

HEARING, COGNITION, AND SOCIAL ISOLATION IN OLDER ADULTS: A PLURALIST APPROACH

NISHA SONIA DHANDA

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ASTON UNIVERSITY

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THESIS ABSTRACT

Hearing, cognition, and social isolation in older adults: a pluralist approach.

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This thesis examined the role of social isolation in older adults living with hearing loss and Dementia. A pluralist approach was used to investigate these associations at both a population and individual level.

A systematic review and meta-analysis investigated whether social isolation was a mediator between hearing loss and later cognitive impairment or onset of Dementia. The review's findings supported an association between hearing loss and later cognitive impairment, but social isolation was not identified as a mediator. The results led to epidemiological analyses of hearing threshold and later cognitive score and hearing threshold and later social isolation score using the Hertfordshire Ageing Study. No statistically significant or clinically significant associations were observed in the multiple linear regression analyses, highlighting the need for more specific measures of social isolation to be used in population-level data.

Substantial planning and engagement work was conducted at four care homes to adequately prepare for ethnographic work, which involved an environmental audit, interviews, and qualitative analysis using Grounded Theory. The ethnographic work aimed to explore the mechanisms that contribute to the experience of social isolation and give voice to the resident, staff, and visitor perspective. The model demonstrated internal and external barriers to communication and how this contributed to sustained social isolation within residential care settings. Residents needed to frequently engage in meaningful conversation and interactions with their peers and staff to feel connected to one another and retain social identity. Their ability to communicate and for care staff to listen through disordered language was the deciding factor in experiencing social isolation. A person's level of hearing impairment was almost irrelevant.

The combined work highlights the complexities of social isolation in older adults. A pluralist approach allowed for novel insight into the mechanisms contributing to and maintaining social isolation.

Index terms by the British Library for the national EThOS Service: Hearing impairment, loneliness, cognitive impairment, residential care, pluralism, communication, ethnography, grounded theory, older adults.

DEDICATION

This thesis is dedicated to my children, Arjan and Amaya. You have been my greatest source of strength throughout this journey and have always helped to put life in perspective. Rajdhir, you have always seen the bigger picture – thank you for helping me to begin seeing it too. Your continued support and encouragement have kept me going these past six years. I will always be grateful. This PhD has seen so many milestones in our marriage and the best is yet to come.

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LIST OF ABBREVIATIONS

AD – Alzheimer’s Disease

ARHL – Age-related hearing loss

BGS – British Geriatrics Society

CI – Confidence interval

CQC – Care Quality Commission

DAG – Directed acyclic graph

GT – Grounded theory

HAS – Hertfordshire Ageing Study

HL – Hearing loss

HR – Hazard ratio

HSE – Health Survey England

IQR – Interquartile range

MCI – Mild cognitive impairment

MMSE – Mini-mental state examination

NIHR – National Institute of Health Research

OR – Odds ratio

PIS – Participant Information Sheet

PPI – Patient and public involvement

PiiAF – Public involvement impact assessment framework

PRISMA – Preferred reporting items for systematic reviews and meta-analyses

SD – Standard deviation

VIF – Variance Inflation Factor

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CHAPTER 1

INTRODUCTION

1.0 Background to thesis

This thesis explores how social isolation and communication impact older adults living with hearing loss and dementia. I examine this complex social experience using a pluralist approach. This introductory chapter provides an overview of my personal interest in the research area, and definitions for the primary conditions investigated in my research. An explanation of pluralism and a framework for the subsequent chapters is outlined. Figure 1 provides a visual representation of how the multiple components within my research were organised.

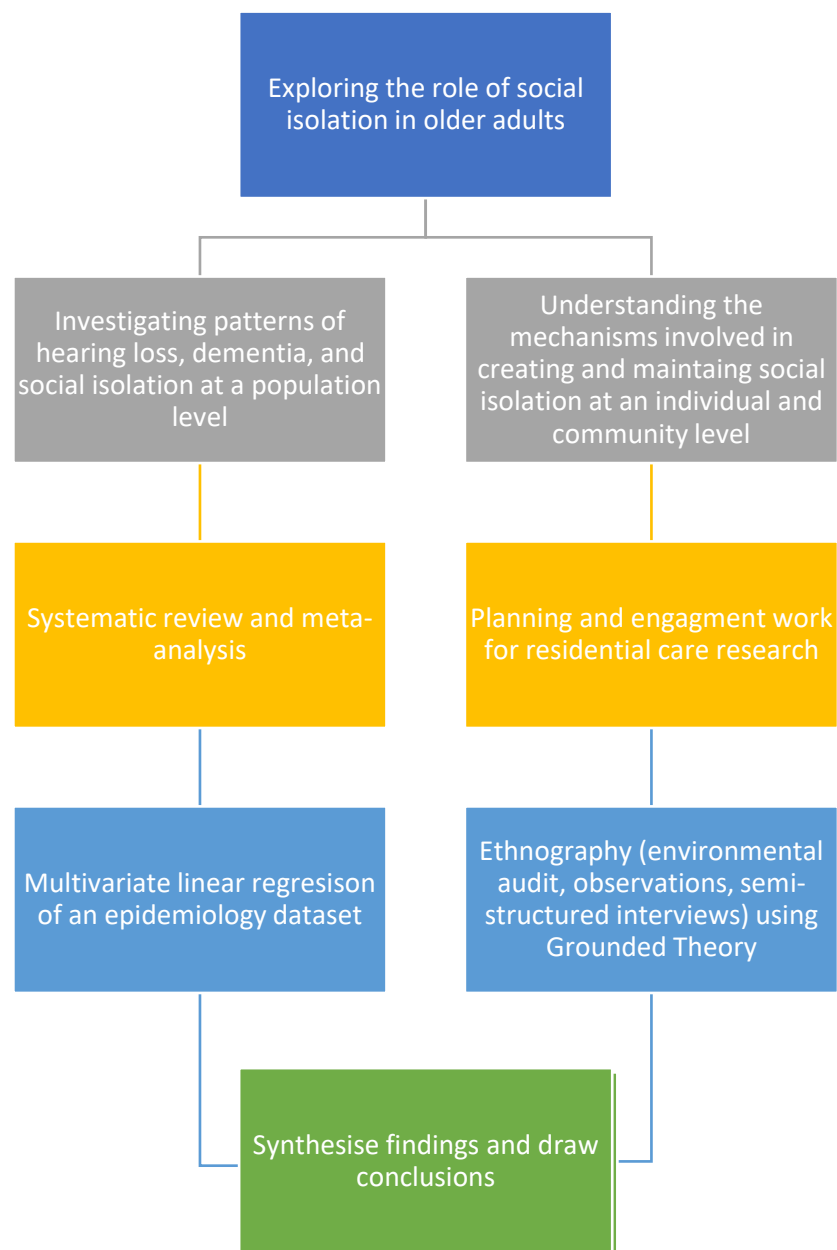


Figure 1: Diagrammatic overview of empirical research

My background in clinical Audiology evoked my interest in the topic area, which stemmed from my undergraduate dissertation topic on the role of hearing aids in auditory-cognitive training. Since then, I have had a variety of clinical, teaching, and public health research roles. They have all contributed to my knowledge and understanding of the topic area, and reinforced the importance of conducting research to enhance the quality of life in older adults.

I have had several years of experience working and talking with older adults who have communication difficulties. When I used to see patients who had multiple comorbidities related to communication such as hearing loss, aphasia, and dementia, it was difficult to witness. This was especially apparent during domiciliary visits to residential care homes. I was struck by the high number of residents who were living with hearing loss and dementia in inept communal environments. What's more, when a monumental paper was published that identified an association between hearing loss and incident dementia (Lin et al., 2011b), there was a lot of traction and interest in understanding the consequences of unmanaged hearing loss. This was a very significant moment in the Audiology community. From a commercial standpoint, hearing aid manufacturers welcomed the news because it implied that hearing aids may have a role in preventing or delaying the onset of dementia. From a clinical standpoint, there was a sense of pride and recognition at the importance of hearing, and related comorbidities. Researchers began to investigate the mechanisms responsible for the association between hearing loss and dementia, from which several studies were borne.

When my clinical career diversified into public health research, the interest in hearing loss, communication, and dementia remained. I kept up with the literature on the topic and started to develop a PhD proposal. Fortunately, a wonderful opportunity arose at Aston University, with like-minded supervisors. The topic area was refined after scoping the literature on mechanism and causal inferences between hearing threshold and later cognitive status. Social isolation was identified as a potential mediator and an outcome of hearing loss and dementia. These hypotheses aligned with my clinical experiences and led me to investigate further using a pluralist approach.

1.1 Age-related Hearing Loss

Age-related hearing loss (ARHL), or presbycusis, is an eventual consequence of ageing (Peelle and Wingfield, 2016). As an individual gets older, there is a decline in their auditory brain's ability to filter out background noise and focus on "wanted" sounds such as speech (Slade et al., 2020). The reason for the decline is a reduction in the outer and inner hair cells found inside the cochlear (hearing organ). Their role is to amplify and fine-tune sounds entering the ear. Most often, there is a loss of sensitivity in the high-frequency sounds, which

are usually at the start and end of words and sentences, i.e., consonants. Still, the sensitivity of low-frequency sounds remains intact or mildly altered (Yamaosba et al., 2013). The difference in sensitivity between high and low frequency sounds can result in a person struggling with the clarity of a conversation or the television, rather than the volume. The methods involved in improving clarity are complex. Whilst hearing aids can help, this is not an optimal solution for many people (Peng et al., 2015). Thus, a situation arises where a person must put in a high amount of effort to listen and engage in conversation (Weinstein, 2019). Listening effort refers specifically to tasks that require attention and is the intentional use of mental resources to overcome difficulties in successful listening (Pichora-Fuller et al., 2016). The consequences of prolonged listening effort may lead to mental fatigue and put pressure on cognitive resources within the brain, which are being used to assist with listening instead of attention, memory, or decision-making (Hornsby et al., 2016).

1.2 Cognition

Cognition covers a broad range of activities including but not limited to learning, remembering, and using knowledge, through thought, experience, and the senses (Belmont, 1989). A natural part of ageing encompasses a reduction in our ability to carry out these processes as sharply and efficiently than as a younger adult (Grady, 2012). However, an important distinction to note is that cognitive impairment, leading to dementia, is not a natural part of ageing (Pacifico et al., 2022). Cognitive impairment is characterised by difficulties with memory, learning new things, focusing, or making decisions that have an impact on daily activities (Petersen, 2016). The spectrum of cognitive impairment extends from mild to severe. Individuals living with mild cognitive impairment may notice alterations in their mental functions but continue to perform their daily activities. Severe cognitive function loss can result in the inability to communicate entirely (Gauthier et al., 2006). When cognitive impairment becomes severe enough, an individual is diagnosed with dementia (Hugo and Ganguli, 2014). Dementia is an umbrella term for loss of memory and other abilities related to thinking and processing. Although age is a big risk factor for dementia, there is no guarantee that developing dementia will be part of the ageing process (Baumgart et al., 2015). The consequences of cognitive impairment and dementia can lead to older adults withdrawing from social interactions out of fear of not understanding/remembering conversation or the context (Goldberg et al., 2021).

1.2.1 Mild Cognitive Impairment (MCI)

Although cognitive deficiencies in people with MCI are often more severe than would be predicted for their age and education level, these deficits do not seriously impair their ability to carry out daily duties (Petersen, 2004). These individuals are at a higher risk of developing dementia, confirming the idea that MCI is a stage between ageing without disease and

dementia (Simons et al., 2002). Individuals with MCI are excellent candidates for cognitive intervention because they are often aware of and concerned about their cognitive abnormalities, which increases their motivation to participate in treatment (La Rue et al., 2015). People with MCI retain a wide range of cognitive abilities, which may be the most important aspect of this condition. The ability of the brain to adapt physically and functionally to changes in its environment and/or its own integrity is known as brain plasticity, which is a crucial aspect of cognitive intervention (Lövdén et al., 2012). Once the severity of MCI extends beyond effective management strategies, dementia begins to take its course (Petersen, 2016). Evidence-based management strategies for MCI include cognitive training (Hill et al., 2017), lifestyle changes such as increased physical exercise and improved diet (Ngandu et al., 2015), and medications such as cholinesterase inhibitors, which are designed to increase communication between nerve cells and stabilise symptoms of MCI (Matsunaga et al., 2019). A recent systematic review investigating the possible treatment options of MCI reported the need for more high quality randomised controlled trials, and to consider the value of both conventional and alternative management strategies (Chen et al., 2021).

1.2.2 Dementia

Dementia is a neurocognitive illness. It is progressive and affects one or more cognitive domains, making it difficult to carry out daily tasks. There are over one hundred types of dementia. All types of dementia affect the language, memory, and decision-making areas of the brain. Alzheimer's disease is the most prevalent form of dementia (Duong et al., 2017), accounting for 60-80% of cases. There are multiple risk factors for Alzheimer's Disease, including potentially modifiable sensory changes (Livingston et al., 2017).

Dementia complications include behavioural and psychological symptoms. The most common symptoms such as agitation and aggression can be distressing for individuals living with the condition (Muangpaisan, 2007). There are very few medical interventions that can support the many behavioural and psychological symptoms associated with dementia (Feldman et al., 2008). Holistic approaches to management are therefore more appropriate, complimenting the management of any comorbidities.

The focus of the thesis was the impact of communication and social isolation on people living with dementia and hearing loss. All types of dementia affect a person's ability to communicate effectively (Banovic et al., 2018). Therefore, dementia as a whole was considered within this research, rather than specifying and differentiating between individual types.

1.3 Social isolation

The definition of social isolation is the lack of meaningful relationships with people (Biordi and Nicholson, 2008), and an individual's level of social connectedness and meaningful engagement within their social context. It is different from loneliness, as loneliness is the distress arising from being alone (Leigh-Hunt et al., 2017). Social isolation is significantly higher in older people, as they often have factors such as loss of friends, illness, loss of sensory functions (such as diminished hearing or vision) that makes a lack of meaningful interactions more likely (Holt-Lunstad et al., 2015). Older adults' physical and mental health is seriously and pervasively threatened by social isolation. It can be said to have both an objective component and a subjective component (having a small social network and participating in few social events) (i.e., the emotional experience of feeling isolated and alone) (National Academies of Sciences Engineering & Medicine, 2020).

1.3.1 Consequences of social isolation

Social isolation can result from unmanaged hearing loss (Shukla et al., 2020), as well as from cognitive impairment and dementia (Poey et al., 2017). Previous studies have not investigated whether social isolation acts purely as an outcome of these conditions when they coexist or as a mechanism or catalyst for cognitive impairment. The opportunities and challenges faced by older adults attempting to communicate with unmanaged hearing loss make this phenomenon complex (Barker et al., 2017). Furthermore, when the environment and other external factors have not been appropriately considered for optimal communication, motivation to communicate and socially interact declines (Ludlow et al., 2018). This decline in communication may be exacerbated when dementia and disordered language are present (Downs and Collins, 2015). Therefore, a person's social context, environment, and motivation for communication impact the extent to which social interaction occurs. I have used these elements to explore social isolation. Three empirical pieces of research were conducted to contribute to the knowledge of social isolation, hearing loss, and dementia. Within a pluralist framework, both quantitative and qualitative methods were used. This approach was based on the possible mechanism between hearing, cognition, and social isolation. The experience of hearing loss cascades into social disengagement which accelerates brain atrophy, leading to cognitive decline (Dawes et al., 2015b).

1.4 Pluralism

In this research, "pluralism" refers to using multiple methods to examine research questions. It may involve combining epistemologies or selecting multiple methods from a single epistemological viewpoint (Lassman, 2011). Pluralism is commonly aligned with the multiple

uses of qualitative methods (Frost et al., 2010). Though it is used across ontological worldviews (May et al., 2017). Therefore, I have interpreted pluralism as using multiple qualitative and quantitative methods guided by the different epistemologies they're associated with. Pluralist approaches embrace the advantages of employing several lenses to examine data as part of a programme of research while acknowledging the complexity of events (Oakley, 1998).

I have used pluralism to investigate and explore the complex phenomenon of social isolation and its interactions with hearing loss, cognitive impairment and dementia. To understand patterns and trends in population-level data, I conducted a systematic review, meta-analysis, and multiple linear regression analyses of a cohort dataset. I conducted an environmental audit, interviews, and ethnographic observations to understand mechanisms, contextual factors, and the lived experience of older adults in residential care settings. Both approaches were vital to grasp the complexities of the conditions being researched, using the most appropriate methodologies and methods. Therefore, the research questions led to the decision of how to research the topics, rather than the methodology or method being the initial focus.

Multiple approaches can be employed to effectively respond to a research issue within the same or different ontological viewpoints. A positivist approach was used to provide a level of objectivity at the population level, and an interpretivist approach was used to generate a comprehensive description of subjective experience and meaning.

This PhD work aims to understand how social isolation and communication impact the relationship between hearing and cognition. At a population level, I identify patterns and trends of hearing loss, social isolation, and dementia. These findings help explain how and why social isolation occurs at a micro level via ethnography and interviews. Adopting different paradigms relevant to each research question allows a better understanding of the multidimensional and multi-ontological complexity of the lived human experience (Shaw and Frost, 2015). Pluralism supports the exploration of complex human experience, which cannot be reduced to single-method studies and will be discussed in detail in the coming chapters.

1.5 Outline of chapters

Chapter 2 provides a comprehensive overview of the background literature relevant to this thesis. The interactions between sensory decline, cognitive decline, and social isolation are discussed. Chapter 3 is a methodology chapter that describes the philosophical underpinnings of the programme of work. Chapter 4 details the systematic review and meta-analysis conducted to investigate the association between hearing loss and cognitive

impairment/dementia and whether social isolation is a mediating factor. Chapter 5 outlines the epidemiological analysis of the Hertfordshire Ageing Study dataset, where two multiple linear regression analyses were conducted to investigate an association between hearing threshold and later cognitive score and hearing threshold and later social isolation score. Chapter 6 details the planning and engagement phase of the qualitative work, which was conducted in four residential care homes prior to the ethnographic research. Chapter 7 explores communication in residential settings to understand the impact of social isolation on people living with hearing loss and dementia at a micro level. In this thesis, residential care settings/care homes are defined as privately owned care facilities for older adults, with nursing care included. The specific residential care settings used in this research specialised in dementia care. This chapter describes the ethnography and semi-structured interviews conducted at two care homes in Birmingham, UK. These homes were contrasting in socioeconomic characteristics. This chapter further outlines the grounded theory model developed inductively from the data. It also describes the recommendations for possible interventions to reduce the risk of social isolation in residential care settings for older adults living with hearing loss and dementia concurrently. Chapter 8 synthesises the overall findings and presents the conclusions of the programme of work. There is also a discussion of the lessons learned from using a pluralist approach, as well as the limitations and recommendations identified from the empirical studies.

The key research questions through this pluralistic approach are listed below.

1.6 Research questions

- 1. What is the current evidence to support the hearing-cognition association?**
- 2. Does hearing loss cause later cognitive impairment and/or dementia diagnosis in adults?**
- 3. Is social isolation a mediating factor in the relationship between hearing loss and later cognitive impairment/dementia diagnosis?**
- 4. Is there population level evidence to support an association between hearing threshold and later cognitive score, and hearing threshold and later social isolation presence in older adults?**
- 5. How is communication affected in older adults living with hearing loss and dementia in residential care settings?**
- 6. How is social isolation created and maintained in older adults living with hearing loss and dementia within residential care settings?**

CHAPTER 2

BACKGROUND LITERATURE

2.1 Introduction

The focus of this background chapter will be to introduce the concepts of ageing in relation to hearing, communication, cognitive impairment leading to dementia, and social isolation. I will discuss the prevalence of hearing loss in older adults, typical management of hearing loss, and consequences of unmanaged hearing loss. This discussion considers studies on ageing, sensory decline, and the effects of hearing loss. The diminished ability to communicate and the consequences of social isolation are discussed in detail.

The population of interest in this thesis is older adults. A brief introduction into care facilities and communication within these facilities is provided to represent the proportion of older adults living in residential care. Additionally, the multifaceted nature of this research inquiry is highlighted, leading to the need for a pluralistic study approach. The topics to be discussed will include communication, social isolation, and cognitive impairment leading to dementia. Furthermore, the landscape of residential care settings within the context of older adults living concurrently with hearing loss and dementia will be explored.

2.2 Sensory decline and ageing

As individuals age, their sensory functioning naturally declines (Fischer et al., 2009; Correa-Jaraba et al., 2016). This decline may be termed "global sensory decline", whereby a noticeable deterioration of all five senses (hearing, vision, touch, smell, and taste) is experienced as an individual ages (Gopinath et al., 2013). The consequences of these declines may involve both social and physical health outcomes (Fischer et al., 2009), but their influence on communication and quality of life among older adults remains unknown.

Age-related alterations should be considered, where chronic conditions in older adults are concerned. The physical outcomes of ageing include reduced balance and gait speed, walking endurance, cognitive decline, and frailty (Davis et al., 2016; Martinez-Amezcuca et al., 2021). However, more research is needed as to how aging results in many of these outcomes (Brenowitz et al., 2020). The social outcomes of ageing may include anxiety and depression, which lead to withdrawal and isolation (Hämäläinen et al., 2019). The effects of these experiences are neither well understood nor well documented (Fried et al., 2020). Gaining insight into the lived experiences of older adults with these conditions may support the development of interventions to tackle both the physical and the social outcomes of the ageing process.

Social isolation is an unfortunate consequence of sensory decline and ageing (Hämäläinen et al., 2019), and by extension, frailty. Frailty exists in a social world full of connections and opportunities that can be embraced voluntarily or that become inaccessible due to a person's

circumstances in a specific setting and within a particular health and social care system (Shaw et al., 2018a). Frailty is characterised by a state of heightened vulnerability brought on by reserve and function declines across several physiologic systems as we age. As a result, it becomes more difficult to manage ongoing or sudden pressures. (Xue, 2011). This definition implies associations between ageing, frailty, and sensory decline (Chen et al., 2015; Swenor et al., 2015), and may provide a gateway to understanding the role of social isolation within the ageing process. Nonetheless, it is important to acknowledge frailty as a contentious concept. Grenier et al. (2017) introduced the concept of "frailed" old age, which refers to the ways in which the social and cultural context of aging can contribute to the vulnerability and precariousness of late life. They argue that a more comprehensive understanding of dementia and ageing must consider the social and cultural factors that shape experiences of dementia and ageing. Grenier's research (2012) has also highlighted the importance of understanding the diversity of experiences of dementia across different cultural and social contexts. For example, she has shown how cultural factors such as ethnicity, gender, and class can shape experiences of dementia and impact on the care provided to older people with dementia. This highlights the need for a more person-centred and holistic approach to care for older people with dementia and underscores the importance of addressing broader social and cultural factors that shape experiences of ageing and dementia (Ferrer et al., 2017).

There is a bidirectional relationship which shows that a person experiencing social isolation may be more vulnerable to becoming frail (Davies et al., 2021), whilst a person that has a high level of frailty may be more likely to be isolated because of their lack of mobility or ability to engage with others (Nicholson et al., 2012; Fried et al., 2020). The rate of social isolation and frailty varies according to an older adults' health and general functioning (Collard et al., 2012). The availability of health resources is likely to vary between communities, but unlikely to account for the variation in health and functioning, which can be as high as 16% (Collard et al., 2012). An individuals' varying levels of resiliency may be one possibility for this variation identified, as it may contribute to how well older adults experience daily life and function (Whitson et al., 2018).

Strong connections between age-related changes in sensory and cognitive tests provide the primary evidence for resilience and compensatory mechanisms (Lindenberger and Baltes, 1994; Baltes and Lindenberger, 1997). Neuroimaging studies that discovered older persons engaged higher cognitive abilities (prefrontal cortex increase in connectivity) to make up for visual processing deficiencies provide more evidence for this notion (Dennis and Cabeza, 2011). These data shows that the impact of declining sensory functioning on brain function is more than previously believed (Grady, 2012). Therefore, an understanding of the mechanisms involved in sensory decline and ageing will help to develop appropriate interventions for

improving the lived experience of older adults, in relation to communication and social interaction. Age related hearing loss and its effects are discussed in detail in the coming sections

2.3. Hearing loss in older adults

Communication is a fundamental component of human connection and social engagement and a breakdown in communication can create feelings of dissolution, disconnect, and withdrawal (Choi et al., 2015). Childhood experiences shape our worldviews and help us understand the world around us. As we proceed into adulthood, our communication patterns and styles reflect our personalities and the quality of our social networks (Socha and Beck, 2015). Communication styles specific to each person is enhanced as we age, reflecting on our lives and what we would like to achieve in our later years. Successful communication facilitates opportunity and happiness within a person's life. Any barriers to successful communication can diminish our ability to feel connected and engaged with those around us (Choi et al., 2015).

