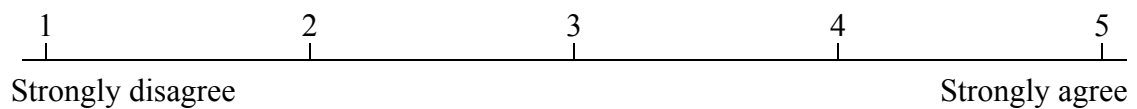
Strongly disagree Strongly agree

## Appendix D: Decision Making Preference Scale

*For each statement, please indicate your level of agreement using a scale from 1-5, where 1 is “strongly disagree” and 5 is “strongly agree”.*

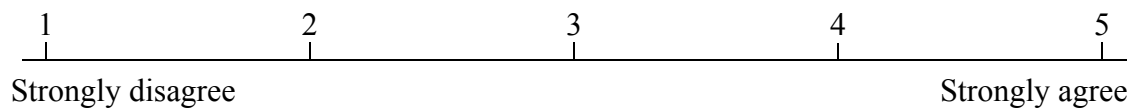
1. Important medical decisions should be made by your doctor/nurse/carer, not you.

*Please circle a number.*



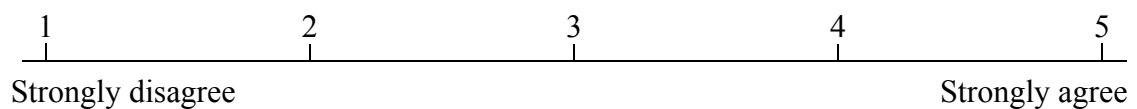
2. Important medical decisions should be made by you, not your doctor/nurse/carer.

*Please circle a number.*



3. Important medical decisions should be made by you and your doctor/nurse/carer together after talking it over.

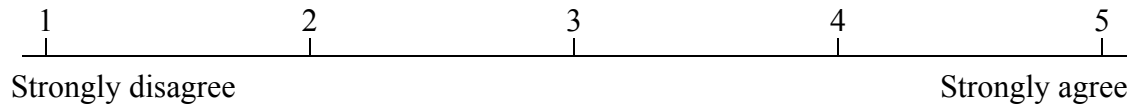
*Please circle a number.*





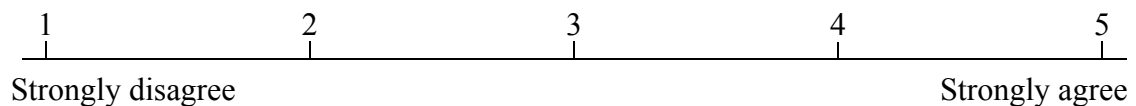
4. You should go along with your doctor/nurses/carers' advice even if you disagree with it.

*Please circle a number.*



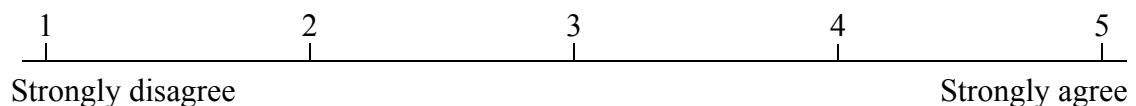
5. You should not go along with your doctor/nurses/carers' advice if you disagree with it.

*Please circle a number.*



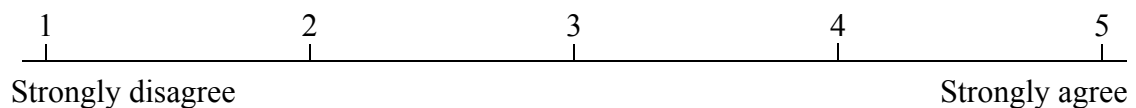
6. If you and your doctor/nurse/carer disagree you should talk it over and decide together.

*Please circle a number.*



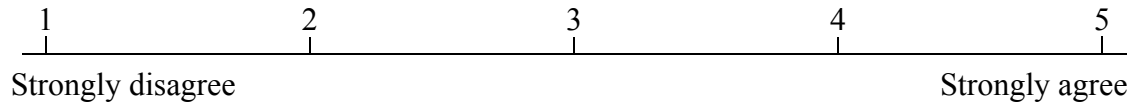
7. When hospitalised, you should not be making decisions about your own care.