2.3.1 Presbycusis

Naturally, hearing deteriorates with age, making it harder for older people to interact with others (Ciorba et al., 2012). Presbycusis affects roughly one third of adults in their 40s, half of adults in their 50s, and three-quarters of individuals in their 60s (Agrawal et al., 2008). Nearly 80% of those over the age of 80 show evidence of clinically relevant sensorineural hearing loss, making age-related hearing loss nearly universal among older people (Lin et al., 2013). Due to its great incidence, presbycusis is one of the most prevalent chronic health diseases in developed countries like the US and the UK and among the major issues impacting ageing populations internationally (Agrawal et al., 2008). Presbycusis is a condition that is becoming more and more common as the world's population ages and grows (Mathers and Loncar, 2006). Recent evidence has indicated a socioeconomic difference in hearing loss prevalence across the UK, with a marked difference between the North and South of England (Tsimpida et al., 2020). Therefore, hearing health inequalities exist and should be considered as part of a wider public health response to auditory rehabilitation in older adults.

Together with cognitive deficits, rapid neurocognitive decline, and an increased risk of dementia, age-related hearing loss has a detrimental effect on communication and quality of life (Ford et al., 2018; Loughrey et al., 2018). Although managing presbycusis has not been a primary consideration for society and health policy makers in the UK, despite the widespread effects of age-related hearing loss, there is a need to better understand the connection

between hearing loss, its effects on cognition, and the likelihood of developing memory loss and dementia.

It is important to understand the complexities of presbycusis and how communication is affected when this problem is left unmanaged, because communication is a social experience that enhances quality of life (Simmons-Mackie et al., 2014). Recent epidemiological data on hearing loss prevalence across the UK has shown a wide distribution in prevalence according to geographical location and socio-economic status (Tsimpida et al., 2020). This variation highlights the modifiable nature of hearing loss and the interventions that may help to overcome associated inequalities. The management of hearing loss among older adults, however, requires further investigation.

Presbycusis has subtleties that can be used to illustrate how it relates to and impacts communication. Typically, age-related hearing loss affects both ears equally and is symmetrical (Cruickshanks et al., 1998; Gates and Mills, 2005). What's more, age-related hearing loss is slightly more common in men than in women (Cruickshanks et al., 2003).

A complete audiological evaluation, which may include threshold and suprathreshold speech perception tests, immittance measurements, pure tone air and bone conduction threshold testing, and detailed case history are used to obtain a clinical diagnosis of age-related hearing loss. Pure tone thresholds measure the lowest volume of sound that a person can hear across the frequencies that are most crucial for speech comprehension (measured in decibels hearing level, dB HL). The frequencies tested range from 0.25–8 kHz. Pure tone hearing thresholds may vary across the frequency range from mild (21–40 dB HL), moderate (41–70 dB HL), severe (71–95 dB HL), to profound (>95 dB HL) (Song et al., 2009). Pure tone average (PTA) or high-frequency pure-tone average (HFPTA) measurements of hearing loss are frequently used to describe the severity of the condition (average pure tone air conduction thresholds at several higher frequency thresholds, e.g., 2, 4, 6 kHz). Loud sounds become uncomfortable considerably more quickly in listeners with sensorineural hearing loss than in those with normal hearing in many persons with age-related hearing loss (Moore, 2015). Communication in social situations where there is background noise or loud music playing may be badly impacted by this acceleration.

Therefore, the complexities of the auditory system should be considered, as communication depends not only on hearing, but also on listening and sound processing. A common misconception about presbycusis is that sound becomes less audible, but in fact, the clarity of the sound is usually the main issue (Chien and Lin, 2012). As most are sensorineural losses, cochlear damage results in processing difficulties and signal degradation (Chang et al., 2012), that can cause increased listening effort.

2.4 Social consequences of hearing loss

Hearing loss can be described as both a sensory loss and a social loss (Heine and Browning, 2004). The ability to communicate successfully is a valuable component of living well and synonymous with quality of life (Kamil et al., 2015). People with hearing loss often find social interactions less gratifying because they find it difficult to discern between background noise and dialogue (Shukla et al., 2020). Therefore, the communication issues brought on by hearing loss may promote seclusion and retreat, which decreases cognitive stimulation (Lara et al., 2019a). Older adults in care settings with significant hearing loss experience up to twice the likelihood of social isolation, which is indicative of a predisposition to isolate oneself (Mick et al., 2014).

Due to the difficulty of separating a conversation from background noise, individuals with hearing loss frequently find social interactions less satisfying. Consequently, they may withdraw from social situations, diminishing their social and cognitive stimulation, increasing their isolation, and possibly leading to depression (Maharani et al., 2019). These skills are lost when they are no longer used or when they are not kept current with participation in social events. This process most likely has neural correlates, such as the deterioration of auditory signal processing (Pelle and Wingfield, 2016).

Much of the current research on hearing loss and social-emotional health focuses on persons aged 60 and older (Dawes et al., 2015b; Heffernan et al., 2019). Previous studies investigated how hearing loss and mental health for this age group are affected by social isolation, stigma, and low self-esteem (Shukla et al., 2020; Xiang et al., 2020). The most prevalent symptoms among older adults with hearing loss included anxiety and social isolation, linked to physical changes (Arslan et al., 2018).

When considering the components of aural rehabilitation as part of an aim to improve communication and social interaction, several approaches can be used, tailored to the individual. Aural rehabilitation consists of a variety of interventions (e.g., auditory training, hearing therapy, amplification devices) designed to alleviate the difficulties experienced by individuals with hearing loss. Hearing aids, the primary intervention, can improve hearing-related quality of life, as well as life overall. However, multiple challenges arise with the use of hearing aids, especially for older adults: for example, the dexterity required to manipulate the small controls (Kumar et al., 2000), as well as having the cognitive ability to process the sounds (Maharani et al., 2018). Aural rehabilitation methods are generally not adopted or followed properly. Particularly, many people who could benefit from wearing hearing aids do not, typically because of poor follow-up care, maintenance issues, discomfort, and stigma

(McCormack and Fortnum, 2013). Additionally, because hearing aids increase both background noise and target sounds (such as a companion's voice), they may be unhelpful in social situations (e.g., music, conversation). Additionally, patients' psychosocial concerns are routinely ignored (Ekberg et al., 2014), and there aren't any standardised, research-based methods to deal with them. As a result, social isolation among people with hearing loss is not well addressed by existing auditory rehabilitation methods (Wallhagen, 2010).

2.5 A review of hearing loss and social isolation

To determine the relationship and direction of causality, a narrative review of hearing and social isolation was done. The assessment of loneliness cannot be disregarded in a review of the literature on hearing loss and social isolation. Older research failed to connect hearing to loneliness (Christian et al., 1989, Chen, 1994). The definition of loneliness and people's understanding of the notion at the time of the investigation could be contributing factors. While prior studies linking hearing loss with loneliness relied on self-report or audiometric hearing evaluation, more recent studies have used online speech-in-noise tests to determine hearing sensitivity. Self-report surveys can show that up to 20% of persons are unaware they have a hearing impairment (Kiely et al., 2012a), when compared to audiometric testing. This discrepancy should be considered when interpreting findings from studies that have used self-report measures.

The 11-item Loneliness Scale (De Jong-Gierveld and Van Tilburg, 1990) and the modified 20-item UCLA Loneliness Scale (Russell et al., 1978) were commonly used in studies investigating hearing loss and social isolation or loneliness. The former is a 3-point scale, and the latter is a 4-point scale. Both questionnaires are scored such that higher values signify greater loneliness. Older adults with hearing loss reported feeling lonelier than those with good hearing, according to several cross-sectional studies (Tomioka et al., 2013; Wells et al., 2020). Since the inception of both questionnaires, the perceptions of isolation and loneliness have changed greatly, and they may no longer reflect today's lived experience (Elphinstone, 2018).

Older individuals who self-reported having a hearing impairment were more than twice as likely to be lonely than those who did not (Tomioka et al., 2013). More specifically, the UCLA loneliness score increased by 1.43 points for every 10 dB increase in pure-tone average hearing threshold. When the results were stratified by severity of hearing loss, the authors found that those with severe or profound hearing loss had scores averaging 13.6 points higher compared to those with normal hearing. Having said that, it is important to recognise there was a wide confidence interval, which may have arisen from the limited sample size among participants with severe to profound hearing loss, leading to lower external validity. The

relationship between hearing loss and loneliness may be influenced by sex in addition to the severity of hearing loss. Ramage-Morin (2016) revealed differences in hearing loss and loneliness when stratified by sex. In contrast to men (OR 1.00; 95% CI 0.97-1.04), loneliness was linked with self-reported hearing problems in women (OR 1.04; 95% CI 1.00-1.09). Even while the difference was minimal, it could be a sign that women are more severely impacted by untreated hearing loss and loneliness than males.

The Amsterdam Longitudinal Aging Study was used to investigate hearing impairment and loneliness (Pronk et al., 2011, Pronk et al., 2014). The 11-item Loneliness Scale (De Jong-Gierveld and Van Tilburg, 1990) consists of 11 questions and is separated into two categories—social loneliness (five of which are related to social integration impairments) and emotional loneliness—was used to quantify loneliness in both investigations (six items related to the absence of intimate attachments with friends and family). There was no correlation between social loneliness and either self-reported or objectively tested hearing status. However, objectively assessed hearing status was linked to feelings of isolation. There is not enough evidence to determine causality from this analysis, however, highlighting the difference in the types of loneliness that can result from unaddressed hearing loss.

Numerous research on the relationship between hearing loss and social isolation show that older people with hearing loss are more socially isolated than those with normal hearing (Mick et al., 2018). For instance, a smaller social network or a poorer social support score were linked to self-reported hearing loss rather than social network variety. Quality therefore prevails over quantity in a person's social network. Hearing loss was linked to social isolation in women but not men, as was the case with the findings of hearing loss and loneliness (Mick and Pichora-Fuller, 2016). Due to poorer auditory processing, older women may be more vulnerable to the social and emotional effects of being cut off from their social surroundings. On the other hand, women might be more prone than men to report feeling lonely or having less social support.

Overall, these results imply that hearing loss may have a major impact on older persons' psychosocial and cognitive health. Despite the diversity of isolation assessment methods, hearing impairment is particularly more typically linked to social isolation than to loneliness. As a result, even while hearing loss can socially isolate older persons by reducing their involvement in activities or shrinking their social network, it may not always result in loneliness. An emotional reaction to the perceived discrepancy between levels of wanted and actual social connection is loneliness. Older persons who consider social isolation as a normal part of ageing or who desire a smaller social circle as they get older may not feel lonely despite their

social isolation. Social isolation and loneliness are therefore related but distinct constructs (Leigh-Hunt et al., 2017).

The link between hearing loss and social isolation and loneliness may be explained by several factors. One of these is age-related hearing loss, which decreases the cochlea's peripheral auditory processing, making it more challenging to understand audio information and follow conversations (Mick et al. 2014). Older adults can avoid potentially embarrassing social situations if they have difficulty following conversations, especially in large groups or with loud background noise. Degraded cochlear auditory processing may also increase cognitive load and diminish a person's cognitive reserves for social activity and interactions (Dawes et al., 2015a).

The relationship between hearing loss, loneliness, and social isolation has significant impact on public health. Older people with hearing loss who are lonely and socially isolated could have depression and other mental health problems as a result (Shukla et al., 2020). Major conclusions can still be drawn despite the diversity of the work that has already been done. Numerous cross-sectional studies with a range of demographics have shown a relationship between hearing loss and increased social isolation and loneliness (Dawes et al., 2015b; Maharani et al., 2019). These findings have significant implications for the mental, emotional, and behavioural well-being of older hard-of-hearing individuals. Additional longitudinal research is required to determine whether there is a causal relationship between hearing loss and a higher risk of social isolation and loneliness. In addition, the associations between hearing and other outcomes related to communication and social interaction are imperative for exploration. The next section discusses the hearing-cognition relationship, including listening effort and possible mechanisms.

2.6 Hearing loss and cognition

2.6.1 Listening effort

The number of resources or amount of energy expended by a listener to meet cognitive demands is referred to as listening effort (Pichora-Fuller et al., 2016). The concept of listening effort ties into the processes of selective attention i.e., the techniques that let someone choose and concentrate on a certain input for further processing while simultaneously quashing irrelevant or distracting information (Stevens and Bavelier, 2012). Words or syllables that are acoustically degraded are more challenging to remember, even when speech is mostly comprehended (Heinrich et al., 2016), making selective attention and listening effort more challenging. This impact is amplified in older adults living with unmanaged presbycusis who struggle with high-frequency clarity and processing of sounds (Heinrich and Schneider, 2011).

The motivation of individuals to persevere with listening effort in the context of hearing loss and cognitive decline, may contribute to the theories and mechanisms linking the two. A recent meta-analysis (Carolan et al., 2022) found that motivational factors such as individual traits, had a moderate effect on listening effort. The studies were classified as having a high a risk of bias, limiting the validity of the findings, but the breadth of motivational factors analysed, provides scope for further investigation into how individual traits and other factors such as perceived competence, interact with listening effort and cognition. What's more, the cognitive processes involved, namely executive function and self-regulation abilities, allow us to prioritise, plan, pay attention to details, recall information, and manage various tasks (Diamond, 2013). These processes must be considered as part of the 'work' required for people with hearing loss to listen to and process sound, whilst selectively attending to wanted sound sources.

2.6.2 Hearing-cognition mechanisms

The literature has frequently referenced the link between hearing and cognition. Hearing loss has been associated with dementia, in addition to social isolation and activity limitations (Lin et al., 2013). Many theories and mechanisms, including widespread neural degeneration, where hearing loss and cognitive decline share neurodegenerative causes that are probably vascular in nature, have been proposed, despite the lack of a clear causal mechanism between hearing loss and later cognitive impairment leading to dementia in older adults. Long-term auditory deprivation impairs cortical input in sensory deterioration, leading to neuroplastic alterations that eventually lead to dementia and cognitive decline (Pichora-Fuller, 2003). In this context, cognitive resource allocation relates to how hearing loss causes cognitive resources to be redirected from memory function to speech perception, increasing cognitive burden and resulting in dementia and cognitive decline.

There are varied prevalence rates of hearing loss and dementia, depending on demographic factors. In the UK, the prevalence of hearing loss is roughly 42% for males and 39% for women between the ages of 71 and 80 (Akeroyd et al., 2013), but it rises dramatically after that. According to Matthews et al. (2013), there is a 6.5% prevalence of dementia among those over 65 in the UK, however this incidence dramatically rises with age, reaching 17% at age 85 to 90 and 30% at age >90. Certain demographic groups, particularly nursing home residents, who are the most impacted, are affected by both illnesses (Gordon et al., 2014b). Hearing loss and dementia usually coexist because they are both age-related conditions that are very common in older age groups. For instance, 60% of patients at a tertiary memory clinic were found by Nirmalasari et al. (2017) to have at least a slight hearing loss in their better-hearing ear.

Dementia is a term used to describe a range of neurological disorders that affect memory, thinking, and social abilities. According to the World Health Organization (2012), dementia is a syndrome that is often characterised by progressive deterioration in cognitive function beyond what might be expected from normal aging. It is estimated that 50 million people worldwide are living with dementia, and this number is expected to triple by 2050.

One of the main challenges in understanding and treating dementia is the fact that it is not a single disease but rather a spectrum of disorders with different underlying causes and manifestations (Ritchie and Lovestone, 2002). The most common types of dementia are Alzheimer's disease, vascular dementia, Lewy body dementia, and frontotemporal dementia. Each of these subtypes has distinct clinical features, pathology, and prognosis.

Alzheimer's disease is the most common type of dementia and is characterised by the accumulation of beta-amyloid plaques and tau protein tangles in the brain. Vascular dementia, on the other hand, is caused by a series of small strokes or reduced blood flow to the brain (Jellinger, 2013). Lewy body dementia is characterized by abnormal protein deposits called Lewy bodies, which affect thinking, movement, and behaviour (McKeith et al., 2017). Frontotemporal dementia affects the frontal and temporal lobes of the brain and can result in changes in personality, behaviour, and language (Ritchie and Lovestone, 2002; Rabinovici and Miller, 2010).

Although the different subtypes of dementia have distinct features, there is also considerable overlap in symptoms and underlying pathology. For example, individuals with Alzheimer's disease and vascular dementia may have similar symptoms, such as memory loss and difficulties with language and spatial orientation (Knopman et al., 2021). Moreover, there is growing evidence that many individuals with dementia have mixed pathology, with multiple brain changes contributing to their cognitive decline.

Communication is a complex and fundamental aspect of human interaction, and it is often one of the first cognitive functions affected by dementia. The effects of dementia on communication can vary depending on the type and severity of the disorder (Egan et al., 2010). In the early stages of dementia, communication difficulties may be subtle and easily overlooked. However, as the disease progresses, individuals with dementia may have difficulty finding the right words, following conversations, and understanding complex sentences. They may also struggle with nonverbal communication, such as interpreting facial expressions and body language. As dementia advances, individuals may experience aphasia, which is a language disorder that affects their ability to communicate effectively (Cations et al., 2020).

The effects of dementia on communication can have significant implications for individuals with the disorder, their families, and their caregivers. Difficulties with communication can lead to frustration, isolation, and social withdrawal, which can exacerbate cognitive decline and reduce quality of life (Ellis and Astell, 2017). Caregivers may also find it challenging to communicate with individuals with dementia, which can contribute to stress and burnout (Boyle et al., 2018). When hearing loss is combined with the communication difficulties associated with dementia, significant consideration is required to enable the wellbeing of individuals.

One of the earliest studies to link hearing loss and dementia used a case-control design to find that people diagnosed with Alzheimer's disease were two times more likely to have a hearing loss of at least 30 dB compared to controls. Since then, numerous research, including extensive longitudinal investigations, systematic reviews, and meta-analyses, have revealed related findings (Lin et al., 2011b; Ford et al., 2018). The risk ratio for incident dementia is 1.89 (95% CI, 1.00-3.58) for mild hearing loss, 3.00 (95% CI, 1.43-6.30) for moderate hearing loss, and 4.94 (95% CI, 1.09-22.40) for severe hearing loss, according to Lin et al. (2011b). More severe dementia appears to be associated with more severe hearing loss. The generalisability for severe hearing loss was constrained by the small sample of participants (six individuals) with severe hearing loss who were included in this analysis, which contributed to the large confidence intervals.

The nature of the relationship between the two conditions, how they develop over time, or the potential underlying mechanisms are all unknown due to the cross-sectional design used in previous studies. Although numerous potential theories (Uchida et al., 2019) have been put forth, the exact process behind the relationship between hearing loss and dementia is unknown (Livingston et al., 2017). Due to diminished or distorted sensory input, hearing loss is likely to elevate the cognitive load needed to process speech (Panza et al., 2015). Consequently, excessive cognitive load may result in structural changes in the brain and further neurodegeneration, although there is little direct evidence for this suspicion (Anwar et al., 2022).

Hearing loss is associated with faster wide-spread brain atrophy and localised right temporal lobe volume reduction, according to findings from the Baltimore Longitudinal Study of Aging (Lin et al., 2011a). Chronic hearing loss reduces the auditory-limbic pathway's function, the central auditory pathway's activation, and the frontal lobe atrophy brought on by deafferentation (Rutherford et al., 2018). Hippocampus atrophy has also been connected to hearing loss (Uchida et al., 2019). This hypothesis proposes a shared link between hearing loss and cognitive deterioration, whereby the deafferentation extends to cognitive centres of the brain, accelerating cognitive decline. What's more, there are various risk factors that both

hearing loss and cognitive decline share, the majority of which are cardiovascular risk factors, which increase the risk of heart disease and stroke (Lin et al., 2013). The APOE 4 allele has been hypothesised to increase risk, however this has not been verified and further genetic studies are needed (Shen et al., 2018).

2.6.3 Clinical considerations

Multiple factors, including sensory impairment, influence people's performance on the cognitive tests used to diagnose cognitive impairment (Dupuis et al., 2015; Jorgensen et al., 2016). For instance, if a person cannot hear the question being asked, they will be less likely to provide the correct response. Under any circumstances, it is easy to underestimate the extent to which hearing loss impairs test performance. Such underestimation is especially problematic when assessments are administered in noisy environments, such as hospitals. Consequently, a person with a hearing loss and normal cognition might be misdiagnosed, carrying obvious negative consequences for that individual.

In patients with dementia, hearing loss is commonly undetected and/or untreated (Mamo et al., 2017). NICE (2018) advises that an audiologist's hearing assessment be taken into consideration for every person who has dementia or mild cognitive impairment and that such an assessment be performed every two years in dementia patients who have not yet been diagnosed with hearing loss. Denial of the issue, resistance to testing, and limited adherence to hearing aids may impede the detection and treatment of hearing loss (Dawes et al., 2022).

2.7 Landscape of residential care settings

The incidence of disability, disease, and chronic disorders has increased because of the rise of an ageing population. This is particularly true for those over the age of 85, since older people are more likely to have poor or deteriorating health (Marengoni et al., 2011; Christensen et al., 2009). Further, even though medical improvements have increased lifespans (Gilleard and Higgs, 2016), it is unlikely that the additional years of life that older people get will be spent in good health (Kingston et al., 2017). Therefore, concepts such as person-centred care, especially for older adults living with communication disorders like dementia (Kitwood, 1998) need to be considered as part of a holistic approach to care.

Person-centred care is a concept of care that is oriented on the needs of the individual and is predicated on getting to know the individual through a personal connection (Fazio et al., 2018). It challenges the conventional medical model of treatment, which frequently emphasises procedures, processes, and staffing requirements. According to Kitwood (1998), dementia is best understood as the result of the interaction between neurological dysfunction and

psychosocial factors, specifically health, personal psychology, and the environment, with a focus on social context. Person-centred care is fundamentally about the self (who we are and what we believe). The foundation of person-centred care is the recognition and maintenance of selfhood (Sabat and Collins, 1999). Whilst person-centred care is theoretically the right approach, in practice it may be difficult to execute because of the realities of residential care.

Residential care in England has a complex past and present. The concerns highlighted by Townsend's (1962) study on residential care provision in the 1960s continue to be felt and observed. Specifically, communal homes "do not adequately meet the physical, psychological and social needs of the elderly people living in them" (Mozley et al., 2017). Residential and nursing care facilities are hugely complex structures. The pressure on care facilities is rapidly rising as the number of older adults leaving hospital and discharged into nursing homes is increasing (Goodwin et al., 2014). Therefore, the current state of care home provision is stretched. Some recommendations for improvement have included funds to be set aside for the training and resources of care facility staff so that they are equipped to support individuals with complex requirements and a history of frailty; easy access to NHS funded rehabilitation and outpatient services; and a defined and standardised multidisciplinary team for residents (British Geriatrics Society, 2021). The recovery from the pandemic has either delayed these recommendations or made them harder to implement.

The culture of a care home has a significant impact on the type of care provided and the residential experience. Culture in care homes can refer to the shared values, beliefs, attitudes, and practices that guide the behaviour of staff and residents in the care home environment. Different care homes can have different cultures, which can have a significant impact on the quality of care and the experiences of residents. One of the most significant cultural differences in care homes is the degree to which they prioritise a person-centred approach to care (Kitwood, 1998). A person-centred approach prioritises the individual needs, preferences, and desires of residents, rather than a one-size-fits-all approach. Care homes that prioritise a person-centred approach often provide more individualised care and are more responsive to the emotional needs of residents.

Dementia Care Matters is an organisation that focuses on transforming the culture of care for people with dementia in care homes and hospitals and promoting the use of Dementia Care Mapping (Brooker, 2005). The organisation advocates for a person-centred approach to care that prioritises the emotional well-being and quality of life of people with dementia. There are several strengths to the approach advocated by Dementia Care Matters. One of the key strengths is the emphasis on the emotional needs of people with dementia. The organisation recognises that people with dementia are not just their diagnosis but are individuals with

unique emotional and psychological needs (DCM, 2019). The approach emphasises the importance of creating a warm and nurturing environment that supports the emotional well-being of people with dementia.

Another strength of Dementia Care Matters is the focus on staff training and education. The organisation provides a range of training and education programs for care home staff, nurses, and other healthcare professionals. The training is designed to help staff understand the emotional needs of people with dementia and develop the skills necessary to provide person-centred care (Surr et al., 2018).

However, there are also some potential weaknesses to the approach advocated by Dementia Care Matters. One potential weakness is the lack of empirical evidence supporting the effectiveness of the approach. While there is some anecdotal evidence supporting the benefits of the person-centred approach, more rigorous empirical research is needed to establish the effectiveness of the approach in improving the quality of life of people with dementia. Another potential weakness is the practicality of implementing the approach in busy care home environments. The person-centred approach requires a significant investment of time and resources, and it may be challenging to implement in busy care home environments with limited staffing and resources (Edvardsson et al., 2011). Additionally, the person-centred approach may be difficult to sustain over time, especially if staff turnover is high.

Other cultural differences in care homes refer to the level of staff engagement and empowerment. In some care homes, staff may feel disempowered and may not have a voice in decision-making processes (Corazzini et al., 2015). In contrast, in other care homes, staff may feel more engaged and empowered, with a greater sense of ownership over the care they provide. This can lead to a more positive culture and better quality of care. The physical environment of care homes can also contribute to cultural differences. Some care homes may have a more institutional feel, with a focus on efficiency and functionality, while others may prioritise creating a more homely and welcoming environment (Abbott et al., 2018). The physical environment can affect the emotional well-being of residents, and a more homely environment can contribute to a more positive culture.

Cultural differences in care homes can also be influenced by the demographics of the residents and the staff. For example, care homes with a predominantly older staff and resident population may have a different culture than those with a more diverse population (Kim and Park, 2017). Care homes that serve residents from different cultural backgrounds may need to be more sensitive to cultural differences and provide more culturally responsive care.

Covid-19 revealed the diversity of social care as well as how little the public and governments knew about the provision of care in nursing homes (Marshall et al., 2021). Care home residents accounted for 35.6% of all deaths related to the pandemic (UK Government, 2021). The disproportional percentage cannot only be attributed to the age and health of care home residents (Mahase, 2021). The realities were restricted access to multidisciplinary care, increased isolation from no visitors, inadequate staffing levels, and limited testing resources (Wu et al., 2021). Although specialists warned that the pandemic would severely harm care homes, these warnings were originally disregarded (British Geriatrics Society, 2021). The consequence was a further fractured system that has become overwhelmed, highlighting the need to prioritise good practice policies (Hinsliff-Smith et al., 2020). Thus, creating a proactive system of improvement for residents, instead of a passive or reactive one.

2.7.1 Communication in residential care settings

For several reasons, communication is difficult in residential care facilities. First, despite some care personnel regularly overlooking them, communication issues, such as hearing impairment, are frequently widespread (Pryce and Gooberman-Hill, 2011). According to earlier studies, 70% of residents failed two or more communication screening tests, with hearing and cognitive impairment accounting for many of these failures (Worrall et al., 1993). Despite the significant prevalence of hearing impairment in these environments, it is essential to prevent workers from underestimating residents' hearing impairment, which impacts communication and the standard of care (Linssen et al., 2013).

The physical environment and construction of residential care settings are frequently suboptimal for communication, with reports of excessive noise and reverberation levels (Hickson et al., 2005). It is commonly known that hearing loss and difficulties hearing in noisy environments correlate. These spaces typically consist of hard surfaces, which create unfavourable acoustics, high noise levels, and reverberation (Bott et al., 2022), all of which hinder communication involving hearing. Bright surfaces usually worsen the auditory environment, making it harder for residents to employ visual cues and limiting their communication ability (Jones and Miesen, 2005). High noise levels may also negatively affect people living with dementia, such as causing increased agitation (Joosse, 2012).

Communication opportunities are limited in residential care settings due to the social climate (Hickson et al., 2005). They found that environmental factors impacted resident communication, such as a lack of engaging activities and conversational chances. The contact between staff and residents, in which carers are frequently the residents' only communication partner, is further evidence of this (Hickson and Worrall, 2003). Due to their excessive workloads, they must put physical care ahead of social and emotional care (Tappen et al.,

1997). As a result, residents' opportunities for meaningful communication are limited to discussions about their daily needs (Carpac-Claver and Levy-Storms, 2007).

Communication between care personnel and residents is essential for high-quality care to be provided, especially in residential settings where carers are frequently the only source of social engagement with residents (Bramhall, 2014). Therefore, effective interpersonal communication skills are crucial for care providers working in these settings (Bowling et al., 1993). According to Kerr et al. (2020), interventions to enhance the communication abilities of care professionals should be multidimensional and include the following three elements: practise, support, and educational training. The purpose of training is to improve staff members' understanding of efficient communication methods that are adapted to residents' communication difficulties. Techniques that are interactive, learner-centred, and didactic may be used in training.

Care workers can identify each resident's specific needs and provide individualised nursing care by communicating effectively (McGilton et al., 2009). In addition to reducing agitation in residents with cognitive impairment, effective communication between care personnel and residents has been associated with increased quality of life and wellness for residents generally (Burgio et al., 2002). Even though the importance of communication in the delivery of care is widely known, residents and care professionals regularly express dissatisfaction with this part of care and commonly feel powerless, dehumanised, and undervalued (Coyle, 1999; Tomkins et al., 2013).

Giving care personnel communication skills training is one way to address the aforementioned communication issues (Chant et al. 2002). Even though the existing communication training is insufficient to address the demands of care staff and residents, communication training has been found to increase care workers' communication skills (Eggenberger et al., 2013). A more comprehensive set of communication skills must be taught within a cogent theoretical framework that articulates the different elements of the intervention (McCormack and McCance, 2006).

Behavioural management tactics must be addressed in addition to communication efforts. When a resident exhibits responsive or disruptive behaviour, how the care team interacts with them might impact the person's behavioural issues (Moriarty et al., 2010). Techniques designed to change staff members' communication styles will enable them to communicate with residents more successfully (Nolan et al., 2008). Effective communication and interaction techniques may be demonstrated during behavioural training, and staff members may practise

these techniques with one another (Levy-Storms, 2008). Additionally, management and clinical support staff must provide opportunities for reflection on their new practice as well as encouragement and feedback for care professionals who are using the new abilities with residents (Moriarty et al, 2010).

Even though researchers and healthcare organisations have shown great interest in improving care staff communication to improve resident care (Moriarty et al., 2010), there is not yet a clear consensus on specific interventions that are the most successful. A recent systematic review by Cross et al. (2022) identified that effective communication techniques and adaptations from care staff had a positive influence on residents participating in group activities and socially interacting with others. Whilst this is highly encouraging, there is still a need to understand the factors that contribute to sustained communication adaptations from care staff, and the long-term benefits of this to residents. It is essential to comprehend the procedures, settings, and behaviours of the personnel and residents at care facilities (McShea and Ferguson, 2022). This would make it possible for treatments to be founded on context-specific evidence, increasing the possibility of successful communication outcomes.

2.8 Current context of care homes

The difficulties of hearing loss, social isolation, and dementia in older individuals are not well understood in nursing facilities. Previous studies have emphasised the impact of social and environmental elements on effective communication among people (Pryce and Gooberman-Hill, 2011). Despite the fact that using hearing aids does not usually improve social interaction (Pryce and Gooberman-Hill, 2013), there are communication hurdles since there is insufficient staff training on sensory impairment (Wittich et al., 2018). To improve residents' overall well-being in a compassionate environment, it is crucial to understand their needs, wants, and lived experiences (Bradshaw et al., 2012). Specifically, regardless of cognitive capacity, connectivity and social engagement were crucial for residents' quality of life (Bergland and Kirkevold, 2005). A study of residents' perceptions of the care home as their home revealed a desire for meaningful relationships within their surroundings (Nygaard et al., 2020). This would enable them to thrive and overcome their feelings of homesickness. This is further supported by the importance of having a private area for residents and visiting spouses to connect and maintain their relationships within a home to sustain meaningful connections (Førsund and Ytrehus, 2018).

A realist synthesis of hearing-related communication in nursing homes revealed several context-specific factors that would improve communication for people with hearing loss and

dementia (Crosbie et al., 2019). Staff training to better understand residents' needs and to 'know the person' was critical in meaningful communication. It is crucial to comprehend the mechanisms that sustain social isolation. Before developing a complex intervention, the Medical Research Council framework (Skivington et al., 2018) recommends a thorough understanding of the mechanisms and active ingredients. This increases the likelihood of effective and targeted interventions for the specific health condition and population (Michie and Abraham, 2004).

2.9 Care home research groups aligned with area of interest

This section reports on existing research groups within England who are interested in improving the quality of care and experiences in residential care settings. Their research approaches align with mine in terms of the qualitative empirical research that was conducted. Specifically, in the areas of improving practice through the development of complex interventions, and most importantly taking the vital steps to develop an intervention with the most appropriate stakeholders. The Quality of Care for Older People (QCOP) Research Group at City University in the UK is dedicated to improving the quality of care for older people in healthcare settings. The group conducts research on a range of topics related to ageing and healthcare, including the experience of residential care for older adults, the management of long-term conditions, and the role of technology in supporting older people to live independently. The QCOP Research Group works closely with healthcare professionals, policymakers, and older people themselves to ensure that its research is relevant and has a positive impact on the lives of older people. Research from QCOP includes a book on understanding care homes from a research and development perspective (Davies et al., 2009). The content of the book is a comprehensive overview of organisational structures, funding models, and regulatory frameworks within care homes, and how these can help and hinder complex intervention implementation within residential care settings.

Peryer et al. (2022) provided a comprehensive review of the contextual factors influencing complex intervention research in care homes. The study aimed to identify and synthesise the contextual factors that influence the processes of implementing complex interventions in care homes for older people. The authors conducted a systematic literature review and framework synthesis of 31 studies published between 2009 and 2019 and identified four main contextual factors influencing complex intervention research processes in care homes: the care home context, the research context, the intervention context, and the wider context. The paper's strength lies in the comprehensive exploration of the different contextual factors that influence complex intervention research in care homes, highlighting the complexity of the issue. However, the framework's construction could be strengthened by providing a clear theoretical

framework that underpins the synthesis. The authors note that the care home context is a significant factor influencing complex intervention research processes.

Care homes are complex environments that present numerous challenges to research processes, such as high staff turnover, lack of research infrastructure, and the need to balance research goals with residents' care needs (Logsdon et al., 2007). The research context, including the study design, recruitment processes, and data collection, also influences complex intervention research processes. For example, recruitment challenges and ethical issues often arise in research involving vulnerable populations. The intervention context, including the complexity and adaptability of the intervention, also influences research processes. Complex interventions may require adaptation to suit the care home context, but such adaptation can also impact intervention fidelity and research outcomes (Goodman et al., 2017).

Spector et al. (2006) aimed to explore the experiences of people with dementia living in care homes and to develop interventions to support their identity and participation in meaningful activities. The study used a mixed-methods approach, which involved interviews with residents, staff, and family members, and developed several interventions, including reminiscence therapy and staff training. One strength of the study was its focus on supporting the identity and participation of people with dementia, which is an important but often overlooked aspect of care. Additionally, the study involved a range of stakeholders, which helped to ensure that the interventions were relevant and appropriate. One limitation of the study was that it did not examine the long-term effects of the interventions, so it is unclear whether the benefits were sustained over time. To further understand lived experience of persons living with dementia, knowledge of their life stories may support a person-centred approach. Using Grounded Theory, Berendonk and Caine (2019) looked at how people who care for people with dementia understand life story work. Thirty-six staff members from seven nursing homes took part in semi-structured interviews or group talks. They found that some people thought the most important thing was to find out the "true facts" about a resident's life. Others pointed out how important narratives and the way people with memory acted out the stories they told were in creating emotionally meaningful situations. Care workers who help people with memory can find it hard to help them tell a good life story. To improve care in nursing homes, it's important to show how important life story work is, but more importantly how important effective communication is.

DePoli et al. (2020), part of the Centre for Applied Dementia Studies at the University of Bradford, highlight the importance of taking a multi-level, cross-sectoral approach to supporting people living with dementia and their carers. The participatory approach used in

the study is a strength, as it ensures that the framework is grounded in the perspectives of those most affected by dementia care. The framework incorporated multiple levels of analysis, which makes it a useful tool for understanding and addressing variations in satisfaction of care needs among people living with dementia. The article highlighted the importance of cross-sectoral collaboration in providing effective dementia care. The lack of diversity among participants may hinder the ability of the framework to be used in different contexts and settings. Additionally, the study did not examine the impact of cultural factors on satisfaction of care needs, which may be an important consideration in some populations.

Research on dementia care and older adults in care homes in England highlights the complexity of the care home environment and the need for tailored, person-centred interventions that consider the diverse needs of residents. The existing research demonstrates the importance of taking a multi-level, cross-sectoral approach to understanding and addressing the factors that influence the quality of care for older people in care homes. By collaborating with healthcare professionals, policymakers, and older people themselves, researchers can ensure that their work is relevant and has a positive impact on the lives of older people. When direct stakeholders of the research are consulted, researchers can use the insight to co-develop interventions. Smith et al. (2022) identified five themes representing quality domains that were important to older adults about to enter residential care settings. These were: staff knowledge, respect for clients, a person-centred approach, a collaborative partnership with clients and clear communication. Thus, highlighting the importance of person-centred care and collaboration. Further research is needed to explore the impact of satisfaction of care needs and to identify effective ways of implementing person-centred, integrated care models that improve the quality of care for older people in care homes.

2.10 Research approach

The prevalence and negative impact of hearing loss, left unaddressed and unmanaged, can be tiring and challenging for older adults. The effort required to contribute to a conversation may result in irritability and fatigue. The individual may begin to avoid tiring situations, such as at family gatherings and social outings (McAuliffe et al., 2012). This disengagement can result in isolation, loneliness, and negative consequences for a person's relationships and significant others (Morgan et al., 2021). Therefore, there is a need for a complex intervention package to be developed to support older adults who are vulnerable to experiencing social isolation.

The Medical Research Council (Skivington et al., 2018) has recommended that qualitative research with key stakeholders be conducted before the development of an intervention. However, qualitative research examining stakeholders' perspectives on interventions for hearing-related social isolation is lacking. Although numerous quantitative studies have

demonstrated that hearing loss and social isolation relate, few qualitative studies have comprehensively been conducted to understand this relationship.

This work addresses several research questions on hearing loss, dementia, and social isolation. I investigate the relationship between hearing loss, social isolation, cognitive decline and dementia because evidence suggests a causal mechanism between them, with social isolation acting as a mediator. Evidence also suggests the combination of living with hearing loss and cognitive decline/dementia can lead to social isolation. I unpick both possibilities. To ascertain whether there is a causal mechanism, I investigated the patterns and trends of hearing loss, social isolation, and cognitive decline at a population level. Then, I set out to determine how and why social isolation occurs and whether it is a cause of hearing loss and dementia. I investigated a community in which previous evidence has shown a high percentage of the population living with hearing loss and dementia but also where people are particularly vulnerable to becoming socially isolated. Each study's findings explain the complex relationship between hearing loss, cognitive impairment/dementia, and social isolation. Given the diversity and complexity of the areas covered, a pluralistic approach, which will be explained in detail in chapter 3 will be employed for analysis.

CHAPTER 3

METHODOLOGY

3.1 Introduction

This chapter will discuss the philosophical underpinnings and design choices of my research. Specifically, how and why a pluralist approach was most appropriate to answer multiple research questions concerning hearing loss, cognition, and social isolation. There will also be an overview of the methodology choices for each empirical study within the programme of work. There will be a justification of the ontological and epistemological positions that have formed the basis of my research.

3.2 Overview of work

This work addressed several research questions on hearing loss, dementia, and social isolation. This programme of work was complex. Not only because of the complexities of each individual condition but because of the multiple layers and intricacies of older adults that this work is centred on. Adopting different paradigms relevant to each research question allowed a better understanding of the multidimensional and multi-ontological complexity of human experience (Shaw and Frost, 2015). Pluralism supports the exploration of complex human experience, which cannot be reduced to single-method studies.

To ascertain whether there was a causal mechanism, I investigated the patterns and trends of hearing loss, social isolation, and cognitive decline at a population level. I concurrently studied a community with a high percentage of the population who live with hearing loss and dementia, but also where people are particularly vulnerable to becoming socially isolated. This enabled me to understand how and why social isolation occurred and whether it was a cause of having hearing loss and dementia. The findings of each study were used to explain the complex relationship between hearing loss, cognitive impairment/dementia, and social isolation.

3.3 Pluralism in practice

Pluralism is when a combination of research methods is used to answer different research questions in a broader topic area. It involves considering multiple perspectives, theories, and methodologies in the topic of interest. For me, that is hearing loss, dementia, and social isolation. My programme of work adopts a "toolbox" approach (Shaw and Frost, 2015) because the paradigm, strategy, and method are led by the research questions (Brooks and King, 2017). Hence, the right "tools" are used for the job. Pluralist approaches acknowledge the complexities of phenomena and embrace the benefits of using different lenses to explore data within a programme of study (Oakley, 1998). These benefits include a shift in focus to the research question(s) and the logic of inquiry instead of the traditional focus on the methods used to gather and analyse data (Novis-Deutsch, 2018). Thus, appropriate methods are

chosen for the research question(s) that can include a degree of objectivity at a population level, alongside a rich description of subjective experience and meaning when exploring lived experience.

The innovative nature of pluralism means that multiple methods can be used to answer a research question within the same ontological worldview appropriately. This approach was taken for the ethnographic research.

By considering multiple perspectives and approaches, a pluralist approach can help provide a more comprehensive understanding of hearing, dementia, and social isolation, its causes, and its impact on individuals and society. Pluralism also addresses different needs for the research stakeholders. For example, a pluralist approach can consider the perspectives of caregivers, family members, and individuals with hearing loss and dementia themselves, and identify approaches that can be tailored to each of their needs. What's more, a pluralist approach can help identify gaps in existing research and suggest new directions for research. For example, if existing research has focused mostly on biomedical approaches, a pluralist approach can highlight the importance of social, cultural, and environmental factors in the development and management of hearing loss and dementia. Finally, by considering multiple perspectives and approaches, a pluralist approach can increase the relevance of hearing loss and dementia research to policymakers, healthcare professionals, and the public. This can inform the development of policies and interventions that are more responsive to the needs of those most affected by the conditions being studied. Section 8.1.2 provides details on how the pluralist approach was utilised to address the overarching research questions, and how each research element informed the other.

3.4 Systematic review and Meta-analysis

A systematic review and meta-analysis were conducted to navigate the breadth of literature on hearing loss and dementia associations. The aim was to understand and explain the patterns and trends at a population level. A positivist ontological worldview led this part of the research because the nature of systematically reviewing research literature and pooling results together, lends itself to supporting or refuting a testable hypothesis (Gordon, 2016). This approach was concerned with deducting answers from the data to identify an observable truth to help answer research questions.

During scoping of this topic, social isolation was identified as a potential mediator within the association and supported the cascade hypothesis. A systematic review was conducted to determine observable evidence about the mediating factors and the role of social isolation between hearing loss and cognition. This was a novel contribution to the topic area. There

was a specific interest in the causal mechanisms of hearing loss, social isolation, and cognitive impairment because this had not been investigated before. Therefore, prospective longitudinal cohort studies were included. A narrative synthesis of findings was planned based on the variance of outcome measures for cognitive impairment and social isolation. A meta-analysis was performed based on the appropriate identification of studies that used the same or similar exposure and outcome measures. Thus, the pooling of results and deduction of data contributed to the observable truth for the positivist part of the research.

3.5 Epidemiological analysis

The findings of the systematic review and meta-analysis identified the lack of cohort studies that have considered social isolation as a mediating factor between hearing loss and cognition. What's more, there was not enough rigour in how social isolation is categorised and described in population-level studies. Hence there was a need to identify an appropriate longitudinal dataset that included hearing threshold, social isolation, and cognitive score variables. After screening several datasets, the Hertfordshire Ageing Study was chosen because of the time points that the hearing, cognition, and social isolation variables were measured, and the demographics of the included participants. This was a novel approach because this combination of variables had not been utilised before and contributed to the qualitative work. I adopted a postpositivist perspective, namely that there is a reality that can be measured and which represents a notion of "absolute truth", although individual differences between people are still acknowledged (Phillips and Burbules, 2000). Distinct cause-and-effect relationships (or correlations) are investigated through observation, making this approach reductionist in nature. Here, ideas tend to be reduced to discrete variables used to test hypotheses (Hudson and Ozanne, 1988), as is appropriate for the investigation of patterns at a population level, where distinct variables are analysed.

3.6 Planning and engagement phase

The qualitative component of this work (planning and ethnography phases) forms a substantive element of the thesis. It can be considered an inclusive venture with the population of interest, i.e., older adults living with hearing loss and dementia residing in care homes. I tried to make sense of the complexities inherent to the topic by listening to stakeholders' voices and taking a multi-method approach.

Existing research that aimed to explore inclusivity for people living with dementia in residential care also guided my thinking and development of the research methods. For example, Newton et al. (2021) described care homes as an increasingly integral part of the dementia care landscape. In their narrative review, they identified literature on the use of gardens by people

living with dementia to understand inclusivity and wellbeing of older adults living with dementia both in the community and in residential care. The findings suggest that access to and use of gardens can have a positive impact on the wellbeing of people living with dementia, as well as their caregivers. Benefits reported included increased physical activity, improved mood, and reduced stress, and enhanced social interaction. However, there were also barriers to garden use, such as physical accessibility issues, lack of outdoor space, and safety concerns. The authors conclude that gardens have potential as a therapeutic environment for people living with dementia, but more research is needed to understand how best to design and use garden spaces in dementia care. The article argues that gardens can provide opportunities for people living with dementia to engage in meaningful activities and experiences, both within care homes and in the community.

When people living with particular conditions are involved in researching those conditions, considerable focus and direction are given to projects (Gove et al., 2018). There is a high prevalence of individuals living with hearing loss and dementia in residential care. Hence these settings were chosen to explore and understand their lived experience. Co-operative inquiry is a methodology that aims to gain knowledge by exploring lived experience through an inclusive approach, using creative and innovative practices (Heron and Reason, 2006). This approach does not have a set protocol in its application, and some have termed it an extension of patient and public involvement (PPI) (Hickey, 2018), and a methodology within its own right by others (Green and Johns, 2019). A co-operative inquiry was used to understand the current culture and communication behaviours of the four care homes that took part in the research.

An initial inquiry was conducted to determine the feasibility of the proposed projects, develop working relationships with care home staff and refine the research questions. This inquiry aimed to establish the importance and relevance of the studies from care home staff and residents affected by dementia. This was in addition to establishing likely methods and willingness to participate and developing partnerships in the research process. My guiding principles for this work were the National Institute of Health Research (NIHR) guidance on patient and public involvement activities (2019) and the Public Involvement Impact Assessment Framework (PiiAF, 2022).

The components of the planning and engagement phase involved identifying opinion leaders in the field, sampling of care homes, and most significantly, building relationships within four care homes during the twelve months before data collection started. These components are detailed in chapter 6. This was a process of understanding the context in which the qualitative work would take place and navigating the processes of undertaking the research successfully. Some of the considerations and realities of residential care settings are outlined below. This

should provide some context and explanation of the challenges and barriers faced when entering residential care settings and attempting to explore lived experience through a complex lens.

Contacting an organisation, arranging access, and early visits are extremely indicative of the environment long before formal data collection operations start (Fetterman, 2010; Eberle et al., 2016). Gatekeepers (often care home managers) who can control the entrance to the location, the mood, and the level of involvement for the duration of your time in the field must be bargained with to get entry (Silverman, 2011; Rankin et al., 2015). Therefore, it is essential to document these interactions' discussions, challenges, fixes, and results.

Research in residential and nursing care environments is often conducted for intervention development or implementation (Lawrence et al., 2016). Yet the people for whom the interventions are designed are seldom included in crucial decisions about the research (Bayer and Tadd, 2000; Sampson et al., 2019). There has been a lack of understanding for care home residents and staff in past research, primarily where randomised controlled trials and other experimental studies have been conducted (Forster et al., 2017). Similarly, qualitative research carried out in care homes has highlighted the power imbalance between researcher and participant during interviews and focus groups (Råheim et al., 2016). This imbalance can occur despite the researcher intending to minimise feelings of authority between themselves and the participant.