*Please circle a number.*



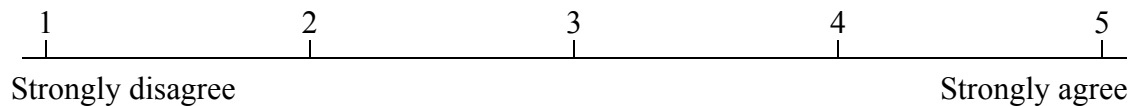
8. When hospitalised, you should be the one making decisions about your own care.

*Please circle a number.*



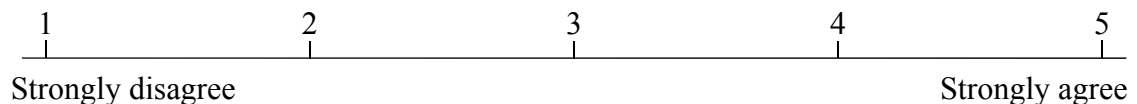
9. When hospitalised, you and your doctor/nurse/carer should talk over decisions about your care and make them together.

*Please circle a number.*



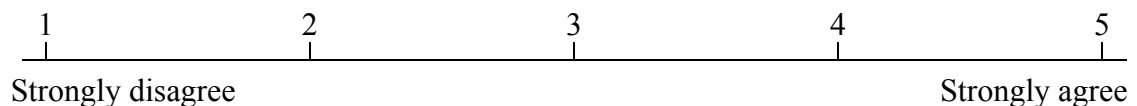
10. You should make decisions about your everyday medical problems.

*Please circle a number.*



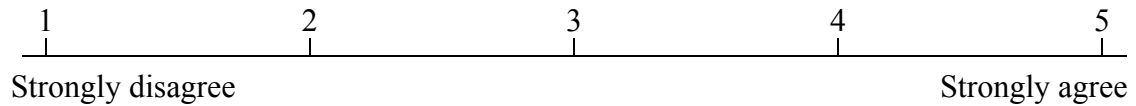
11. Your doctor/nurse/carer should make decisions about your everyday medical problems.

*Please circle a number.*



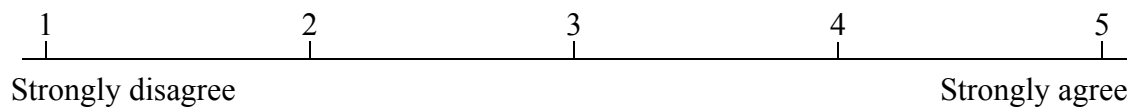
12. You and your doctor/nurse/carer should talk over your everyday medical problems and make decisions together.

*Please circle a number.*



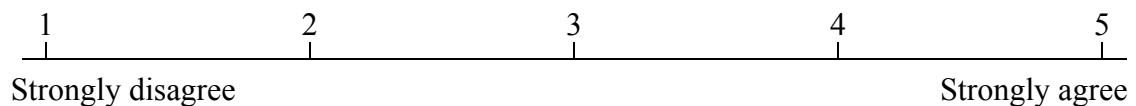
13. If you were sick, as your illness became worse you would want your doctor/nurse/carer to take greater control.

*Please circle a number.*



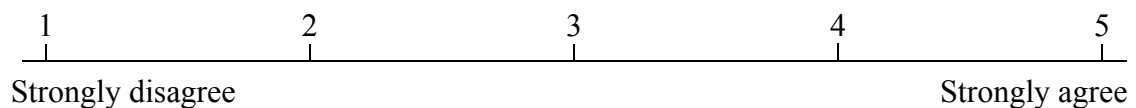
14. If you were sick, as your illness became worse you would want greater control.

*Please circle a number.*



15. If you were sick, as your illness became worse, you would want more discussion and mutual decision making with your doctor/nurse/carer.

*Please circle a number.*



## **Appendix E: Preferences for Involvement in Shared Decision Making Interview Tool (SDM Interview Tool)**

Instructions: *“I am going to ask you some questions about your involvement in your everyday care. By everyday care I am referring to the non-medical aspects of your care. This includes personal care, social and individual activities, relationships with others, your living environment, your routines, and food and dining.”*

1. Do you receive as much information as you would like about your everyday care?  
For example, what activities are on during the day, or what is served at mealtimes.
2. When would you like to receive information about your everyday care?  
For example, at the start of each day or when each activity is happening.
3. How would you like to receive information about your everyday care?  
For example, through conversations with staff, or from noticeboards.
4. Do you think you have enough control in making personal decisions?  
For example what clothing you wear, or what or when you eat.
5. Do you think you have enough control in making social decisions?  
For example, what activities you participate in, or who you sit next to at mealtimes.
6. Do you think you have enough control in making decisions about your environment? For example, the layout of your room, or communal furnishings such as plants.