Previous research has suggested that care home residents and staff view the role of the researcher as somebody entering their environment solely to collect data (Luff et al., 2011a). Therefore, a lack of follow-up and maintaining relationships between the researcher and participants does not allow for meaningful change. Furthermore, the lack of coproduced research conducted in care homes (Backhouse et al., 2016) highlights either the lack of willingness of researchers to address the power imbalance or the unfortunate reality of the pressures to produce “discovery research” that so many researchers face. Either way, participants are not involved in designing studies. This made the planning and engagement phase more significant. I ensured that I learned and listened to the stakeholders to become a welcomed part of the community before conducting any research. This was not a linear approach. Several components were involved in the co-operative inquiry to capture as much of the nuance and detail of the settings as possible. It is also important to note the ethical considerations and problems that can arise when including persons living with dementia in co-production. Whilst this was not formal research, I had a duty to ensure that the individuals offering their time and experiences were fully aware of my purpose. I used the learning from the Mental Capacity Act (2005) training course to continuously assess the residents’

fluctuating capacity. I reminded residents about my agenda and purpose for speaking with them several times to ensure they were kept aware. It is imperative to include people living with dementia in research and in preparatory activities, but the practical and ethical considerations should be at the forefront of the work. For example, I ensured that the times of day when I approached residents were adequate for their physical and bodily needs such as between mealtimes, and during the morning where they were generally more alert and rested. Another example of a practical consideration was ensuring that the environment was appropriate for the resident i.e., not too loud, or bright. I sought quiet areas of the home to have discussions with the residents but also was mindful to enter their private spaces due to ethical reasons. If I felt at any point that residents were no longer interested or aware of my purpose, then I was morally and ethically obliged to cease conversations concerning the research and engaged in other conversations instead.

Co-operative and participatory initiatives in healthcare research are very much encouraged (Dewar, 2005), but the tools to involve marginalised members of society are not readily available (Baur et al., 2010). As described by the World Health Organisation (2000), institutions have a social responsibility to use education and research to address the “priority health concerns of the community”. Recognising this responsibility can precipitate an increased sense of ownership among community members and focused healthcare needs wholly relevant to the community of interest (Ramsden et al., 2010). However, marginalised communities, such as older adults living in residential care, may be unwilling to engage in research because of their residential life's physical and social construction (Baur et al., 2010). For example, the strict eating and activity schedules that shape a day can reinforce an institutionalised system. The reinforcement of schedules can make residents reluctant to respond to invitations to participate in research (Backhouse et al., 2016).

Stocker et al. (2021) discussed the reflections and experiences of patient and public involvement (PPI) partners in the process of qualitative data analysis and interpretation in care home research. The authors found that involving PPI partners in this stage of research allowed for more diverse perspectives, increased transparency, and better communication of findings to a wider audience. PPI partners also provided valuable insights into the interpretation and meaning of data that researchers may have overlooked or misunderstood. However, the authors note that involving PPI partners in data analysis and interpretation requires careful planning and consideration of their needs and expertise, as well as clear communication and support throughout the process. Overall, the findings suggest that involving PPI partners in qualitative data analysis and interpretation can improve the quality and relevance of research findings, but the planning of the PPI is wholly important. This method of inclusive research can

come with certain difficulties and conflicts, such as addressing and balancing power dynamics, and acknowledging the unique input of individuals with dementia (Williams et al., 2020).

The culture of a care home can also considerably influence the type and extent of research conducted within a home (Dewing, 2009), which may derive from past experiences with research (positive or negative) that make a care home more or less likely to engage with researchers. There is a detailed account of culture within care homes in section 2.7. The perceived value and benefit that the study will bring to the home and its residents may also have an influence. Whether it does is primarily dictated by the communication practices of the care home management team (Dewing, 2009). For example, the frequency and quality of time that care home managers spend in communal areas of the home may indicate their level of involvement and concern for residents' needs beyond the physical. Therefore, research aiming to investigate communication practices, social interaction, emotional well-being, and so forth will be strongly welcomed or dismissed. In one study that aimed to develop a theory about communication practices of care home residents living with hearing loss and dementia, an "expert" group of care staff, managers and policy makers were consulted (Crosbie et al., 2019). Although the views of these groups are essential, people living with hearing loss and dementia were not consulted. Therefore, any future interventions put in place because of the research would be implemented without the voice of those most concerned. Thus, highlighting the lack of involvement and empowerment given to care home residents.

Strong leadership complemented by transparent and effective communication throughout a care home has led to more delivery of successful research, as compared to care homes lacking these traits (Wilson, Davies, and Nolan, 2009).

The empowerment of people living with dementia has many components. It can involve an individual gaining personal control, being an active participant in decision-making, and having the tools and autonomy to improve their quality of life (McConnell et al., 2019). Such empowerment not only supports the avoidance of social isolation (Zimmerman, 2000) but also enables individuals to be equal partners within a care environment. In practical terms, I considered 'equal partners' to mean residents living with dementia to provide me with the answers about their living environment and experiences in an open and non-restrictive manner. They would provide me with the 'how, when, where, who' answers to my questions about the homes and the feasibility of the research (see chapter 6 for more details). This was a challenging task because I often needed to repeat my line of questioning or move to different topics in line with the resident's level of attention and interest.

Involving persons living with dementia in the research process can be an effective form of empowerment, as it enables them to have their voice heard when they might feel redundant

and increasingly dependent on others. Thus, PPI activities can extend far beyond the researcher's benefit alone. These preparatory activities are not only to determine the proposed project's feasibility but also to ensure that the voices of potential participants and the target population are echoed throughout the research design and methods. I acknowledge the difficulties of co-production whilst believing it is the moral obligation of researchers to involve persons living with dementia in the preparatory activities and in the research itself. There was a wealth of valuable information gained from the planning and engagement phase, as detailed in chapter 6, which led me to adapt my research approach for the ethnographic component of the work. The data collection methods and approach were informed by the elements of co-operative inquiry and the intelligence gained from visiting the homes prior to the formal research starting.

3.7 Development of Grounded theory model

The reality of older people in care has multiple layers and intricacies: for example, navigating a new environment and home, understanding the routine and schedule imposed upon residents, and adapting to shared communal space with others. An inductive approach was used to understand the real-world experience of people living with dementia and hearing loss and to give them a voice within the research since the social experience of participants is crucial to “knowing and understanding” lived experience (Heron, 1996).

The development of the grounded theory model was guided by past qualitative research that had sought to understand the lived experience of care home residents living with dementia. The work of Pryce and Goberman Hill (2011, 2013) undoubtedly influenced my work. In their ethnography they found that two key themes emerged from the study: contextual issues that compounded communication difficulties, and environmental noise that restricted communication choices. Communication issues were observed during all activities, and the use of hearing aids did not improve social engagement. To improve communication opportunities in residential care homes, it is important to consider environmental and social factors, and involve residents and staff in implementing changes. They developed their work to include involvement of important stakeholders of care home settings to produce an intervention that would help alleviate the challenges associated with hearing loss in residential care. The process of ethnography followed by intervention development is the journey I plan to take following my PhD research.

Clare et al. (2008) used interpretative phenomenological analysis (IPA) to explore the experiences of individuals with dementia living in residential care homes. The study involved in-depth interviews with 10 residents with dementia living in care homes in the UK. The study identified three main themes related to the experience of living with dementia in residential

care: the experience of loss and change, coping strategies, and the importance of relationships. Participants discussed the loss of their independence and identity, as well as the challenges of adjusting to life in a care home. Coping strategies included finding meaning in everyday activities, maintaining a sense of self, and seeking out social connections with others. The importance of relationships was highlighted as crucial for maintaining a sense of identity and connection to others. The study provided valuable insights into the subjective experiences of individuals with dementia living in residential care homes. The findings suggest that addressing the emotional needs of residents, promoting individualised care, and fostering positive social relationships are all important factors for improving the quality of life for individuals with dementia in residential care.

IPA has very different philosophical underpinnings to grounded theory, as the latter is aimed at the development of theory from empirical data. Nonetheless, as both methodologies are concerned with subjective experience using qualitative methods, previous research from the two approached can be used to strengthen understanding of the topic area. Haunch (2018) used Interpretivist Grounded Theory methodology to understand what facilitates nursing home staff to connect with residents living with advanced dementia. The results of the study showed that most connections between nursing home staff and residents with advanced dementia occurred during personal care. The theory that emerged from the data, called 'making the most of time,' suggests that both contextual and individual factors played a role in facilitating staff to connect with residents. Effective leaders created a caring culture, while experienced staff acted as role models. This facilitated staff to understand, accept and tolerate dementia, and express caring values, leading to better connections with residents. A suitable physical environment also helped staff to make the most of time during personal care. Additional training and education from specialised dementia units and experiential knowledge from family engagement further enhanced the process. These findings align with those of Beer et al. (2012) who found a need to transform how caregivers are trained in communication techniques. Specifically, incorporating the training into nursing education would have the potential to increase quality of life for people with dementia.

The interpretivist paradigm was embedded in the qualitative work, emphasising subjective experience and meaning. Since individuals seek to find meaning in their lives and the world in which they live (Lincoln and Guba, 2009), I carefully considered the context, settings, and relationships within residential care, which has stemmed from the extensive planning and engagement phase that has developed my understanding of residential care settings. The context, setting, and relationships were considered through constant comparison of the environmental audit, observations, and interview findings (see chapter 7), and supported by the intelligence gained during the planning and engagement phase. This phase aimed to

capture the willingness of residents and care staff to participate in the proposed research. What's more, it aimed to engage key stakeholders within residential care settings to understand the intricacies and nuances of these settings. This laid a strong foundation for the ethnography and interviews, where I tried to understand the "reality" of participants, which lies behind the details of subjective meaning and is constructed through engagement and participation in the social world (Dahlberg, 2006). What's more, I used aspects of realist thinking to determine "what works, for whom, and under what circumstances" (Pawson, 2006) to provide an understanding of the causal mechanisms underlying social isolation in residential care settings. To be clear, this piece of work was not a realist synthesis or realist review. Rather, in keeping with the pragmatic approach of grounded theory and focussed ethnography, there were aspects of realist thinking used. This was important because there were different settings planned for data collection so an understanding of how the context may or may not influence lived experiences was needed. The residential care homes can be considered Moreover, there is much to learn about context-mechanism-outcome (CMO) configurations from rapid realist reviews. Weide et al. (2023) explored the concept of supporting autonomy for people with dementia living in nursing homes. Data extraction from the included articles ultimately resulted in sixteen CMO configurations on four themes: 1) preferences and choice: interventions for supporting autonomy in nursing homes and their results, 2) personal characteristics of residents and family: people with dementia and their family being individuals who have their own character, habits and behaviours, 3) competent nursing staff each having their own level of knowledge, competence and need for support, and 4) interaction and relationships in care situations: the persons involved are interrelated, continuously interacting in different triangles composed of residents, family members and nursing staff. These findings indicate the importance of a range of factors needed in care home settings such as the physical environment, personnel, and inclusion of family members, in order to provide autonomy for residents.

Research on the physical environment of care homes has clarified the needs of people living with dementia and hearing loss. Grounded theory research on socio-spatial relationships in design of residential care homes for people living with dementia helped to inform the components of the environmental audit that was used as part of the ethnography (and grounded theory model). The study by Burke and Veliz-Reyes (2020) aimed to explore how the design of residential care homes for people living with dementia affects their socio-spatial relationships. The authors used a grounded theory approach to analyse data from observations and interviews with staff and residents in three care homes in the United Kingdom. The study found that the design of the care homes, such as the layout and organization of spaces, can have a significant impact on the relationships between residents,

staff, and family members, as well as their overall well-being. What's more, de Boer et al. (2018) found that the physical environment of small-scale residential care settings can potentially enhance the daily life of people with dementia. However, it was observed that even with a potentially beneficial physical environment, the nursing staff must encourage and facilitate residents to utilise the physical environment to its full potential. The study highlights the importance of nursing staff in providing residents with meaningful activities that stimulate them to be active and utilise the physical environment fully. This research supports the need for understanding the role, knowledge, and motivations of care staff when developing the grounded model.

It was impossible to conduct the research at all four care homes that were involved in the planning and engagement phase due to COVID-19 restrictions at the time. Fortunately, substantial data was collected from two homes, enabling the development of a Grounded Theory model. The initial plan for involving participants in data checking, respondent validation, and contribution to the final model could not be carried out because researchers were not allowed to visit care homes in England during the period of data analysis.

3.7.1 Grounded theory overview

A key component of grounded theory is the simultaneous process of data collection and analysis (Glaser et al., 1967). The reasoning is that if researchers actively question their data as they acquire it, their initial hypotheses might then guide later data collecting. Glaser et al. (1967) recommended comparing and coding data before beginning to analyse it. Initial coding referred to labelling data fragments to dissect them while paying attention to the meanings and behaviours this data indicated. Line-by-line coding was recommended as a first step because it compels the researcher to examine the data from a new perspective, contrast different portions of the data, and pose analytical queries about them (Charmaz and Thornberg, 2021). This approach moves beyond description through the development of fresh concepts to explain observations.

The advantage of grounded theory is that empirical study can be started without specific hypotheses. There might be some assumptions based on broad cultural understanding and educational background, but a grounded theory can entail learning more about a topic that has never been examined in a particular way before (Bakker, 2019). Although the results of research prompted by the grounded theory methodology won't be entirely conclusive, it will be feasible to make some tentative generalisations after it appears that the information being discovered has reached a saturation point (Charmaz and Thornberg, 2021).

Contemporary iterations of grounded theory adhere to the notions of recognising different realities, seeking out other viewpoints, and conducting critical analysis all along the research process (Bryant, 2019). If every methodological approach, including grounded theory, assumes an epistemology, this approach is appealing to researchers who engage in reflexivity (Corbin and Strauss, 2008). In addition, researchers who read theoretical and substantive literature on their topics before starting research but do not necessarily take these pieces of literature as factual or conclusive statements will be drawn to this version of grounded theory (Thornberg and Charmaz, 2014). This aligns with my research philosophy and reasoning for using grounded theory. Thus, I developed techniques in my empirical work that were appropriate for the grounded theory approach, based on previous research (see sections 2.8, 3.6 and 3.7) and the planning and engagement work findings (see chapter 6). Pragmatism was important in this research. Not only because of the type of participants involved (residents with fluctuating mental capacity and hearing loss, and busy care staff members), but also because I was a sole researcher undertaking grounded theory methodology for the first time. Previous research in care homes using qualitative methods, my clinical experience, service user involvement, and expert advice obtained in the planning and engagement phase all informed my thinking and decisions, to guide my eventual practice within the care home settings. The valuable insights gained from the planning and engagement phase allowed for efficiencies in the data collection phase and prepared me for working with participants who had comprised cognitive abilities.

3.7.2 Multi methods approach

An environmental audit, ethnographic observations, and semi-structured interviews were conducted to develop a Grounded theory model that was rooted in data and created through a constant comparison approach of observations and interviews (Glaser et al., 1967). The environmental audit, ethnographic observations, and interviews were conducted at two private residential/nursing care homes in Birmingham, UK, specialising in dementia care. A proforma of the acoustic environment was used to identify the barriers and facilitators to communication within the homes. The ethnographic observations were used to understand the lived experience of older adults who were living with dementia and hearing loss. The interviews were used to investigate participant views in detail and gather further detailed descriptions of the behaviours observed by residents and staff members. Doing an environmental audit was fundamental when researching communication because it allowed us to triangulate the data with the observations and interviews. A model outlining internal and external communication barriers and reduced opportunities for meaningful conversation within the homes was developed using abductive reasoning (Shaw et al., 2018a). Abductive reasoning is when observations guide the development of theory or reasoning. Therefore, the use of pluralist

methods informed how I might model a contextual and mechanistic understanding of communication in residential care homes. There was consideration of the compromised cognitive abilities of some of the participants. Although only those who had the capacity to consent during the data collection time points were included, their compromised cognitive abilities may have influenced the narrative or their specific responses. These factors are considered in relation to Carspecken's (1996) work on critical ethnography. Carspecken's Five-Stage Critical Qualitative Research Method acknowledges the role of power and thought in research. Carspecken (1996) argues that power relations and social structures shape the way people think, feel, and act, and that these factors must be considered when conducting qualitative research. Specifically, the method emphasises the need for researchers to be aware of their own assumptions and biases, as well as the power dynamics that exist between the researcher and the participants.

By acknowledging power and thought in research, Carspecken's method encourages researchers to be more reflexive and critical in their approach, and to consider how their own biases and assumptions may influence their interpretations of the data. This approach can help to ensure that research is conducted in a more ethical and socially responsible way, and that the findings accurately reflect the experiences and perspectives of the participants. Although a critical ethnography was not utilised (see section 3.8), some elements of the methodology were incorporated into the analysis.

The findings present a contextual account of factors related to the creation and sustenance of social isolation in residential care settings for older adults with hearing loss and dementia. An ethnographic methodology was used to comprehend how and why social isolation is maintained in residential care settings, specifically in older adults living with hearing loss and dementia. The data from the ethnography and interviews inform a grounded-theory model to help explain the mechanisms contributing to social isolation.

3.7.3 Supporting theories

The social identity theory (Tajfel and Turner, 1986) helped to make sense of the data and provide insight into the levels of social connectedness between residents, staff members, and relatives. According to social identity theory, individuals work to develop and preserve a feeling of positive distinction for their group memberships (Tajfel and Turner, 1986). From a self-esteem standpoint, the desire to perceive our ingroups favourably makes intuitive sense, but individuality also serves an epistemological purpose. By comparing ourselves to members of related outgroups, group affiliations help us "know" ourselves. Therefore, the roles that people played within the care home settings were closely observed and guided the interpretation of the data.

Another psychological theory that helped guide the data interpretation was the four stages of psychological safety (Clark, 2020). This theory was developed for workplace teams but can be applied well to stakeholders within residential care settings who live or work within a complex cultural environment. The four stages are inclusion safety, learner safety, contributor safety, and challenger safety. Inclusion safety relates to individuals feeling safe, welcome, and valued. Most importantly, not being made to feel excluded. Learner safety is promoted by people feeling empowered to ask questions, experiment, and make mistakes within a safe space. Contributor safety is when group members do not fear ridicule or shame when contributing their own thoughts. Challenger safety is when members of the group have the right to disagree with others' opinions, especially those of people in positions of authority. The four types of psychological safety were applied to the lived experiences of both residents and care staff members, who had varying levels of autonomy.

The complex nature of this qualitative strand highlighted the importance of quality and rigour within the research. Not only to provide integrity to the findings but also to pay homage to the individuals involved. The methodology of this study is ethnographic because it aims to investigate prevalent social, intellectual, and experiential patterns in communities (Hammersley and Atkinson, 2019; Fetterman, 2010). I view social isolation as a phenomenon produced by relationships and interactions within the communities studied. My study applies "focussed ethnography". This method enables the investigation of familiar phenomena occurring in complex communities (Cruz and Higginbottom, 2013; Rashid et al., 2015).

3.8 Focused Ethnography

Focused ethnographies are differentiated by several traits that are consistent with the goal and results of my study. First, they substitute intensity for the duration of data gathering, using brief field visits instead of long-term placements (Knoblauch, 2005). For instance, a researcher spent only one month, but 45 hours per week in the adult day programmes she researched for one focused ethnography of staff-client interactions (Liou and Dellmann-Jenkins, 2020). This study's length stands in contrast to other, more conventional ethnographies, in which participants can stay at study locations for up to a year while intermittent observations are made (Bailey et al., 2015). Second, a particular group or groups of participants within the organisation are chosen as the primary sources of data collection (Higginbottom, 2011; Rashid et al., 2015). As an example, Wall (2015) and Wegener (2014) concentrated on employee groups such as nurses in their ethnographies of learning in health and social care contexts.

Focused ethnographies are context- and problem-specific as opposed to traditional ethnographies, which try to describe a complete phenomenon (Knoblauch, 2005; Stephens et al., 2013). As a result, a focused ethnography may choose the subject of inquiry in advance

and organise data collection accordingly (Muecke, 1994). For instance, researchers primarily examined staff decisions about resident mobility in a care home-centred ethnography (Taylor et al., 2014). This contrasts with a more general beginning emphasis, like Cain's (2012) investigation on the identities of hospice care providers.

The researcher must first decide what to investigate and who to study it with, paying close attention to the people, circumstances, and environments engaged in "living" the research issue (Bowen, 2008; Silverman, 2011). This is sampling, and in ethnography, the insight's quality—not its quantity or representativeness—is the essential factor in deciding how to proceed (Crang and Cook, 2007; Bourbonnais and Ducharme, 2010). The researcher examines resemblances, distinctions, and untold perspectives (Sherman Heyl, 2001; Miles et al., 2018). I was influenced by the type of residential care setting, its socioeconomic status, and the demographic makeup of residents and staff when making decisions about sampling and recruitment (Hammersley and Atkinson, 2019).

Instead of just explaining what already exists, I also wanted to question culture by looking at how the status quo constrains behaviour, encouraging change, and exploring the nuances of a community (Beach et al., 2003; Clarke and Braun, 2013; Rashid et al., 2015). This approach would have formed the basis of critical ethnography. To question current care practices, some authors have investigated various aspects of the care experience in residential settings using critical ethnography (Carspecken, 2013). Criticality is also beneficial when the goal is to highlight the opinions of people who are not generally given voice or those that pose a threat to the status quo (Foley and Valenzuela, 2005; Black and Rabins, 2007). However, due to the limited resources and time constraints of the PhD, it was not appropriate to undertake an in-depth critical ethnography. A focussed ethnography was the most appropriate and practical methodology, which enabled the inclusion of reflexivity and triangulation from the interviews and environmental audit.

3.9 Reflexivity

During the planning and engagement, and ethnography phases of the research, I kept a reflective journal of my experiences. When undertaking co-operative inquiry and Grounded Theory methodology, it is vital to embrace reflexivity as a researcher because my personality and experiences are inevitably embedded in the data collection and analysis. This was especially true because of my extensive experience working with older people clinically, in hospital and community settings. In addition to the reflective journal, I also had regular debriefing sessions with my supervisors to reflect on my experiences at the care homes and work through the emotional challenges and sensitive data to which I was exposed to. The reflections were based on how I, as a researcher, shaped my data. As a healthcare

professional, I have a vested interest in improving the quality of life and experience for older adults living with hearing loss and dementia. This may have coloured my reading of the situations that I came across because of how much I value communication. For example, I may have explicitly been looking for problems in communication or had the inclination to dislike management who didn't seem to prioritise communication. After my observations, I reflected deeply with my primary supervisor and discussed how I might risk shaping the data. This helped to ensure that the data interpretation was minimally biased because the unconscious biases were highlighted and acknowledged.

The process of reflection and reflexivity throughout was vital because it acknowledged how I may or may not have influenced the interpretation of the data because of my experiences working with older adults, my passion for good communication, and my learnings as a PhD researcher. My reflections and reflexive tendencies occurred throughout data collection, data analysis, and write-up. The details are outlined further in chapters 6 and 7.

3.10 Summary

Using pluralistic methodologies to examine how various academics interpret data offers many viewpoints on how meaning in data is attained (Frost et al., 2010). Together, the layers of interpretation might offer a variety of views on the narratives of the participants' experiences. It is possible to extract the view(s) from the many dimensions from alternative interpretations of the data most relevant to the researcher (Easterby-Smith et al., 2008).

I used a positivist approach to conduct a systematic review, meta-analysis, and multiple linear regression analyses. The findings of this quantitative research were used to inform the most appropriate language and approach to explore lived experience. I creatively adopted an interpretivist paradigm and combined qualitative methods to explore the role of social isolation in residential care settings. The planning and engagement phase laid the foundation for the environmental audit, ethnography, and interviews conducted within two care homes. Data were triangulated to develop a grounded theory model. The purpose of the model was to outline the multiple factors that contribute to the occurrence and maintenance of social isolation in care home residents who are living with hearing loss and dementia.

CHAPTER 4

DOES SOCIAL ISOLATION MEDIATE HEARING LOSS AND
COGNITIVE DECLINE?
A SYSTEMATIC REVIEW AND META-ANALYSIS

4.1 Introduction

This chapter describes a systematic review and meta-analysis of hearing loss and later cognitive decline/ dementia diagnosis. The specific area of inquiry was whether social isolation had been investigated as a mediating factor between hearing and cognition in longitudinal cohort datasets.

In the context of hearing impairment, cognitive decline, and dementia, it is crucial to understand changes in central auditory structures (Park et al., 2016). The hypothesised mechanisms and possible biological connections between hearing and cognition are vital for understanding the intricacies of the association and determining causality (Gates et al., 2010).

4.1.1 Hearing-cognition relationship

Over three decades have been spent researching the connection between hearing and cognition. Folstein et al. (1975) used the Mini-Mental State Examination (MMSE) to show that people with more severe hearing loss had lower MMSE scores (Uhlmann et al., 1989). The English Longitudinal Study of Ageing dataset was used more recently to examine the connections between hearing loss, cognitive decline, and social isolation (Ray et al., 2018). In adults who did not utilise hearing aids to manage their hearing loss, this study showed a link between hearing impairment and cognitive decline. Moreover, social isolation was substantially related to cognitive deterioration in both those who treated their hearing impairment and those who did not. Social isolation may mediate hearing and cognition (Dawes et al., 2015b). These assumptions must be treated with caution since they are based on cross-sectional observations, hindering the ability to infer causality.

In recent years, meta-analyses have increasingly included cross-sectional and longitudinal research findings investigating the relationship between hearing loss and dementia. A review by Livingston et al. (2017) found that 9% of dementia was attributable to hearing loss in middle age (45-65 years). Since the publication of this article, the relationship between hearing loss and dementia has been supported by three further meta-analyses (Ford et al., 2018; Loughrey et al., 2018; Liang et al., 2021). Pure tone audiometry was utilised in a meta-analysis of cohort and cross-sectional studies to investigate the relationships between hearing loss and Alzheimer's disease and cognitive impairment (Loughrey et al., 2018). A substantial relationship between hearing impairment and later incidence of dementia was identified in the cohort studies, but causality is yet to be determined (Taljaard et al., 2016). In other words, it is yet to be determined whether unaddressed hearing loss causes dementia in later years. Although the meta-analyses arrived at the same conclusion—that hearing impairment increases the risk of dementia—their validity is constrained by their heterogeneity. Importantly,

they are heterogeneous in design, in the method of hearing impairment assessment, in the measures of dementia or cognitive status, and in the population sample size and characteristics.

A further challenge to establishing causality is the abundance of cross-sectional studies that only provide a snapshot observation of variables combined with the absence of randomised controlled trials. Cross-sectional studies, which are usually seen as being only moderately helpful for causal inference, are those in which exposure and outcome are examined simultaneously. This makes the interpretation of results vulnerable to reverse causality as it is difficult to ascertain whether the exposure preceded the outcome temporally (Savitz and Wellenius, 2022). Whilst randomised controlled trials would be optimal in determining a cause-and-effect relationship between hearing loss and dementia, it would be unethical to use hearing loss as an independent exposure variable that is manipulated between a treatment and control group. That's not to say that randomised controlled trials assessing the efficacy of interventions would not be useful in providing clarity to the topic area. For example, using hearing aids to assess the cognitive decline rate in older adults (Jayakody et al., 2020). This RCT is still underway. The results will be fascinating in determining the direction of this topic area, and contributing to causal inference.

Causality criteria were proposed by Hill (1965). There were nine viewpoints of causation: namely "strength of association, consistency, specificity, temporality, biological gradient, plausibility, coherence, experiment, and analogy" (Hill, 1965). The strength of association is pretty intuitive since causality is more likely to occur if the connection between an exposure and outcome variable is substantial. This does not only refer to statistical significance but clinical significance too. Hill (1965) emphasised the value of repeated findings since, despite a robust statistical design, one or few studies cannot be trusted to establish causation due to ongoing risks to internal validity. Although the definition of consistency has evolved due to data integration procedures, this criterion is still a very effective way to identify causal links (Fedak et al., 2015). In terms of temporality, exposure must occur before the disease manifests itself for an exposure-disease association to be causative. Therefore, epidemiologic study designs that guarantee a temporal progression between the two measurements are more convincing in inferring causation. This is perhaps the universal criterion agreed on by epidemiologists for determining causal inference.

All of the viewpoints have varying levels of emphasis and importance depending on the study type and topic interested in causation. The important factor to consider in longitudinal cohort studies is the ability to separate the effects of confounders from the exposure-outcome variable relationship. One way to eliminate or minimise the impact of confounding variables in

observational studies is by using Mendelian randomisation (Sanderson et al., 2022). Mendelian randomisation examines the causal relationships between potentially modifiable risk variables and health outcomes in observational data by using genetic variation as a natural experiment (Davies et al., 2018). What's unique is the use of genetic variants, fixed at conception, to support causal inferences about the effects of modifiable risk factors, which can overcome some types of confounding (Evans and Davey Smith, 2015). Findings from Mendelian randomisation research depend on certain assumptions, much like with all epidemiological techniques. The method may be the future for causal inference based on observational data as the genetic landscape is further understood.

4.1.2 Potential mechanisms

It is challenging to examine potential mediating factors in the association between hearing loss and an increased risk of dementia due to cross-sectional research methodologies. According to the sensory deprivation theory, reduced sensory input (induced by hearing loss) results in irreversible cognitive impairment and resource reallocation. There is not enough evidence to fully support this argument because, if it were true, hearing loss would always be present before dementia, which is not the case (Nirmalasari et al., 2017). The hypothesis of cognitive resource allocation contends that due to hearing loss, working memory or attention is diverted to speech recognition (Pichora-Fuller, 2003). If this hypothesis were true, however, cognitive problems would only be brief and no longer be an issue after receiving assistance for hearing loss, such as using hearing aids (Nguyen et al., 2017). There is presently no conclusive evidence that hearing aids improve cognitive performance in Alzheimer's patients or lessen the chance of long-term cognitive decline (Dawes et al., 2019; Mamo et al., 2018).

The shared cause hypothesis (Nixon et al., 2019) states that as age-related neurodegeneration impacts both cognitive and sensory systems, any theory that employs the concept of "age" should also take into account the age-related comorbidities of cognitive and sensory deterioration. The alternative framework postulates that dementia and hearing loss may be connected because hearing loss affects social isolation and depression and dementia is linked to social isolation, depression, and dementia (Dawes et al., 2015b). Although there is some empirical support for this idea (Dawes et al., 2015b; Ray et al., 2018), causation cannot be substantiated because it is inappropriate and unethical to use "social isolation" or "depression" as the exposure variables in a randomised controlled trial.

4.1.3 Social isolation, hearing, and cognition

Social isolation has been associated with negative health outcomes, including increased risk of mortality in severe cases (Cohen, 2004), and it is proposed that social isolation could

mediate the relationship between hearing thresholds and later cognitive impairment (Maharani et al., 2019). The “cascade” hypothesis (Birren, 1964) proposes that long-term auditory deprivation arising from hearing loss, results in (i) reduction of one’s ability to process sound input and, therefore, reduced stimulation in the auditory areas of the brain, and (ii) reduction in social interaction because of hearing difficulties, leading to reduced cognitive and auditory stimulation. The consequences of hearing impairment extend far beyond auditory difficulties. It can lead to speech perception difficulties, which can then cascade into social withdrawal and isolation (Lin and Albert, 2014). For example, an individual cannot hear clearly when multiple family members are speaking at once. This inability to hear can lead them to withdraw from social interactions due to the difficulties arising from persistently unsuccessful communication (David et al., 2018). Overtime, the reduced auditory input and social interactions can reduce stimulation in the cognitive centres of the brain (Uchida et al., 2019).

Despite the strong theoretical underpinnings, however, there is weak evidence of an association between social isolation and later cognitive impairment (Plassman, 2010; Liu et al., 2023). This lack of evidence may be because social isolation has not been consistently defined in the sparse epidemiological literature, or it may be because cognitive impairment precedes social isolation, instead of vice versa (Kuiper et al., 2016). It is important to acknowledge that an individual may perceive their social relationships to be inadequate even though they have a sizeable social network (de Jong Gierveld and van Tilburg, 2010). Nevertheless, any feelings of inadequacy or isolation can lead to an individual withdrawing from their social network and, consequently, experiencing negative health outcomes (Uchino, 2006), either through increased vulnerability to disease or reluctance to attend to their healthcare needs (Schwarzer and Leppin, 1991).

4.1.4 Limitations of existing epidemiology studies

Several epidemiological studies have examined the association between hearing loss and cognition (Park et al., 2016; Dawes et al., 2015a; Kuiper et al., 2016). Much of this literature has relied on cross-sectional data (Ray et al., 2018; Dawes et al., 2015b), utilising self-report hearing difficulties as an exposure variable (Amieva et al., 2015) or data in which cognitive testing preceded hearing testing (Kiely et al., 2012b). Self-report hearing difficulties do not accurately account for an individual’s hearing status (Louw et al., 2018) and are highly subject to bias. Although pure tone audiometry is a subjective measure of peripheral hearing, it is a relatively fast and simple way to capture hearing sensitivity (Kiely et al., 2012b), and it is, therefore, the preferred method to capture hearing sensitivity. Furthermore, to infer that hearing threshold causes later cognitive impairment, hearing testing should precede cognitive testing or dementia diagnosis, ensuring baseline cognitive scores are known (Yue et al.,

2021). Studies using participants with a dementia diagnosis or who have cognitive impairment at baseline cannot reliably conclude that hearing loss is causally associated with cognitive impairment or incident dementia (Gurgel et al., 2014; Deal et al., 2015).

According to the updated 2020 Lancet Commission on dementia prevention, hearing loss remains the single most significant modifiable risk factor for dementia incidence (Livingston et al., 2020). The conclusions of this report were initially based on the findings of (Deal et al., 2017, Gallacher et al., 2012, Lin et al., 2011b), as there were no systematic reviews or meta-analyses published on this topic at the time of the 2017 report. Whilst these studies include prospective longitudinal cohorts and have utilised audiometry for hearing measurement, there were shortcomings in their design and analysis. For example, high noise levels during hearing testing, analysis of change in hearing thresholds rather than the degree of hearing status at separate time points (Gallacher et al., 2012), the use of categorical rather than continuous data (Deal et al., 2017), and high rates of attrition (Lin et al., 2011b).

4.1.5 Gap in knowledge

To determine whether there is a causal pathway between hearing threshold and later cognitive impairment, a systematic review including only prospective longitudinal observational studies (Sun et al., 2011) and consistent methods of hearing loss ascertainment (e.g., pure tone audiometry) was required (Carl et al., 2022). This would allow mechanisms and mediators of hearing threshold and later cognitive impairment/dementia to be identified, specifically the role of social isolation. Figure 2 shows a diagram of the potential causal pathway between hearing threshold and cognitive impairment, and where social isolation fits in. The potential confounding variables are included within the diagram (figure 2) to demonstrate the number of factors that can influence the hearing-cognition association, and which should be accounted for in epidemiology studies.

The systematic reviews and meta-analyses in this topic area provide evidence to support a causal pathway for hearing loss-cognitive decline (Thomson et al., 2017; Loughrey et al., 2018; Liang et al., 2021). However, there has not been enough rigour in the included studies, so biases are still possible. Furthermore, the role of social isolation within the causal pathway has not been investigated. These gaps in knowledge led to the formation of the research questions in section 4.2.

4.2 Research Questions

1. Does hearing loss cause later cognitive impairment and/or dementia diagnosis in adults?
2. Is social isolation a mediating factor in the relationship between hearing loss and later cognitive impairment/dementia diagnosis?

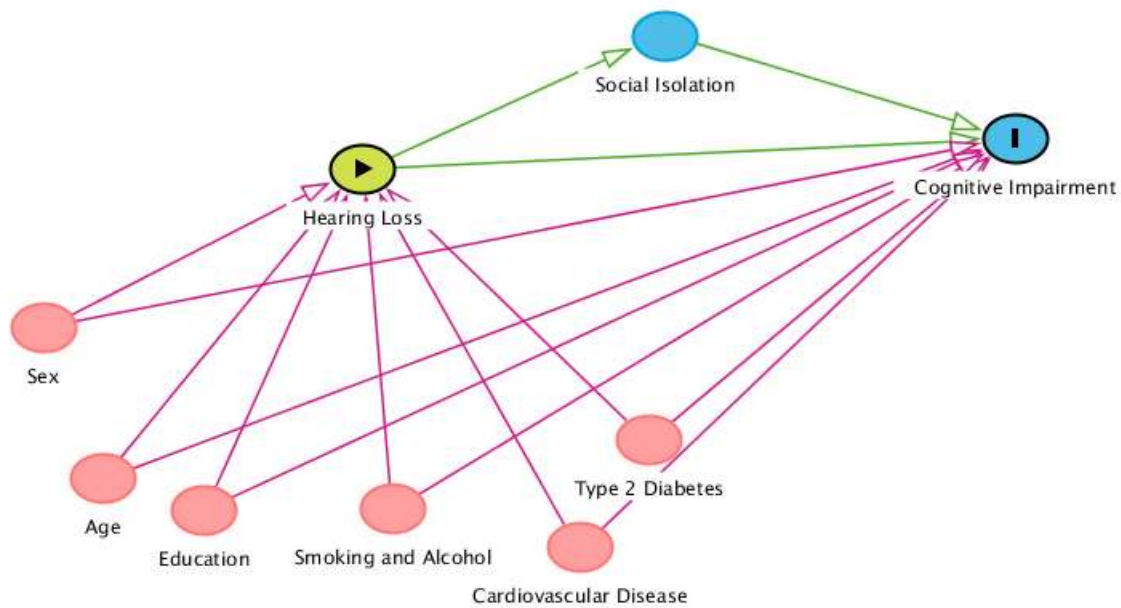


Figure 2: Proposed model of the pathway between hearing threshold, social isolation, and cognitive score/dementia diagnosis.

Figure 2 is a directed acyclic graph outlining the proposed relationship between hearing loss, social isolation as a mediator, cognitive impairment, and potential confounders.

Red variables = potential confounders in chronological order

Blue variables = outcomes/mediators

Green variable = exposure.

4.3 Methodology

4.3.1 Search strategy

A systematic literature search was conducted in January 2019, and an updated search was conducted in December 2022. The search was conducted across several academic databases, and has been reported according to the PRISMA checklist (Moher et al., 2009) and Conducting Systematic Reviews and Meta-Analyses of Observational Studies of Etiology (COSMOS-E) guidance on conducting systematic reviews and meta-analyses on observational studies of aetiology as provided by Dekkers et al., (2019). PRISMA guidelines are developed by the University of Oxford in collaboration with other research institutes to increase the reproducibility and transparency of literature reviews. PRISMA checklist guides authors about the reporting of search and screening methods. COSMOS-E is a set of guidelines specifically developed to address systematic literature reviews in the field of aetiology i.e., studies on a cause-and-effect relationship between variables. It guides authors through specific biases that do not appear in other reviews such as dealing with confounding variables and information biases (Dekkers et al., 2019). The use of COSMOS-E influenced the searching approach in the following ways: applying an iterative approach to the research question and scoping existing literature before deciding on a focussed question; ensuring a variety of medical databases were searched for thoroughness; extending searching beyond electronic databases such as reference lists of relevant articles; and meticulously considering the role of confounding, selection bias, and information bias in the chosen studies.

Pre-searches to identify relevant search terms and MeSH headings related to hearing and cognition were carried out prior to the main search. Moreover, the international prospective register of systematic reviews (PROSPERO) and Cochrane library were both searched using the terms “hearing and cognition” to ensure there had been no previous systematic reviews conducted that had addressed our research questions.

Table 1: Search string

Scientific Databases Searched	Search String
Web of Science PubMed (Medline) Scopus EMBASE PsychInfo ProQuest (PsychArticles and ProQuest Dissertation and Theses)	(hearing OR hearing-loss OR hearing-impair* OR deaf* OR sensorineural-hearing-loss OR SNHL OR presbycusis OR hearing-disorder OR age-related-hearing-loss OR inner-ear-loss OR hearing-ability OR auditory-threshold OR sensory OR audiometry)) AND (cognition OR cognitive-decline OR cognitive-deficit OR mild-cognitive-impairment OR dementia OR cognitive-impairment OR cognitive-difficulty OR cognitive-defect OR Alzheimer's-disease OR cognitive-function OR demented OR incident-dementia).

All search terms were searched in the fields for “title” or “title/abstract/keywords” as an alternative. The main search string was replicated in all databases (see table 1). OpenGrey, a grey literature database, was also searched using the terms “hearing and cognition”. No filters, time, or language limitations were applied. All returned searchers were exported into Endnote X7 software where duplicates were removed using a built-in function. Titles and abstracts were then exported into a Microsoft Excel spreadsheet for study selection.

4.3.2 Eligibility criteria

The inclusion criteria for literature comprised longitudinal repeated-measures studies to allow the temporal nature of hearing to be addressed; hearing threshold measured via pure tone audiometry at time point 1 (minimum) to reduce bias from self-reported hearing; measure of cognitive function at time point 1 or 2 and subsequent time points, or dementia diagnosis at subsequent time points for time of exposure and outcome; and adult human participants aged 18 or over.

The exclusion criteria for literature comprised studies using self-reported hearing loss (i.e. people identifying whether or not they have hearing issues with or without formal testing); studies using speech threshold testing, as this was not a consistent measure of hearing sensitivity; narrative reviews and commentaries, as empirical data was required for synthesis; systematic reviews and meta-analyses; animal studies; and dementia diagnosis at baseline, to ensure causality could be determined between hearing and later dementia diagnosis. These were excluded as the information lacked reliability or consistency as with self-reported measures or threshold testing or were not related to the research question as with animal studies.

4.3.3 Study selection

Using EndNote X7, two reviewers (myself and my supervisor A.H.) independently screened titles and abstracts in duplicate (Clarivate Analytics, Philadelphia, PA) during the first search in January 2019. Using the established eligibility criteria, we independently evaluated full-text publications in duplicate. Regarding inclusion and exclusion criteria, both reviewers concurred. Discussion and evaluation of the inclusion and exclusion criteria were used to settle disagreements.

4.3.4 Data extraction and study quality

One reviewer (N.D.) extracted data independently from the included studies using a standardised electronic data form. A second reviewer (A.H.) independently checked a selection of the data related to the first search in January 2019. The data elements extracted

included basic study information, participant demographics, the cognitive measurement tool used, and the dementia diagnosis measurement tool used (see tables 3 and 4). Included studies were critically appraised using the Critical Appraisal Skills Programme (CASP) checklists for cohort studies (Critical Appraisal Skills Programme, 2019). Risk of bias was assessed using the Item Bank for Assessment of Risk of Bias and Precision for Observational Studies of Interventions or Exposures (Viswanathan and Berkman, 2012). These tools were used to ensure that both quality assessment and risk of bias were considered for the included studies, appropriate to the study type. The Newcastle Ottawa Scale (NOS) has traditionally been used to rate the quality and assess risk of bias for studies included in a systematic review (Wells et al., 2018). However, when compared against the Item Bank for Assessment of Risk of Bias and Precision for Observational Studies of Interventions or Exposures, NOS has been shown to have lower validity and less thoroughness for assessing risk of bias in observational studies (Viswanathan and Berkman, 2012).

4.3.5 Planned meta-analysis

Two a priori meta-analyses were planned for cognitive score and dementia diagnosis outcome if the included studies used the same cognitive test or dementia diagnosis criteria for the outcome (Borenstein and Higgins, 2013). As long as there was no high risk of bias or red rating, as determined by table 2 and appendix 2, the studies were included in the pooled calculation. Meta-analysis can be performed using the fixed effects model or random effects model based on the studies' methods. If all studies have similar methods, instruments and outcome measures, a fixed effects model is better suited. In this case, the heterogeneity should be low. In random effects model, the assumption is that all studies are measuring a relevant outcome using different methods and thus can be combined under the assumption that the difference in the effects is random and can be explained by the differences in population, methods, and outcome measurement.

A generic inverse variance method was applied on the studies reporting hazard ratios using log-rank or cox proportional hazards regression models (Cox, 1972). The inverse-variance method is a well-known and straightforward variant of the meta-analysis process (Sutton et al., 2000). The name "inverse-variance technique" refers to how each study is assigned a weight that is equal to the inverse of the variance of the effect estimate, or 1 over the square of the effect estimate's standard error. Therefore, studies with a greater number of participants (and lower standard error) are given more weight than those with fewer participants with larger standard errors. This method of weighting reduced the pooled effect estimate's uncertainty. A fixed effect model was applied for studies using the same method to measure exposure and outcome. The RevMan 5 software (Cochrane, 2020) was used to calculate the summary effect

and heterogeneity.

4.4 Results

4.4.1 Selected studies

The abstracts of retrieved titles were screened based on the inclusion and exclusion criteria. Figure 3 illustrates the screening and study selection process using the PRISMA (Page et al., 2021) flow diagram template. Following the search of academic databases and grey literature, a total of 1724 articles were identified, of which 929 were duplicates. The abstract screening of the remaining articles ($n = 795$) further excluded 760 studies that did not meet the predefined inclusion criteria. A total of 15 publications fit the inclusion criteria and were analysed further as part of the narrative synthesis of this systematic review.

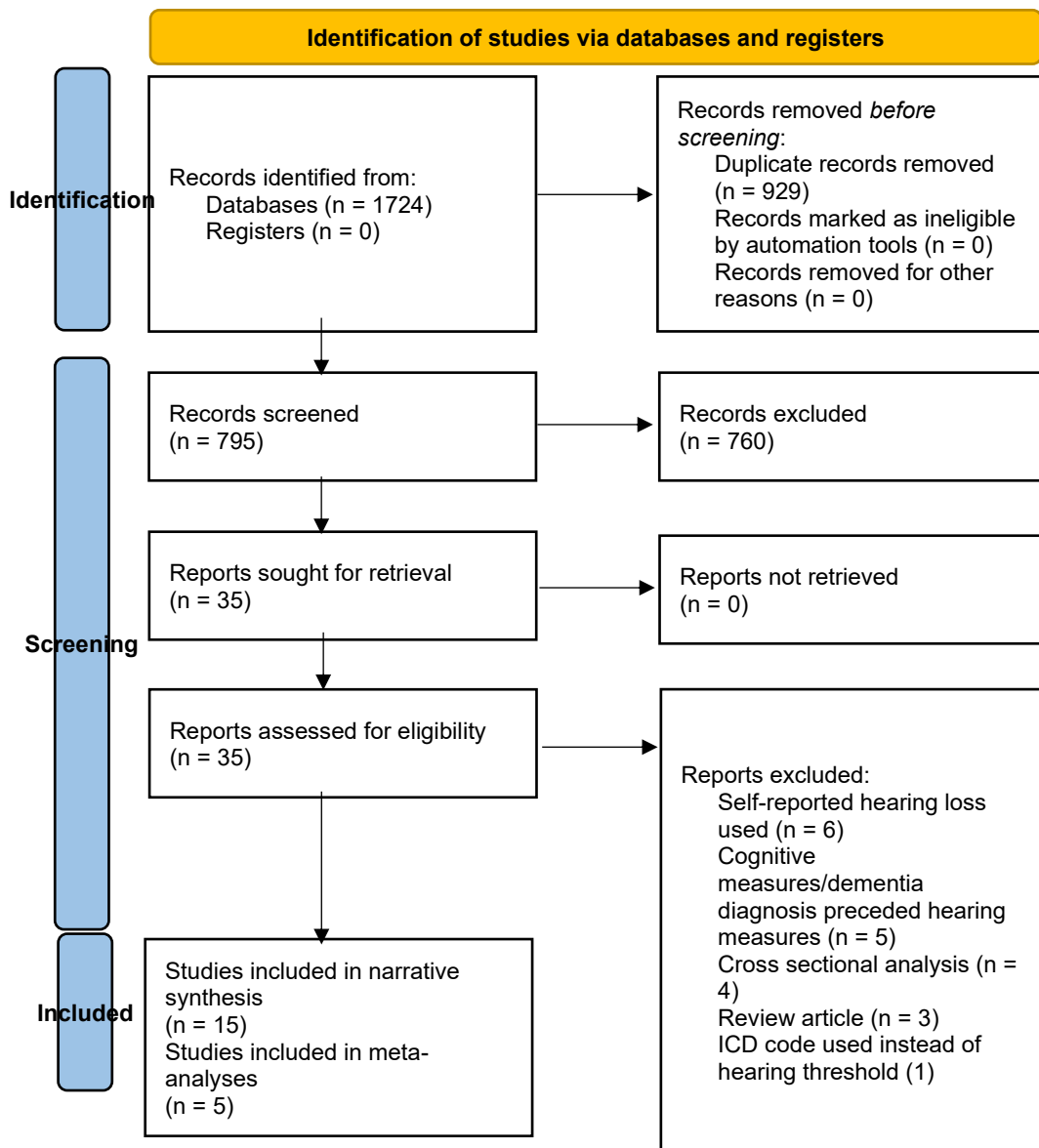


Figure 3: PRISMA flow diagram (Page et al., 2021).