## Appendix F: Analytic framework

CATEGORY/CODES	DESCRIPTION	EXAMPLES
Addressing hearing loss		
Acceptance	Participant accepts hearing loss or does not view it as a problem	<ul style="list-style-type: none"> <li>Participant accepts hearing loss as God's will</li> <li>Participant does not view hearing loss as problematic</li> </ul>
Denial	Participant denies hearing loss or tries to hide hearing loss	<ul style="list-style-type: none"> <li>Participant denies hearing loss</li> <li>Participant tries to hide hearing loss</li> </ul>
Outcomes of hearing loss		
Emotional response	Participant expresses an emotional response to hearing loss	<ul style="list-style-type: none"> <li>Participant is frustrated by hearing loss</li> <li>Participant is upset by hearing loss</li> <li>Participant expresses a desire to have better hearing</li> </ul>
Loss of information	Hearing loss makes receiving information difficult	<ul style="list-style-type: none"> <li>Hearing loss results in loss of information</li> <li>Participant does not hear parts of conversations</li> <li>Participant experiences difficulty hearing people over the phone</li> </ul>
External factors		
External attribution	Participant attributes communication breakdown to external sources	<ul style="list-style-type: none"> <li>Participant attributes communication breakdown to other people—not the resident's hearing</li> <li>Participant experiences problems understanding accents</li> <li>Participant experiences problems hearing other residents who whisper</li> </ul>

		<ul style="list-style-type: none"> <li>• The setup of the facility makes it hard to hear other people</li> </ul>
Background noise	Background noise contributes to communication breakdown	<ul style="list-style-type: none"> <li>• Background noise leads to communication breakdown</li> <li>• Participant finds background noise distracting</li> <li>• Participant finds it hard to hear other people in a group situation</li> </ul>
Hearing loss coping strategies		
Workarounds	Participant manipulates their environment to improve their ability to receive information	<ul style="list-style-type: none"> <li>• Participant uses closed-captions</li> <li>• Participant turns up the volume on the television</li> <li>• Participant avoids the television or radio</li> </ul>
Enhancing information exchange	Participant employs communication strategies to enhance information exchange	<ul style="list-style-type: none"> <li>• Participant asks people to repeat themselves</li> <li>• Participant lip-reads</li> <li>• Participant informs people of hearing loss</li> <li>• Participant asks people to speak louder</li> <li>• Participant requires close proximity to communicate</li> <li>• Face-to-face communication enhances exchange</li> </ul>
Hearing aids		
The use of hearing aids	Whether the resident wears hearing aids or not or under what circumstances	<ul style="list-style-type: none"> <li>• Participant chooses not to wear hearing aids</li> <li>• Participant finds hearing aids improve hearing ability</li> <li>• Participant has selective use of hearing aids e.g., only during church</li> </ul>

Barriers to hearing aid use	Reasons for non-use of hearing aids	<ul style="list-style-type: none"> <li>• Participant thinks that hearing aids are expensive</li> <li>• Participant's hearing aids are broken</li> <li>• Participant finds that hearing aids do not improve hearing</li> </ul>
High preference for communication with health professionals		
Desire to be informed	Participant wants to be informed about medication, treatments, and illness	<ul style="list-style-type: none"> <li>• Participant expresses a desire for information</li> <li>• Participant needs information to cope with illness</li> <li>• Participant thinks that understanding information is important</li> <li>• Participant would rather receive information than be worried</li> <li>• Participant asks health professionals questions</li> </ul>
Dissatisfaction with communication	Participant prefers to be informed but receives less information than they want	<ul style="list-style-type: none"> <li>• Participant does not receive as much information as they would like</li> <li>• Participant expresses that tests (e.g., blood tests) are not explained</li> <li>• Participant expresses that doctors are too busy to talk to the resident</li> <li>• Participant expresses that doctors do not listen to them</li> </ul>
The provision of choice	Participant would like to be offered choices and options	<ul style="list-style-type: none"> <li>• Participant would like to be offered alternative treatment options</li> <li>• Participant wants to discuss options with a doctor</li> </ul>
Minimal preference		
Little preference for information	Participant has little or no preference in regards to receiving information	<ul style="list-style-type: none"> <li>• Participant believes that sometimes it is better not to be informed</li> </ul>

		<ul style="list-style-type: none"> <li>• Participant believes that there is no use worrying about illness</li> <li>• Participant does not want to be given choices</li> <li>• Participant is not concerned about being informed</li> </ul>
Acceptance of situation	Participant cites age, the stage in life they are in, or the inevitability of illness as reasons for minimal preference for information	<ul style="list-style-type: none"> <li>• Participant has an acceptance of death</li> <li>• Participant believes they are too old to make decisions</li> </ul>
Health professionals as decision makers		
Health professional as experts	Participant views health professionals as medical experts and therefore they should be the ones making medical decisions	<ul style="list-style-type: none"> <li>• Participant believes that doctors' opinions are best</li> <li>• Participant believes that doctors are experts</li> <li>• Participant lacks medical knowledge</li> </ul>
Residents do as they are advised	Participant follows the advice of health professionals	<ul style="list-style-type: none"> <li>• Participant does not want to disagree with a doctor or anger them</li> <li>• Participant believes that it is easier not to ask questions and cause conflict</li> <li>• Participant takes health professionals' advice even when they disagree with it</li> </ul>
Dependence on doctors	Participant reports a high dependence on doctors, and prefers them to make medical decisions	<ul style="list-style-type: none"> <li>• Participant depends on doctors</li> <li>• Participant believes that doctors should make medical decisions</li> <li>• Participant believes that decisions are out of their control</li> </ul>
Residents as decision makers		
Residents want to make decisions about end-of-life care	Participant holds strong opinions about end-of-life care	<ul style="list-style-type: none"> <li>• Resuscitation</li> <li>• Transfusions</li> <li>• Life support</li> </ul>



Resident autonomy	Participant demonstrates autonomy, or makes decisions for themselves	<ul style="list-style-type: none"> <li>• Participant disagrees with doctors</li> <li>• Participant refuses to take medication</li> <li>• Participant makes a decision without assistance from health professionals</li> </ul>
Shared decision making		
Desire for shared decision making	Participant want to engage in shared decision making through consultation with health care professionals and/or family members	<ul style="list-style-type: none"> <li>• Participant has a desire for shared decision making</li> <li>• Participant has a desire for consultation</li> <li>• Participant needs information from a doctor in order to make decisions</li> <li>• Participant wants to be included in decision making</li> <li>• Participant would like to be involved but prefers to leave final decisions to doctors</li> </ul>
Family involvement	Family members are important parties in the decision making process	<ul style="list-style-type: none"> <li>• Participant want family to be involved in the decision making process</li> <li>• Participant recognises the importance of family</li> </ul>
Situational factors		
Health professionals make decisions in serious situations	Participant wants health professionals to take more control over decision making in more serious situations	<ul style="list-style-type: none"> <li>• Participant believes that health professionals should have control when an illness is serious, e.g., during hospitalisation</li> <li>• Participant thinks that they should take doctors' advice when they are very sick</li> </ul>
Self-management of everyday medical problems	Participant prefers to make decisions about minor everyday medical problems such as a cold	<ul style="list-style-type: none"> <li>• Participant knows how to treat themselves for everyday medical problems</li> <li>• Participant believes that there is no point consulting health professionals about minor illnesses</li> </ul>

		<ul style="list-style-type: none"> <li>• Participant prefers to make decisions for minor health problems</li> </ul>
The health professional-resident relationship		
Important relationship characteristics	Participant refers to characteristics that they deem important in the health professional-patient relationship	<ul style="list-style-type: none"> <li>• Trust</li> <li>• Respect for residents</li> <li>• A doctor who listens and will take time to explain information</li> <li>• Personalised care</li> <li>• Supportive health professionals</li> </ul>
Familiarity with health professionals	Participant believes that finding the right health professional and becoming familiar with them is important. Participant draws on experiences with their own doctor/nurse/carer	<ul style="list-style-type: none"> <li>• Participant believes that familiarity with health professionals is important</li> <li>• Participant believes that it is important to find the right doctor</li> <li>• Participant prefers own doctor</li> </ul>
Residents' capabilities		
Body autonomy	Participant has a knowledge of their own body and how they are feeling, or wants control over their own body	<ul style="list-style-type: none"> <li>• Participant understands their illnesses</li> <li>• Participant has knowledge of their own body</li> </ul>
Cognitive abilities	Participant is aware that their mental capabilities can diminish with age and believes that this as an important factor when considering who should make medical decisions	<ul style="list-style-type: none"> <li>• Participant wants to be informed if they are mentally capable</li> <li>• Participant has concerns of mental capacity</li> <li>• Participant has a desire to remain cognitively alert</li> </ul>