The five main reasons studies were excluded were as follows: self-reported hearing loss was used rather than pure tone audiometry; cognitive measures or dementia diagnosis preceded hearing measures, thus not matching the temporal requirements of the causal relationship; an ICD code was used instead of numerical hearing thresholds; studies were cross-sectional rather than longitudinal; and narrative or systematic reviews were used that did not follow the inclusion criteria.

The data from the selected studies were narratively synthesised and tabulated (tables 2-6). A narrative synthesis and meta-analysis of a subset of studies were used to conduct the entire review (Lisy and Porritt, 2016). Two meta-analyses were performed for the studies that used similar outputs and similar methods (Borenstein and Higgins, 2013). There were ten studies that were not included in the meta-analyses. This was because the type of statistical analysis used in these studies did not match with other studies, where the same or similar outcome measurement(s) were used. Therefore, pooling results that were highly heterogenous in terms of the statistic calculated and the type of outcome being measured, would have provided an inaccurate estimate of the hearing-cognition association.

4.4.2. Study characteristics

All included studies were prospective longitudinal studies. The studies were based in USA (46%), Europe (33%), Australia (13%) and one study was based in Japan. All chosen studies were cohort studies part of wider longevity and ageing studies. The sample size ranged from 295-2336 (SD 923). The included studies had several differences despite having a particular inclusion criteria in terms of population size 295-2336 (mean 1465 SD 923), follow up years 2-24 (mean 11.13 SD 6.85), follow up frequency (1 time – 6 times), and in definitions of exposures, outcome, and confounders (tables 3 and 4). The definitions for dementia, hearing loss, cognitive impairment, and confounders differed substantially across the studies. The differences and similarities are discussed in later sections in addition to social isolation as a mediator, cognitive tests, attrition rates, selection bias, choice of cohort, confounders, and choice of statistical tests.

Of the 15 included papers, two studies exclusively used dementia diagnosis as an outcome (Lin et al., 2011b; Deal et al., 2017), 12 studies used cognitive score as an outcome (Valentijn et al., 2005; Uchida et al., 2016; Lin et al., 2013a; Hong et al., 2016a; Fischer et al., 2016;

Armstrong et al., 2018; Anstey et al., 2003; Alattar et al., 2020; Okely et al., 2019; Croll et al., 2021; Ge et al., 2021), and one study used both (Gallacher et al., 2012) (table 4).

The narrative synthesis revealed that 11 of the 15 included studies provided evidence of a dose-dependent association between hearing threshold and later cognitive impairment or incident dementia. The summary of findings, along with the risk of bias assessment, is presented in table 2, and more detailed in appendix 2. The quantitative results in terms of hazard ratios, odds ratio, and effect sizes are tabulated in tables 5, 6 and 7.

4.4.3 Risk of bias assessment

The Item Bank for Assessment of Risk of Bias and Precision for Observational Studies of Interventions or Exposures (Viswanathan and Berkman, 2012) was used for the qualitative assessment of the included studies. The analysis revealed that only 6 (40%) studies were free of any biases. None of the studies had a high risk of bias but 60% of the studies were at a moderate risk of bias due to reporting bias, information bias, selection bias, attrition bias, diagnostic bias. The detailed assessment sheet is provided in the appendix with author's comments and analysis. Most studies did not report the inclusion and exclusion criteria clearly (Hong et al., 2016; Alattar et al., 2020, Anstey et al., 2003, Armstrong et al., 2018), some studies also did not provide the detailed account of exposure measurements (Valentijn et al., 2005; Lindenberger and Ghisletta, 2009). Only 3 studies addressed the attrition rate using sensitivity analysis and 3 studies did not have a high attrition rate (Alattar et al., 2020; Anstey et al., 2003; Fischer et al., 2016; Lin et al., 2013; Lindenberger and Ghisletta, 2009, Uchida et al., 2016). The analysis of the risk of bias indicates that the studies need to make their reporting much more explicit and transparent.

The risk of bias assessment does not include a formal rating or scoring system like other assessment tools. The purpose of the tool is to consider the believability of study results across a wide range of factors, which are outlined in table 2 and further detailed in appendix 2. The reviewer has the discretion to interpret the levels of bias within the context of the other studies included in the review, and within the context of the topic area. A red, amber, green (RAG) rating was added to aid the reader in the overall levels of bias within each study. For example, if the duration between exposure and outcome measures were less than 10 years, then a study would have an amber rating. Similarly, if there are not valid and reliable measures used for the exposure or outcome, then an amber rating would be given. If there were four or more occurrences to warrant an amber rating, then a study would have a red rating. This did not occur in any of the included studies. Therefore, there was a combination of low bias (green rating) and medium bias (amber rating) studies included within the review. Similar risk of bias assessment tools, such as Risk Of Bias In Non-

randomised Studies - of Exposure (ROBINS-E) use formal RAG rating software to assist with the interpretation of high, medium, and low risk of bias studies included within the review. For example, 'robvis' software was produced by McGuinness and Higgins (2021) for this purpose. However, on balance, the Item Bank for Assessment of Risk of Bias and Precision for Observational Studies of Interventions or Exposures tool was the most appropriate for the included cohort studies.

Table 2: Summary of Risk of Bias using the Item Bank for Assessment of Risk of Bias and Precision for Observational Studies of Interventions or Exposures.

Author (year)	Are exposures assessed using valid and reliable measures?	Are outcomes assessed using valid and reliable measures?	Is the time following exposure sufficient to support the evaluation of primary outcome?	Risk of Bias RAG Rating Red – High Risk Amber – Medium Risk Green – Low Risk	Showed age adjusted causal relationship between HL and CD or ID Y/N/NS
Alattar (2020)	Yes	Yes	Yes	Green	Y
Anstey (2003)	Yes	Yes	Yes	Green	NS
Armstrong (2018)	Yes	Yes	No – only 2 years	Amber	Y
Deal (2017)	Yes	Yes	Partially – 6 years	Amber	Y
Fischer (2016)	Yes	Yes	Yes	Green	Y
Gallacher (2012)	No*	Yes	Yes	Amber	Y
Hong (2016)	Yes	No – MMSE blind version used.	Yes	Amber	N
Lin (2011b)	Yes	Yes	Partially – 6 years	Amber	Y
Lin (2013)	Yes	Yes	Yes	Green	Y
Lindenberger (2009)	Yes	Yes	Yes	Green	Not sure
Okely (2019)	Yes	Yes	No – only 3 years	Amber	Y
Uchida (2016)	Yes	Yes	Yes	Green	Y
Valentijn (2005)	Yes	Yes	Partially – 6 years	Amber	Y
Ge (2021)	No	Yes	Partially – max 6 year	Amber	Y
Croll (2021)	Yes	Yes	No-only 4 years	Amber	N

* PTA covering four frequencies and analysed as a continuous variable but noise levels high under which hearing was tested and correlations not high/consistent (better to know degree of difference).

HL; Hearing loss, CD, Cognitive decline, ID; Incident Dementia, Y: Yes, N: No, NS, Yes but not significant

4.4.4 Hearing loss ascertainment

Pure tone audiometry was the method of obtaining hearing levels in all included studies. However, there was variation in the definition of hearing loss, and whether it was explicitly defined in the methods. Table 4 provides details on how each study defined hearing loss. Most studies measured hearing at baseline only compared to a few studies that measured hearing at different time points and used the hearing as a change predictor. Hong (2016) defined hearing loss as the pure-tone average of 0.5, 1, 2 and 4kHz being greater than 40dB

HL, whilst Lin et al. (2013), Uchida et al. (2016), and Fischer et al. (2016) defined hearing loss as the pure-tone average of 0.5, 1, 2 and 4kHz being greater than 25dB HL. Lin et al. (2011b), Deal et al. (2017), and Alattar et al. (2020) all defined hearing loss in categorical terms where normal hearing was less than 25dB HL, mild as 25-40dB HL, moderate as 41-70dB HL and severe as greater than 70dB HL for the pure-tone average of 0.5-4kHz in the better ear. Deal et al. (2017) and Alattar et al. (2020) combined moderate-severe hearing loss as greater than 40dB HL. Lin et al. (2011b) also used hearing threshold as a continuous variable, as did Gallacher et al. (2012) and Armstrong et al. (2018) who used 10dB steps but did not define hearing loss in their methods, whilst Valentijn et al. (2005) used 1dB steps also without a definition of hearing loss.

All studies measured hearing at baseline only apart from Gallacher et al. (2012), Hong et al. (2016) and Anstey et al. (2003). However, Gallacher et al. (2012) used the mean hearing thresholds of the two time points where hearing was measured and a change in hearing (although no association was found between change in auditory threshold and cognitive decline). Hong et al. (2016) measured hearing at three time points but the latter two were compared to baseline rather than measured as change predictors. Anstey et al. (2003) also measured hearing loss at three time points but estimated whether change occurred in hearing threshold over the eight-year period of the study. Okely et al. (2019) did not undertake conventional pure tone audiometry but used a hearing screening device instead. This device measured hearing at 55, 35, 20dB for 1 kHz and 75, 55, 35dB for 3 kHz. Hearing was then categorised according to the number of tones out of the six listed that were successfully heard. Although a crude measure of hearing categorisation compared with the other studies, the others matched their conversion of hearing categories to the World Health Organisation's definitions very closely.

These differences in how hearing loss has been defined provide an increased risk of misclassification bias within the selected studies and can make comparing and generalising findings difficult.

4.4.5 Dementia ascertainment

Deal et al. (2017) defined incident dementia as the use of a prescribed dementia medication, identification of diagnosis from hospital records, or a race-stratified Modified Mini-Mental State Examination (3MS) score decline more than 1.5 standard deviations from the baseline mean. Lin et al. (2011b) defined dementia using the Diagnostic and Statistical Manual of Mental Disorders (DSM) (Third Edition Revised) and National Institute of Neurological and Communicative Disorders and Stroke-Alzheimer Disease and Related Disorders Association (NINCDS-ADRDA), criteria for diagnosing Alzheimer's disease. Whilst Gallacher et al.

(2012) also used NINCDS-ADRDA and DSM (Fourth Edition), in addition to National Institute of Neurological and Communicative Disorders and Stroke-Association Internationale pour la Recherche et l'Enseignement en Neurosciences (NINCDS-AIREN) criteria for vascular dementia diagnosis.

Table 3: Population characteristics of the included studies.

Author (Year)	Cohort (Country)		Participants including age	Total n baseline (T1)	Total n analysis
Alattar (2020)	Rancho Bernado Study of Healthy Aging	USA	Wealthy community dwelling older adults living in retirement community of Rancho Bernado, San Diego. 31–92 years.	1781	1164
Anstey (2003)	Australian Longitudinal Study of Aging	Australia	Sampled from South Australian electoral roll — men and those >85 years were oversampled	1620	T2 – 1229 T3 – 457
Armstrong (2018)	Baltimore Longitudinal Study of Ageing (BLSA)	USA	Community-dwelling participants aged 61–98 years	319	313
Croll (2021)	Rotterdam Study	Netherlands	Adult residents from Ommrood area 65.2 (DS 7.3)	3590	
Deal (2017)	Health Ageing and Body Composition (ABC) Study	USA	Community dwelling black and white older adults aged 70–79 years living in Memphis, Tennessee or Pittsburgh	2034	1889
Fischer (2016)	Epidemiology of Hearing Loss Study	USA	Residents based in Beaver Dam, Wisconsin	1884	1470
Gallacher (2012)	Caerphilly Cohort as part of Caerphilly Prospective Study (CaPS)	Wales	Men born between 1920 and 1939 resident in neighbouring towns of Caerphilly	1612	1057
Ge (2021)	Health and retirement study (HRS) and Aging, demographics, and memory study (ADAMS)	USA	Older adults that were part of the HRS and ADAMS, 73-10	295	268
Hong (2016)	Blue Mountains Eye Study (BMES)	Australia	Suburban Australian population who are 49+ years resident in Blue Mountains, West Sydney	2334	1952 at T2 1149 at T3
Lin (2011b)	Baltimore Longitudinal Study of Ageing (BLSA)	USA	Community-dwelling adults from and around Baltimore, USA	639	638
Lin (2013)	Health Ageing and Body Composition ABC Study	USA	Community dwelling black and white older adults aged 70–79 years living in Memphis, Tennessee or Pittsburgh	1984	1626

Author (Year)	Cohort (Country)		Participants including age	Total n baseline (T1)	Total n analysis
Lindenberger (2009)	Berlin Ageing Study	Germany	Participants aged 70–100 living in West Berlin.	516	46 (T6)
Okely (2019)	The Lothian Birth Cohort 1936	Scotland	Participants living in Edinburgh and Lothian areas of Scotland who were born in 1936	696	550
Uchida (2016)	National Institute for Longevity Sciences – Longitudinal Study of Ageing	Japan	Community dwellers in Aichi Prefecture in central Japan aged 60–79 years	2267	1109
Valentijn (2005)	Maastricht Aging Study	Netherlands	Healthy older Dutch adults aged 55–81 years	418	391

SD: Standard deviation, T: time point

Table 4: Outcome measures, follow-up and confounders in the included studies

Author (Year)	Time Points	F (yr)	Exposure	Outcome	Confounders	Type of Analysis
Alattar (2020)	T1 (1992–1996)– AM and CT T2-T6 every four years CT only	24	PTA 0.5-4 kHz Categorical HL	MMSE, Trail-Making Test Part , VFT	LDL, HDL, lifestyle factors, physical health, depression diagnosis	Linear Regression
Anstey (2003)	T1 – AM and CT T2 – AM and CT, T3 – AM and CT	8	PTA at 2,3 and 4 kHz Change in HL from baseline — continuous 10 dB steps	Similarities, Picture naming, National Adult Reading Test, Digit Symbol Substitution Test, Symbol Recall, Picture Recall, Word Recall	Depression, self-rated health, physical health	Latent growth curve models using individual change scores
Armstrong (2018)	T1 – AM and CT, T2 – AM and CT	2	PTA – average of 0.5–4 kHz HL continuous 10 dB steps	Trail-Making Test Part B, Digit Symbol Substitution Test, California Verbal Learning Test, Digit Span Forward/ Backward, Benton Visual Retention Test, MMSE	Vascular burden	Bivariate auto regressive cross-lagged models
Croll (2021)	T1 (2011-2014) T2 (2015-2016)	3-4	PTA at 0.25., 0.5, 4 and 8. HL categorical	MMSE, Stroop test, LDST	Demographics, lifestyle factors. Physical health, dementia at baseline	Linear mixed models.
Deal (2017)	T1 – AM T2, T3, T4 – dementia diagnosis	6	PTA – average of 0.5–4 kHz HL categorical: Normal/mild/ mod/severe	Dementia diagnosis at T2, T3, and T4	Study site, physical health, lifestyle factors	Cox proportional hazards models
Fischer (2016)	T1 – AM, T2 and T3 CT	10	PTA – average of 0.5–4 kHz	MMSE	Lifestyle factors, physical health mean IMT, frailty score	Kaplan-Meier survival analysis

Author (Year)	Time Points	F (yr)	Exposure	Outcome	Confounders	Type of Analysis
			HL > 25 dB (Y/N)			
Gallacher (2012)	T1 – AM T2 – CT, T3 – AM and CT, T4 – CT and dementia diagnosis	17	PTA – average of 0.5–4 kHz HL continuous 10 dB steps	Decline in cognitive score at T2 and T4) or dementia diagnosis at T4	Social class, anxiety symptoms, premorbid cognitive ability score (NART)	Logistic and Linear Regression
Ge (2020)	Every 2 years With up to 4 assessments	8	PTA at 0.5,1,2,4 kHz HL>25 (y/n)	Telephone interview for Cognitive Status (TICS). Vision loss, dual sensory loss	Demographics, socioeconomic status, health status, lifestyle factors, Alzheimer’s risk gene.	Linear mixed effects model
Hong (2016)	T1 – AM and CT, T2 – AM and CT, T3 – AM and CT	10	PTA – average of 0.5–4 kHz HL > 40 dB (Y/N)	MMSE-Blind	Walking disability, living arrangements, home ownership, education, baseline MMSE score, ≥3 major comorbidities, depressive symptoms	Logistic Regression
Lin (2011b)	T1 – AM T2 – dementia diagnosis	17	PTA – average of 0.5–4 kHz (better hearing ear) HL categorical: Normal/mild/ mod/severe	Dementia diagnosis at T2	Physical health, hearing aid use, Blessed score	Cox proportional hazards models
Lin (2013)	T1– AM and CT, T2, T3 and T4–CT	6	PTA – average of 0.5–4 kHz (better hearing ear) HL > 25 dB (Y/N)	3MS	Study site, Physical health, lifestyle factors	Mixed effects models
Lindenberg r (2009)	PTA at T1–T6	13	PTA at 2,3,4 and 6 kHz (averaged)	Digit Letter, Identical Pictures, Paired Associates, Memory for Text, Category, Word Beginning, Vocabulary, Spot a Word	Time to death, risk of dementia	Random coefficient modelling

Author (Year)	Time Points	F (yr)	Exposure	Outcome	Confounders	Type of Analysis
	All cognitive measures at T1, T3, T4, T5, T6					
Okely (2019)	T1 – HearCheck and cognitive measures, T2 – HearCheck and cognitive measures	3	HearCheck at 1 and 3 kHz	Spatial Span, Matrix Reasoning, Block Design, Symbol Search, Digit Symbol Substitution Test, Inspection Time Test, Four Choice Reaction Time Test, Digit Span Backwards, Verbal Paired Associated, Logical Memory, National Adult Reading Test, Phonemic Verbal Fluency	Childhood cognitive ability, socioeconomic status, physical health, lifestyle factors	Latent change score model
Uchida (2016)	T1 – AM and CT, T2 – CT	13	PTA – average of 0.5–4 kHz (better hearing ear) HL > 25 dB (Y/N)	Information, Similarities, Picture Completion, Digit Symbol Substitution	Physical health, socioeconomic status	Linear Regression
Valentijn (2005)	T1 – AM and CT, T2 – AM and CT	6	PTA at 1,2 and 4 kHz HL continuous 1 dB steps	Visual Verbal Learning Test, Stroop, Colour Word Test, Concept Shifting Task, VFT LDST		Linear Regression

Demographics (age, sex, gender, education, race) were confounders in all studies.

Pure Tone Average (PTA), Cognitive testing (CT), Audiometry (AM), Timepoint 1 (T1), Hearing loss (HL), Letter-Digit Substitution Test (LDST), Verbal Fluency Test (VFT). Mini-Mental State Examination (MMSE)

Lifestyle factors (smoking, alcohol, exercise), physical health (hypertension, diabetes, stroke), Follow up (F)

Table 5: MMSE Cognitive Score with continuous and categorical hearing threshold measurement.

Study Author (Year)	Outcome and Exposure	Effect Size* – Unadjusted	Confidence interval	P-values	Effect Size* - Adjusted	Confidence interval	P-values	PTA continuous or categorical	Number of participants in sub-analysis
Gallacher (2012)	MMSE on hearing threshold (higher usual hearing threshold)	-0.58	-0.707 to – 0.453	<0.001	-0.27	-0.391 to -0.149	<0.001	Continuous	1057
Armstrong (2018)	MMSE and hearing threshold per 10 dB hearing threshold	Not displayed	Not displayed	Not displayed	-0.059 (0.046) SE	N/A	0.201	Continuous	313
Alattar (2020)	Change in MMSE performance – mild hearing loss	-0.14 (0.13) SE	N/A	0.29	-0.19 (0.13) SE	-0.445 to 0.064	0.15	Categorical	580
Alattar (2020)	Change in MMSE performance- moderate/ severe hearing loss	-0.49 (0.19) SE	N/A	0.009	-0.54 (0.19) SE	N/A	0.004	Categorical	196

*Effect size unit is change in MMSE score

Table 6: Hazard ratios for incident cognitive impairment using MMSE and hearing loss

Study Author (Year)	Outcome Incident Cognitive Impairment	HR _{unadj}	CI	P-value	HR _{adj}	CI	P-value	PTA Cont./Categ	Subanalysis (n)
Lin (2013)	MMSE-mild HL	NA	NA	NA	1.19	0.99-1.44	0.01	Categorical	762
Lin (2013)	MMSE moderate/severe HL	NA	NA	NA	1.36	1.08-1.70	0.008	Categorical	400
Lin (2013)	MMSE per 10 dB hearing threshold	NA	NA	NA	1.07	1.01-1.14	0.03	Continuous	1626
Lin (2013)	MMSE-HL vs no HL	NA	NA	NA	1.24	1.05-1.48	0.01	Categorical	1162
Fischer (2016)	MMSE-HL vs no HL	2.11	1.30-3.40		2.09	1.29-3.39	NA	Categorical	449
Alattar (2020)	MMSE-mild HL	NA	NA	NA	1.08	1.01-1.74	NA	Categorical	580
Alattar (2020)	MMSE-moderate/severe HL	NA	NA	NA	1.32	0.87-1.34	NA	Categorical	196

HR_{unadj}: Hazard Ratio Unadjusted, HR_{adj}: Hazard Ratio adjusted, CI: Confidence interval, Cont.: Continuous, Categ.: categorical, . Mini-Mental State Examination (MMSE), HL: Hearing loss, PTA: Pure tone auditory, NA: Not available

Table 7: Hazard ratio for the incidence of dementia stratified by severity of hearing loss

Study Author (Year)	Outcome Incident Dementia	HR _{unadj} Odds ratio	CI	P-value	HR _{adj} Odds ratio	CI	P-value	PTA Cont./Categ	Subanalysis (n)
Lin (2011b)	ID and mild HL	4.9	2.6-8.8	NA	1.89	1.00-3.58	0.49	Categorical	125
Lin (2011b)	ID and moderate HL	12.1	6.2-23.9	NA	3	1.43-6.30	0.004	Categorical	53
Lin (2011b)	ID and severe HL	21.9	5.1-94.2	NA	4.94	1.09-22.40	0.04	Categorical	6
Lin (2011b)	ID per 10 dB of HL	NA	NA	NA	1.27	1.06-1.50	0.008	Continuous	638
Gallacher (2012)	ID per 10 dB rise in usual PTA	OR: 2.23	1.04-4.77	0.039	OR: 1.32	0.57-3.12	0.52	Continuous	46
Deal (2017)	ID and mild HL	1.03	0.75-1.41	0.86	1.02	0.74-1.40	0.91	Categorical	716
Deal (2017)	ID and mod-severe HL	1.63	1.16-2.30	0.01	1.55	1.09-2.18	0.01	Categorical	387
Deal (2017)	ID per 10 dB of HL	1.15	1.04-1.27	<0.01	1.14	1.03-1.25	0.01	Continuous	1889

HR_{unadj}: Hazard Ratio Unadjusted, HR_{adj}: Hazard Ratio adjusted, CI: Confidence interval, Cont.: Continuous, Categ: categorical, HL: Hearing loss, PTA: Pure tone audiometry, NA: Not available, OR: Odds ratio, ID: Incident Dementia

4.4.6 Cognitive tests

The most frequent cognitive test used was the Mini-Mental State Examination (MMSE), which appeared in five of the ten papers using cognitive test score as a primary outcome, with a cut-off score of 24 out of 30 for cognitive impairment (Lin et al., 2013; Hong et al., 2016; Fischer et al., 2016; Armstrong et al., 2018; Alattar et al., 2020). MMSE is primarily used as a screening tool within clinical practice and is often criticised for not being specific enough to detect lower levels of cognitive domains associated with various dementias (Siqueira et al., 2019). Hence, the use of MMSE as a cognitive test was interesting. Having said that, as a relatively quick and easy tool to administer, it is used to assess a broad range of cognitive domains. Variations of MMSE included 3MS (a longer version of MMSE with a broader range of scoring from 0–100), and MMSE-Blind where visual elements were taken out. After MMSE, the Digit Symbol Substitution Test, a processing speed test, was often included in the battery of cognitive tests. Since problems with recall and processing speed are often initial symptoms of dementia, these tests may be well suited to the detection of cognitive decline (Barnford et al., 2007). Tests of immediate and delayed recall were used by Gallacher et al. (2012) and Anstey et al. (2003), and Trail Making Test Part B (used to assess executive function) was used in Valentijn et al. (2005), Armstrong et al. (2018), and Alattar et al. (2020). Okely et al. (2019) used the greatest number of cognitive measures in their study, most of which were subsets of the Wechsler Adult Intelligence Scale tests (Table 4).

A variety of cognitive tests were used in the included studies. Some tests (or components of tests) were administered verbally. This could have biased participants with hearing impairments, who answered questions incorrectly from not hearing rather than not knowing. Specifically, components of the MMSE, tests of immediate and delayed recall (Rivermead Memory Scales), and California Verbal Learning Test may have affected participants' performance. Some studies reported that those administering the tests had appropriate training in communication techniques (i.e., ensuring to face the participant when speaking in a well-lit environment). However, it is difficult to conclude whether this is enough to prevent those with hearing loss from being disadvantaged when undergoing cognitive assessment. Furthermore, it is unclear whether participants could use hearing aids whilst undergoing cognitive assessment. If this occurred, it would present a higher risk of bias.

4.4.7 Attrition rates

Overall, the attrition rates in the included cohorts were lower than 30%, with the main reasons for the missing data being that participants did not attend due to death (Alattar et al., 2020), relocation, cognitive tests not completed at follow-up (Lin et al., 2013), or hearing corrected

by use of a hearing aid (Hong et al., 2016), thereby making a person ineligible to continue to participate. However, only two studies (Anstey et al., 2003; Gallacher et al., 2012) provided information on the characteristics of participants who did not receive follow-up. Therefore, it is unclear whether those participants who were not followed through to the final timepoint in the other studies, had dropped out due to poorer health and disease burden or volunteered to do so for another reason. Usually, the attrition rates are dealt with through sensitivity analysis or full-information maximum likelihood-based statistical methods, as done by (Anstey et al., 2003). An inability to address high attrition rates may increase the risk of attrition and selection bias within the included studies, leading to findings that lack external validity.

4.4.8 Selection bias

Regarding selection bias, there is clear information on the inclusion and exclusion criteria of the original cohorts from which participants in the included studies were selected and the sub-cohorts used for the analysis. Yet, initial recruitment of those cohorts may not be entirely representative of the older adults within the countries where the studies were conducted regarding race, gender, and age. For example, Lin et al. (2013) used the Health ABC Study for their analysis, recruiting only participants of white and black ethnicity. Including more ethnicities within the study may have influenced the results, as a greater proportion of participants would be exposed to the included confounders, leading to a dilution in the results.

4.4.9 Choice of longitudinal cohort

Deal et al. (2017) and Lin et al. (2013) both used the Health ABC Study of Ageing cohort dataset, but they used different primary outcomes: dementia diagnosis versus cognitive decline, respectively. Although Deal et al. (2017) included analysis of cognitive test scores, these scores were conducted earlier than the audiometry measures, so did not meet the inclusion criteria of the review. Similarly, the same cohort dataset (Baltimore Longitudinal Study of Ageing) was used by Lin et al. (2011b) and Armstrong et al. (2018) but Lin et al. (2011b) used incident dementia as the primary outcome, whereas Armstrong et al. (2018) used change in cognitive score. More than double the number of participants were used in the analysis carried out by Lin et al. (2011b), as compared to Armstrong et al. (2018): 638 versus 313, respectively. This increase in number of participants was largely to the difference in follow-up time periods used in each analysis (11 years vs 2 years) and the number of participants who had undergone all cognitive tests during the 2012–2017 period of data collection that Armstrong et al. (2018) was based on.

4.4.10 Confounding variables

All the included studies used some or most of the confounders identified in the proposed DAG. The main confounding variables used in the included studies were age, sex, race/ethnicity, education, hypertension, diabetes, stroke history, and smoking status. Other studies included confounders such as depressive symptoms, alcohol consumption, occupation, marital status, frequency of contact with close family and friends, and social group involvement. Depression and social group involvement were also used as mediators by (Lin et al., 2013, Alattar et al., 2020), respectively. The details of confounders for each study are given in table 4.

In some of the included studies, separate analyses were conducted for participants using hearing aids; Lin et al. (2011b), Lin et al. (2013), and Deal et al. (2017) did not find reduced risk of dementia or cognitive decline with hearing aid use. Although the estimations were in the anticipated direction of reduced risk, they had wide confidence intervals and did not achieve statistical significance.

One study used a potential mediator variable “lives alone” as a confounder in their statistical analysis (Hong et al., 2016). Living alone can be used as a proxy measure for loneliness/social isolation, which may mediate the hearing-cognition relationship. Therefore, using the variable ‘lives alone’ as a confounder, could provide an inaccurate estimate and interpretation of the strength of the hearing-cognition relationship.

4.4.11 Statistical analysis methods

Linear mixed effects regression models were mostly used to assess the association between the variables. All the studies used appropriate methods for the purpose of their analysis. However, for the purpose of meta-analysis hazard ratio is the most suitable measure to compare the onset of an event in relation to time and is the suggested measure for time-to-event meta-analysis by the Cochrane Handbook of Systematic review and Meta-Analyses (Higgins et al., 2022). Hazard ratios can be measured through Cox-proportional hazards model, Kaplan-Meier survival analysis and survival curves (Higgins et al., 2019). Only five studies (Deal et al., 2017; Lin et al., 2011b; Fischer et al., 2016; Lin et al., 2013, Anstey et al., 2003) allowed the calculations of hazard ratios. Table 2 and the detailed risk of bias table in appendix 2 gives a detailed account of the methods used in each study.

Alattar et al. (2020) used change scores of cognitive tests as an average measure between two time points. However, this is inappropriate in longitudinal studies, as only randomised experimental conditions can determine causality when outcome change scores are analysed (Tennant et al., 2022).

4.4.12 Mediation

One of the reasons for conducting this systematic review was to investigate how many studies have analysed the role of social isolation as a mediator to cognitive impairment due to hearing loss. Only one paper assessed for mediation (Alattar et al., 2020) of social engagement. This was completed by social-related variables added to the analysis such as social group involvement, number, and frequency of contact with close family and friends, and marital status. There were no differences in social engagement baseline characteristics between participants with and without hearing loss. When these variables were controlled for within the mediation analysis, the observed associations between hearing loss and cognitive decline were not attenuated. Therefore, social engagement did not appear to influence the findings, which could be due to the makeup of the study sample, namely majority white, highly educated, middle-class participants who attend social groups frequently and have regular contact with friends and family. Alternatively, the reason for social engagement to have no influence on the findings could be because it is not a suitable proxy measure for social isolation, and indeed a poor measure of social engagement. Another paper assessed the mediation of depressive symptoms in the association between hearing and cognition (Lin et al., 2013). The findings were not reported as the paper reported no substantial change in the size of the association between hearing loss and accelerated cognitive decline, when adjusting for depressive symptoms using the Centre for Epidemiological Studies Depression Scale scores at baseline.

4.4.13 Meta analysis

A meta-analysis of eligible studies was performed to pool the effect of hearing loss on cognitive impairment (figure 4) and dementia incidence (figure 5). Five studies were eligible for inclusion in the meta-analysis based on their risk of bias rating and specific approach to outcome measurement and reporting. The pooled result of the fixed effect model for cognitive impairment due to hearing loss is 1.11 with a p-value below 0.0001, indicating that the results are statistically significant. However, a hazard ratio of 1.11 (95% CI 1.06, 1.15) is not particularly high, indicating that people with hearing loss have an increased risk of 11% of developing cognitive impairment.

In a meta-analysis, heterogeneity is the difference in results between studies. The heterogeneity was as low as $I^2 = 34\%$ for the meta-analysis of hearing loss and cognitive impairment (see figure 4). The hazard ratio for incident dementia was slightly higher at 1.21, with a p-value of 0.002. The heterogeneity was 61% for this meta-analysis which is considered substantial by Cochrane guidelines (Higgins et al., 2022). The differences in the severity of

hearing loss across groups might have added to the heterogeneity, limiting the validity of results.

The meta-analysis was performed on a minimal number of studies thus, the results may be difficult to generalise. A meta-analysis of all the studies was impossible due to differences in the measurement of cognitive status, differences in defining and categorising hearing loss, and statistical methods to calculate associations. What's encouraging is that the quality of the included studies was high or medium, and the exposure variables were measured appropriately using a variation of pure tone audiometry.

There is a need to use more standardised methods and analyses to study the effect of hearing loss on dementia incidence and cognitive decline in longitudinal studies so that a pooled effect can be measured. It should also be noted that the studies that did not show a significant effect of hearing loss for example Hong et al. (2016) could not be included in the meta-analysis as they reported their findings in odds ratio rather than hazard ratio. The article did not provide enough information to calculate a hazard ratio.

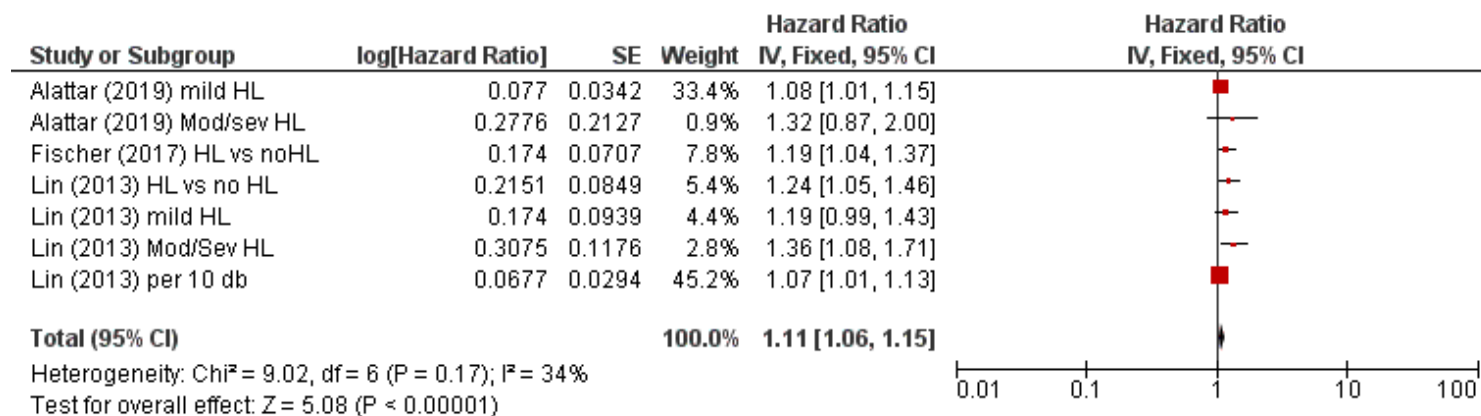


Figure 4: Forest plot for hearing loss and cognitive impairment

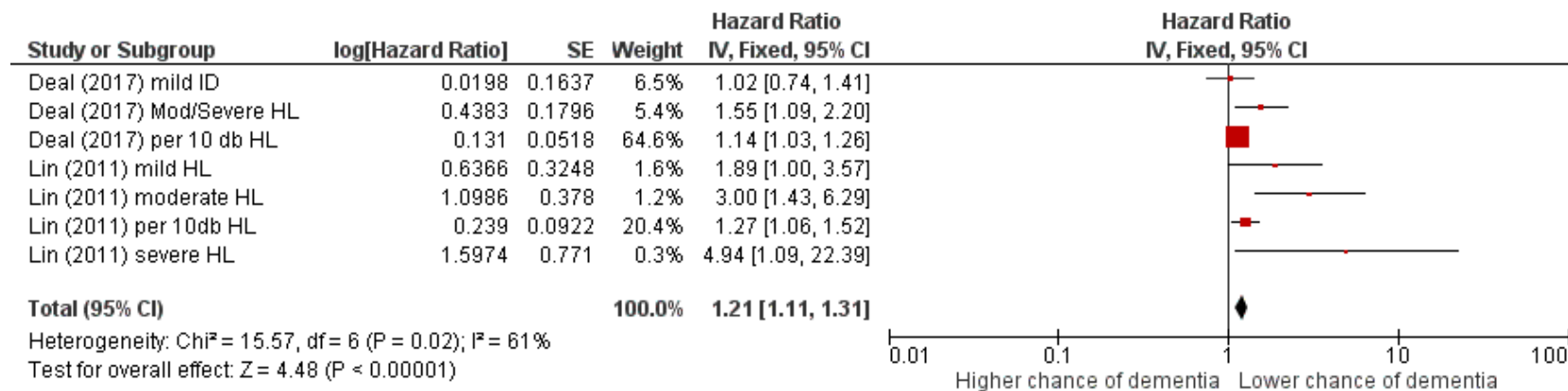


Figure 5: Forest plot for hearing loss and incidence of dementia

4.5 Discussion

4.5.1 Main findings

This was the first systematic review to include only longitudinal studies of hearing and cognitive status and dementia and investigate social isolation as a mediator. The analysis of included studies indicate that level of hearing threshold affects later cognitive status or dementia diagnosis. 11 out of 15 studies showed a causal relationship between hearing loss and incidence of dementia and cognitive impairment after adjusting for confounders (table 2). The pooled hazard ratio also confirmed that hearing loss had a statistically significant but small impact on cognitive decline (HR 1.11). The pooled hazard ratio for hearing loss and incident dementia was slightly higher at 1.21. These findings answer the first research question proposed in this study. But how and why hearing loss and cognitive impairment are associated with each other, can only be explained through mediation analysis.

The second research question of this systematic review was to identify the studies on mediation of hearing loss and cognitive impairment through social isolation. Only one study (Alattar et al., 2020) was identified that fit the inclusion criteria. There has been research conducted using self-reported hearing loss (Amieva et al., 2015) to determine whether social isolation links hearing loss to cognitive loss. However, the use of self-reported hearing assessment makes the study biased. Self-reported hearing measures also add subjectivity to the study and increase inaccurate measures underestimating the associations with other variables (Armero, 2001). As the criteria for inclusion was use of standardised PTA testing to ascertain hearing loss, these studies were excluded.

4.5.2 Validation of findings

The findings on the association of hearing loss and dementia or cognitive impairment of our systematic review aligns with the findings of other similar studies, which also depicted an association between hearing impairment and the incidence of dementia (Ford et al., 2018; Loughrey et al., 2018; Liang et al., 2021). The review by Ford et al. (2018) demonstrated a hazard ratio of 1.49 (95% CI 1.30-1.67) on dementia for those with hearing impairment. This was higher than the pooled effect reported here but still followed the same direction. The review by Loughrey et al. (2018) who included cross-sectional and longitudinal studies, calculated an odds ratio of 1.28 (95% CI 1.02-1.59) for the longitudinal cohort studies' hazard of dementia and hearing loss. Whilst this was similar to the HR of 1.21 reported here, it is essential to note that odds ratios often exaggerate risk and are not measuring the same effect as a hazard ratio (Andrade, 2019).

Moreover, a statistically significant odds ratio was calculated for dementia in general, but not specifically Alzheimer's disease, which is surprising. For cognitive impairment and hearing loss, I obtained a similar result to Loughrey et al. (2018) but again odds ratios were used. When the odds ratios for cross-sectional studies were used, an inflated result was obtained with a very wide confidence interval (OR 2.00, 95% CI 1.29, 2.89). This result reveals the challenges of using cross-sectional studies to imply cause-effect relationships and demonstrates that a high odds ratio result with a wide confidence interval lacks external validity. Finally, the review by Liang et al. (2021) found a hazard ratio of 1.59 (95% CI 1.37, 1.86) for the independent association between hearing loss and dementia. This was higher than my pooled effect because more studies were included in the analysis, of which some used self-report hearing loss as an exposure variable. Thus, inflating the results.

A recent systematic review and meta-analysis on association of age-related hearing loss with cognitive decline and dementia in English and Chinese speaking populations also reported similar results (Fu et al., 2022). This study was specifically interested in populations who spoke Sinitic-tonal languages, to see whether the hearing-cognition causal inference was supported. They found that the odds of cognitive decline and dementia increase with hearing loss by 1.85 and 1.89 times through an analysis of 25 studies, but the speaking language was not a factor (Fu et al., 2022). Similar conclusions have been made by previous systematic reviews and meta-analyses even though they have not been rigorous in their inclusion and exclusion criteria, as cross-sectional data and self-reported hearing loss studies have been included (Loughrey et al., 2018; Yuan et al., 2018; Thomson et al., 2017).

The study characteristics, differences in methods, and risk of bias in the included studies are presented in the results section. Overall, the studies used appropriate methods for assessing the impact of hearing loss on cognitive decline and vice versa but the lack of standardised outcome measures, different follow up times, high attrition rates, use of different statistical analysis make it difficult to compare the results of the studies. A narrative synthesis of individual studies indicated that 11 studies (table 2) showed a significant association of hearing loss and cognitive decline. These studies also provided evidence that hearing loss precedes cognitive decline and may be a modifiable solution for preventing cognitive decline.

4.5.3 Social isolation as a mediator

The literature regarding mediation of social isolation in hearing loss and cognition studies is very sparse despite social isolation being largely evidenced as a negative health outcome of hearing loss (Mick et al., 2014). Evidence for associations between social isolation and cognitive impairment are also widespread (Evans et al., 2018). Thus, there is a need for longitudinal studies to investigate the mediating role of social isolation on cognitive impairment

and hearing loss. In future studies, social isolation should be measured at several timepoints to allow for mixed-effects longitudinal analyses, and mediation analysis if the timepoints are appropriate.

Similarly, cross-sectional data has been used as evidence of the presence of mediation (Dawes et al., 2015b; Ray et al., 2018), but mediating factors are usually revealed temporally (MacKinnon and Luecken, 2008) thus a sequential assessment through longitudinal studies can increase the reliability of the mediation effect (O’Laughlin et al., 2018). Cross-sectional studies are not suitable for the studying mediation effects as they can generate biased or false results. Several researchers (MacKinnon and Luecken, 2008; O’Laughlin et al., 2018; Maxwell et al., 2011) have demonstrated it through careful analysis of previous studies and concluded that cross-sectional studies can over-estimate the mediation of a variable or produce a false-positive mediation effect. Instead, longitudinal mediation models such as cross-lagged panel and latent difference score models are suggested to identify complete or partial mediation of a variable (O’Laughlin et al., 2018; Maxwell et al., 2011).

Several studies (Maharani et al., 2019; Dawes et al., 2015b) investigating the association between social isolation, hearing, and cognition were excluded from our analysis as they used self-reported hearing loss that can be inaccurate. Maharani et al. (2019) depicted the mediating role of social isolation and loneliness between hearing loss and episodic memory scores but they used self-reporting hearing measures which as depicted in the previous sections are not accurate. Dawes et al., (2015b) used structural equation modelling in cross-sectional data of the UK biobank to determine whether hearing aid use, social isolation, and depressive symptoms were mediators in the association between hearing loss and cognition. Their findings suggested a positive effect of hearing aid use on cognition, but this effect was not associated with reducing social isolation or depressive symptoms. Brewster et al. (2020) also hinted at the role of depression as a mediator for dementia due to hearing loss. This lack of effect on social isolation and depression could be because hearing aid use can promote social withdrawal, due to excessive amplification of background noise in social situations or may be due to inappropriate measures of social isolation. Another reason for social isolation not showing an effect could be the use of cross-sectional data for mediation analysis, which is not a suitable approach, as discussed earlier. Cross-sectional studies have provided numerous hints that social isolation might be important, but longitudinal studies have not been conducted to support this suspicion.

4.5.4 Role of hearing aids

A prior longitudinal investigation indicated that hearing aids mitigated the impact of hearing loss on cognitive deterioration (Amieva et al., 2015). A recent meta-analysis found that hearing

aid users had lower levels of cognitive decline than those with unmanaged hearing loss (Yeo et al., 2022). They reported a hazard ratio of 0.81 (95% CI 0.76, 0.87), indicating lower risk of decline for hearing aid user participants. Whilst this appears encouraging, results must be interpreted with caution. Hearing aids are not a “one size fits all” solution for older adults with hearing impairment. The additional work and burden of managing hearing devices, processing sound through them, and the overall listening effort may not be of value to some individuals (Hornsby, 2013). Thus, a holistic approach to hearing healthcare would better support older adults (Campos and Launer, 2020).

Hearing aid wearers with Alzheimer's disease have not shown enhanced cognitive performance in prior randomised controlled studies (Nguyen et al., 2017). Numerous randomised controlled trials are being conducted to see whether using hearing aids can help prevent dementia in adults with hearing loss (Lin and Albert, 2014). Use of hearing aids has shown a delay in dementia incidence (Bucholc et al., 2021; Byun et al., 2022) thus, monitoring hearing threshold regularly after 60 years can help prevent or delay dementia and cognitive impairment. Many older adults living with dementia will have hearing loss, regardless of the role that hearing aids play in the prevention of dementia or the underlying mechanisms that link hearing loss and dementia. Therefore, there is an urgent need for research into treatments that will improve the health of those who have dementia and hearing loss as well as their carers (Livingston et al., 2017).

4.5.5 Reverse causality

However, this does not mean that reverse causality should be ruled out. There is some evidence of cognitive decline leading to peripheral hearing decline. In a study to determine the predictors of longitudinal hearing decline in older adults, Kiely et al. (2012b) found an association between the presence of cognitive impairment and faster rates of decline in peripheral hearing. The MMSE was used to measure cognitive impairment in most cohort studies that include cognitive testing, as it provides a measure of global cognitive function. However, further research is required to investigate the specific areas of cognitive function responsible for hearing decline, or because of hearing decline in older adults. Genetic data from UK Biobank (Brenowitz et al., 2020) has been analysed to investigate whether cognitive ability predicts hearing loss. Over 80,000 participants aged 55 and older had undertaken a measure of speech-in-noise that allowed a speech reception threshold (SRT) to be calculated. A genetic risk score for Alzheimer's disease was also calculated and used to predict SRT. An odds ratio of 1.06 (95% CI 1.01,1.11) was calculated, which demonstrated a statistically significant association between higher Alzheimer's Disease genetic risk score and poor speech-in-noise hearing. Therefore, a shared biological mechanism via neurodegeneration

may be responsible for this finding, but genetic predictors of hearing loss must also be applied in future research to determine the true direction of causality.

4.5.6 Recommendations

There remains a need for further epidemiological analysis to be conducted where hearing threshold data is available longitudinally at several time points, and later cognitive testing or dementia screening and diagnosis of at least ten years follow-up. Only one study, Gallacher et al. (2012), measured dementia and cognitive decline at all time-points. To appropriately assess for mediation, social isolation variables must be determined at a time point in between initial hearing testing and later cognitive testing and dementia incidence. These variables should explicitly capture the concepts of social isolation beyond the simplicities of a person living alone or their marital status. Having said that, finding such a dataset may prove very difficult. Whilst hearing, dementia, and cognitive tests are common measures in large-scale cohort studies, social isolation measures are less common. Where social isolation measures exist in cohort studies, they may be measured inaccurately at time-points between hearing and cognition, for mediation to be conducted. If this is not possible, then it may be of value to separately assess the relationship between hearing threshold and later social isolation and hearing threshold and cognitive score. This would provide supporting evidence to determine the individual relationships, which can be compared to the included studies within the review.

What's more, exploratory work related to the lived experience of social isolation in older adults would help to determine the appropriate mediating variables to understand the mechanisms underlying hearing threshold and later cognitive impairment.

CHAPTER 5

INVESTIGATING PATTERNS OF HEARING LOSS, COGNITION,
AND SOCIAL ISOLATION USING POPULATION LEVEL DATA

5.1 Introduction

As a complex and multifaceted phenomenon, defining and measuring social isolation within the context of epidemiological studies is challenging (Loughrey et al., 2018; Kotwal et al., 2021). A systematic review of longitudinal studies was carried out (see Chapter 4) to investigate whether hearing loss leads to cognitive impairment, mediated through social isolation. The included studies offered strong evidence that hearing loss and cognition are associated, with hearing loss preceding cognitive decline, but there is still very limited knowledge of how (or whether) social isolation is a factor within the casual chain. The limited research that has investigated the relationship between hearing loss, social isolation, and cognition has suggested differing associations. Some cross-sectional studies and studies using self-reported hearing loss have indicated a connection between hearing loss, social isolation, and cognitive decline (Dawes et al., 2015b; Ray et al., 2018; Armero, 2001; Amieva et al., 2015). A hypothesised pathway by which hearing loss impacts cognition is through social isolation; however, only one identified paper tested whether social isolation was a mediator between hearing threshold and cognitive score (Alattar et al., 2020). The authors found that social isolation did not mediate the hearing-cognition relationship, which could have been because of how social isolation was defined and measured, or the demographics of the participants included in the study by Alattar et al., (2020).

The basis of mediation analysis is to analyse three relationships between variables. These are: exposure leading to mediator, exposure leading to outcome, and mediator leading to outcome. The ability to successfully conduct analyses on all three relationships relies on a dataset measuring the exposure, mediator, and outcome variables in chronological order for temporality to be demonstrated (Baron and Kenny, 1986). This is especially needed when inferring causality (Hill, 1965). When a dataset does not have the temporal measures to examine all three relationships together, it is still valuable to do the foundational work of mediation analysis by investigating one or two out of the three relationships. Consequently, there will be an insight into the strength of any observed associations, and the effect of confounding variables will also be known.

5.1.1 Development of research questions

The findings from the systematic literature review of longitudinal studies (see chapter 4) identified the need for further epidemiological analysis to investigate the longitudinal relationship between hearing loss, social isolation, and cognitive decline (see table 8). Most importantly, a cohort dataset with an appropriate follow-up period between timepoints was needed to ascertain temporality (Twisk, 2013). In addition, a sensitive measure of social isolation was required to investigate its role at a population level. While many datasets

available had hearing threshold and cognitive score data, marginally few included validated social isolation measures (English Longitudinal Study of Ageing, Medical Research Council Cognitive Function and Ageing Studies, 1946 British Birth Cohort Study). Of those that did, none had social isolation measures at timepoints conducive to mediation analysis (see table 9). This supports the lack of evidence regarding longitudinal studies investigating social isolation as a mediator, since very few have measured social isolation to begin with. In order to set a foundation for future explicit study of social isolation as a mediator between hearing loss and cognition, I set out to explore whether hearing was a predictor of future cognition and social isolation independently. Specifically, I investigated:

- Does hearing level predict later cognitive impairment in older adults?
- Does hearing level predict later social isolation in older adults?

Table 8: Findings of the systematic review of longitudinal studies and their epidemiological implications

Systematic review findings	Implications for epidemiological analysis
Studies that have defined hearing level into categories as well as continuous data per 10 dB HL provide meaningful information and allow sensible conclusions to be drawn.	A dataset will be chosen where hearing levels are expressed as a continuous variable because categorising hearing levels can reduce the integrity of the data.
Only one paper assessed for mediation — there is a need for further work on this.	Limited evidence of mediation analysis provides support for the need to complete this, but this can only be completed if the acquired dataset uses appropriate variables at appropriate timepoints.
Measures of social isolation are sparse within the literature.	Find a dataset that has a detailed and valid measure of social isolation.
MMSE was the most frequent cognitive test used.	Although this is a screening tool, it appears sensitive to the diagnosis of dementia and cognitive impairment and will therefore be the primary outcome variable used in the analysis.
Potential to control for many confounding factors identified from different studies.	Subject to the available variables in the chosen dataset, the ideal confounders would include age, sex, years of education, baseline MMSE score, and ≥ 3 major comorbidities i.e., angina, acute myocardial infarct, arthritis, hypertension, diabetes.

Table 9: Potential longitudinal cohort datasets that were considered for analysis

Cohort Name	Cost to access	Sample Size	Measures Used	Time points of data	Age range of participants	Social isolation measures	Variables of interest measured sequentially?
English Longitudinal Study of Ageing	Free - Dementias Platform	12099 at recruitment, 10317 currently	Self-reported hearing, standard dementia global cognition scale, MMSE, living situation, socioeconomic measures	Study start date 2002, and then followed up 7 time with interviews every 2 years and nurse clinical visits every 4 years.	50 years and older	Living situation, socioeconomic measures	No
Medical Research Council Cognitive Function and Ageing Studies	Free - Dementias Platform	18005 at baseline	Hearing impairment, standard dementia global cognition scale, MMSE, ACE, living situation, socioeconomic measures	1, 2, 6, 8, and 10 years	65 years and older	Living situation, socioeconomic measures	No
Hertfordshire Cohort Study/ Hertfordshire Ageing Study	Free - CLOSER	2621 at baseline, 653 at follow-up 2	Audiometry, cognitive function inc AH4 IQ, Mill Hill vocabulary tests, abbreviated MMSE, social support and networks by interview, accommodation	Baseline, 1994, 2003	0-83 years	Social support and networks, accommodation via MOS Social Support Survey	Yes, but social isolation same timepoint as cognition.
1946 British Birth Cohort Study	To be determined - CLOSER	5362 at baseline	Cognitive tests and social environments	23 time points from 1946-2011	0-68 years	Social environments	No

5.1.2 Theorised causal pathway

In all studies, especially longitudinal studies, controlling for possible confounders that could impact the relationship between exposure and outcome is an important step (Tuokko and Frerichs, 2000). Directed Acyclic Graphs (DAGs) illustrate the relationship between exposure and outcome relationships. They are employed here to explain the relationship between hearing loss and cognitive decline and hearing loss and social isolation. The variables in red depict the possible confounders between the exposure and outcome causal chain, displayed in chronological order within a person's life course (Tennant et al., 2021). The variable in green is the exposure or risk factor, and the variable in blue is the outcome. A DAG was used to identify appropriate exposure, alongside confounder and outcome variables within this model. Figure 6 shows the DAG representing the relationship between hearing threshold and cognitive score. The possible confounders of hearing thresholds and cognitive score are included within the DAG. Figure 7 shows the DAG representing the relationship between hearing threshold and social isolation score.

The confounding variables identified are very similar for both models. The addition of alcohol consumption and smoking status for the hearing-cognition DAG was included because there is evidence to support associations between alcohol consumption and hearing loss (Gopinath et al, 2010), and alcohol consumption and cognitive decline (Sabia et al, 2014). This is also true for smoking status (Gopinath et al, 2010; Sabia et al, 2012). However, these were not included as confounders in the hearing-social isolation DAG because alcohol consumption can increase a person's social interactions and engagement because it is a social activity (Aan Het Rot et al., 2008). There is weak evidence to support a link between smoking status and social isolation (Nicholson, 2012). Although being socially isolated may lead to an increased likelihood in the uptake of behaviours such as smoking (Ikeda et al., 2021) and drinking alcohol (Le et al., 2021). In terms of the chronological order of the confounders, it is of interest to note that the cardiovascular risk factors and Type 2 diabetes occur at the same time as the onset of age-related hearing loss. Whilst there is evidence to support these variables as confounders, it may be difficult to separate their effects longitudinally (McKee et al., 2018). These findings were used for designing the regression analysis for this study.

5.1.3 Chosen dataset

The Hertfordshire Ageing Study (HAS) dataset (Syddall et al., 2010) was freely available and allowed for analysis that addressed some of the limitations of previous studies. HAS used appropriate measures for hearing, cognition, and social isolation, was longitudinal in nature – hearing was measured prior to cognition and social isolation and was a representative cohort. Hearing threshold was measured using pure tone audiometry, which has been identified as a

reliable and minimally biased method of determining an individual's hearing sensitivity (Carl and Cornejo, 2022). Cognition was measured using the Mini-Mental State Examination, which is a widely used clinical screening tool and forms part of the battery of tests for dementia diagnosis (Folstein, 1975) Most significantly, the social isolation measure used was more detailed than others that have been included in longitudinal datasets. This is because the MOS social support survey (Sherbourne and Stewart, 1991) encompassed the multifactorial nature of social isolation. Instead of asking a simple question about a person's social network, or whether they feel lonely, the validated questionnaire used a range of social domains that were interspersed within the questions. Therefore, the HAS dataset was the best option for allowing me to look at both outcomes longitudinally.

The choice of the HAS dataset led to the following detailed research questions:

1. Does hearing threshold at time point 1 predict change in cognitive score on MMSE 9-10 years later in older adults aged 63-73 years?
2. Does hearing threshold at time point 1 predict change in social isolation score 9-10 years later in older adults aged 63-73 years?

5.2 Methods

5.2.1 Sample

The Hertfordshire Ageing Study (Syddall et al., 2010) dataset was deemed most appropriate for this work because it included hearing threshold data that preceded cognitive and social isolation data, with a suitable follow-up period of a maximum of ten years. There were also an array of other variables measures that could be potential confounders in the association, allowing multiple linear regression to be conducted. Whilst mediation analysis would have been the preferred method of investigating the desired variables, this was not appropriate because of the temporal nature in which the variables were collected. If hearing data were collected at timepoint 1, social isolation at timepoint 2, and cognition at timepoint 3, then there would be a scientific and statistical justification to complete a mediation analysis (Baron and Kenny, 1986). Since social isolation and cognition data were collected at the same timepoint, following hearing data, two separate linear regression analyses were planned. This allowed a temporal association to be investigated between the hearing exposure and two outcomes in the same sample, which is rare in the existing literature on this topic.

Examining life course factors that affect healthy ageing was the main goal of the HAS through birth cohort research (Syddall et al., 2010). Midwives in Hertfordshire, England, kept thorough records on all newborns between 1911 and 1948. 6,803 live singletons were born in North Hertfordshire between 1920 and 1930. 1,428 people who were still living there in 1995 could

be located with the help of the National Health Service Central Register. Of those, 824 (or 58%) consented to a home interview. Following the interview, 717 men and women went to a clinic to have several clinical measures, including hearing testing. To verify that measurements within and between observers could be compared, inter- and intra-observer reliability assessments were conducted at regular intervals throughout the fieldwork.

Participants in the second HAS follow-up and those in the nationally representative Health Survey for England (HSE) (2006) were compared for ageing characteristics at timepoint 2. Using the t-test, Mann-Whitney, and chi-squared tests, the ageing features of the second HAS follow-up and HSE study populations were compared. Participants in HAS and HSE had ageing characteristics that were essentially equivalent. As a result, no evidence supports the claim that HAS participants were consistently older or younger than their HSE counterparts.

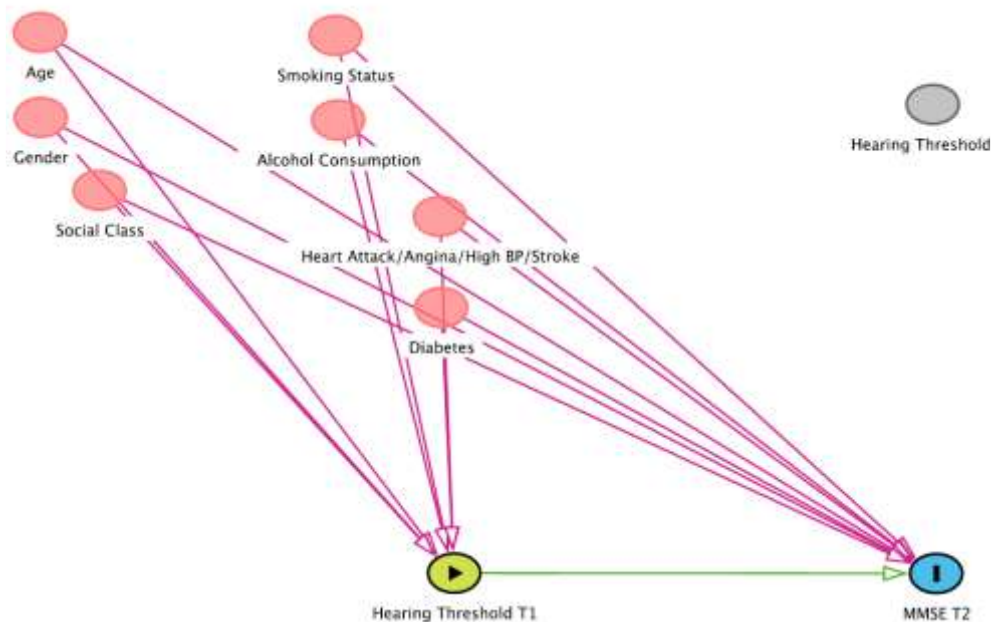


Figure 6: Theorised model for hearing and cognition analysis based on HAS variables

Directed acyclic graph outlining the relationship between hearing threshold, cognitive score using MMSE and potential confounders. Red variables = confounders, Blue variable = outcome, Green variable = exposure. Grey variable = hearing threshold at time point 2. This was not used in the analysis because I was interested in the absolute hearing threshold at timepoint 1 with a cognitive score instead of a change score (Tennant et al., 2022).

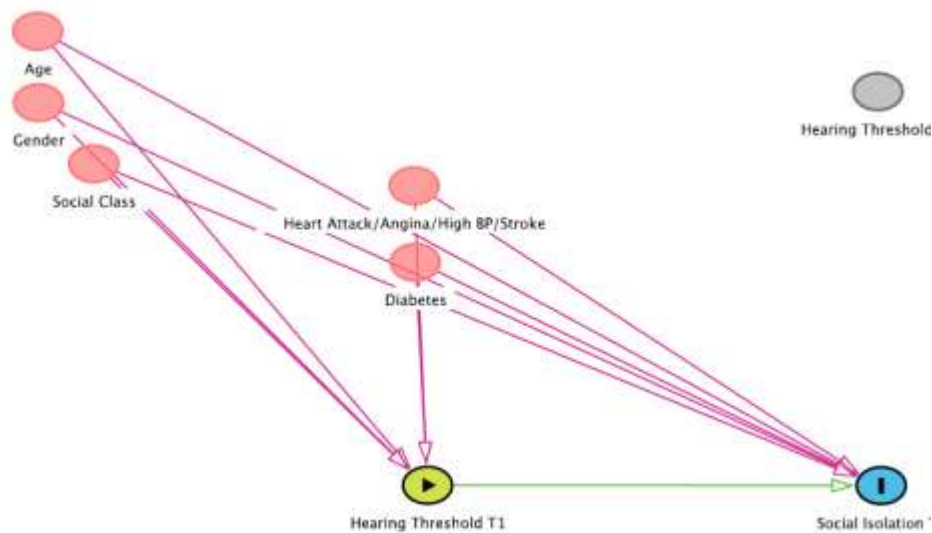


Figure 7: Theorised model for hearing and social isolation analysis based on HAS variables

Directed acyclic graph outlining the relationship between hearing threshold, social isolation and potential confounders. Red variables = confounders, Blue variable = outcome, Green variable = exposure.

The average age of the study participants was 67 years at time point 1 and 76 years at time point 2. The first HAS follow-up (time point 1) was conducted in 1994–1995 when the participants ranged in age, 63–73 years (mean 67). This consisted of 717 participants who underwent pure tone audiometry (0.5–4 kHz). There were 254 complete datasets for hearing and cognition, and 231 complete datasets for hearing and social isolation.

G*Power software (Faul et al., 2009) was used to calculate a sensitivity power analysis since the sample size was already known and fixed at the beginning of the study. The sensitivity analysis computes the required effect size given the alpha value (0.05), power (0.8, 0.9 and 0.95), sample size (231), and 10 predictors. The family of tests used was F tests, and the specific test chosen was fixed model R^2 deviation from zero. The linear multiple regression test is used to examine the linear relationship between a continuous outcome variable and one or more predictor variables, while controlling for the effects of other covariates. The R^2 deviation from zero option in G*Power calculates the sample size (or other derivatives) needed to detect a statistically significant deviation from the null hypothesis that the R^2 value (proportion of variance explained by the predictors) equals zero. For a fixed model, the R^2 deviation from zero test is appropriate when the goal is to determine whether the model as a whole is a good fit for the data (Faul et al., 2009). The effect size test is appropriate when the goal is to determine the strength of the relationship between the predictor (hearing threshold

and confounders) and outcome variables (MMSE score and social isolation score).

Table 10a: Calculation of effect sizes using different levels of power in G*Power (Faul et al., 2009)

F tests: Linear multiple regression: Fixed model, R² deviation from zero			
Sensitivity analysis in G*Power			
Alpha	N	Power	Effect Size f ²
0.05	254	0.8	0.07
0.05	254	0.9	0.08
0.05	254	0.95	0.10

Therefore, the different values of power provide different minimum effect sizes related to the chosen statistical analysis method. Prior to this calculation, a conservatively small effect size of 0.02 was considered appropriate based on similar effect sizes within the literature using Mini-Mental State Examination as an outcome (Lin et al., 2013; Alattar et al., 2020) and the threshold for multiple regression effect sizes. However, a much larger sample size would be required to achieve this effect size (822 participants for 0.8 power, 1036 participants for 0.9 power, 1229 participants for 0.95 power) and since the sample size is fixed there is more merit in completing a sensitivity analysis to identify the range of effect sizes possible with varying levels of power. This will determine whether the study is indeed underpowered based on the final results, since 0.8 power is recommended as a minimum power level to minimise the occurrence of a type 2 error (Serdar et al., 2021).

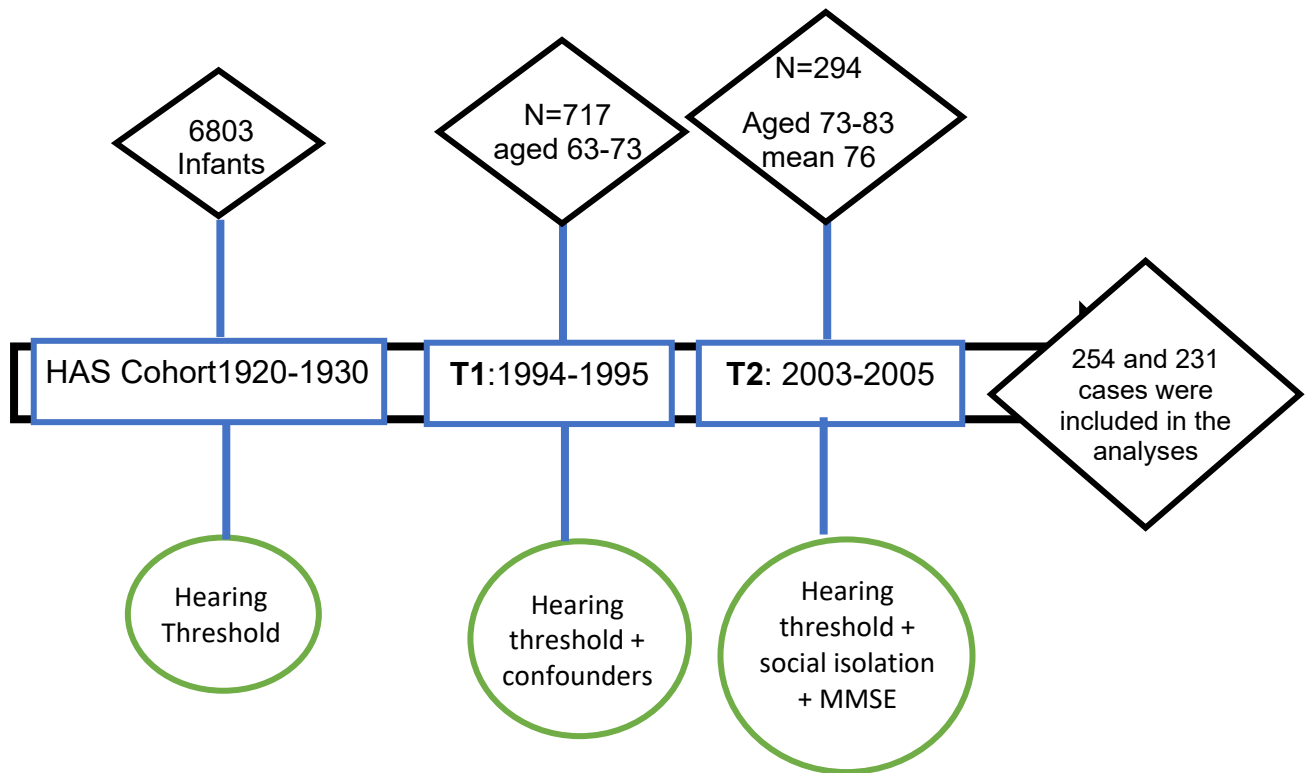


Figure 8: Timepoints and measurements of the Hertfordshire Ageing Study

5.2.2 Hearing measures

Pure tone audiometry was used to measure hearing thresholds. 714 individuals had their hearing evaluated by qualified researchers. Air conduction was used to measure the audiometric thresholds at four frequencies (500, 1,000, 2,000, and 4,000 Hz). For any participants who had a worse hearing ear or discrepancy between the two ears, the average hearing threshold was the mean of the air conduction thresholds at 500, 1,000, 2,000, and 4,000 Hz. Higher values denoted greater hearing loss. The British Society of Audiology Recommended Procedures defines normal hearing as having a hearing threshold of 20 dB or below (BSA, 2018). These clinical recommendations, followed by clinicians throughout the UK, are a valid way to distinguish between “normal” and “abnormal” hearing thresholds.

5.2.3 Cognitive measures

Cognition was assessed using the Mini-Mental State Examination (MMSE) (Folstein et al., 1983) at time-point 2. This 30-point cognitive screening tool assesses the following cognitive functions: orientation, registration, attention and calculation, recall, language, and copying. The MMSE allows for a maximum score of 30. A normal score is one of 25 or higher. A score

of less than 24 is typically seen as abnormal and indicative of possible cognitive impairment. The MMSE was analysed continuously, therefore increasing its precision and integrity within the data compared to other studies that have used the Mini-Mental State Examination categorically.

The Mini-Mental State Examination was the most popular choice of assessing cognitive status in the studies included within the systematic review and meta-analysis (chapter 4). The MMSE is easy to administer and has been psychometrically studied in similar populations (Pernecky et al., 2006). Some components are administered verbally, which would disadvantage people with unmanaged hearing loss. This tool is used widely in clinical practice as a screening tool and as part of the test battery for dementia because it tests such a wide range of cognitive domains (Kukull et al., 1994).

The Alice Heim (Heim, 1970) cognitive test (AH4) test was administered at time-point 1. The AH4 contains 130 items, with 65 items each measuring verbal and non-verbal ability. The items include mental arithmetic, vocabulary, and reasoning by analogy. Since the AH4 test was only completed at time-point 1, it was not considered within the regression analysis for hearing threshold and later cognitive score. The results of the AH4 test were considered as part of the baseline statistics only.

5.2.4 Social isolation measures

Marital status and frequency of contact with relatives and friends are often used as proxy measures for social isolation (Alattar et al., 2020). Combined measures related to social support and the size of social networks are also used (Ray et al., 2018). Outcome measures such as the Medical Outcomes Survey and eSocial Support Survey encompass a range of components related to the phenomenon of social isolation (Sherbourne and Stewart, 1991). This includes emotional/informational support, tangible support, affectionate support, and positive social interaction. So, this type of tool to measure a person's level of isolation is more appropriate than other simplified tools because of the acknowledgement of the different elements and components that make up social isolation.

Social isolation was assessed using the Medical Outcomes Study (MOS) Social Support Survey (Sherbourne and Stewart, 1991). The survey consists of four functional support scales (emotional/informational, tangible, affectionate, and positive social interaction) and the construction of an overall functional social support index. Items included the following:

- “Someone you can count on to listen to when you need to talk”
- “Someone to confide in or talk to about yourself or your problems”
- “Someone to share your most private worries and fears”

- “Someone who understands your problems”
- “Someone who shows you love and affection”
- “Someone to do something enjoyable with
- “How often do you see your children?”
- “How often do you see neighbours?”

Each answer was rated from 1–5 on a Likert scale, with a lower score indicating greater social isolation. 8 out of the 19 items (listed in bullet points) on the social support survey were used. A score for each subscale was calculated, and then averaged together for an overall score. Four distinct social support subscales and an overall functional social support index (this term) are included in the Medical Outcomes Study (MOS) Social Support Survey. The overall functional social support index is derived from the subscale and additional item scores by averaging the individual scores for all 19 items. The formula $100 \times \frac{(\text{observed score} - \text{minimum possible score})}{(\text{maximum potential score} - \text{least possible score})}$ can be used to convert scores to a scale of 0-100. A higher score on the scale is indicative of more support for a particular individual (Sherbourne and Stewart, 1991). The absence of 11 of the items within the survey may have reduced the validity of the questionnaire and thus affected any observed associations.

5.2.5 Potential confounding variables

The variables measured at time point 1 included age, gender, social class, smoking status, number of alcoholic units drunk per week, marital status, years of education, diagnosed angina, stroke, heart attack, high blood pressure, type 2 diabetes, or depression. These measures were potential confounding variables for the regression analyses. At time point two, which was conducted in 2003-2005, there was high attrition, resulting in 294 participants who had completed measures at both time points. At this time, pure tone audiometry was repeated, along with the Mini-Mental State Examination and Medical Outcomes Study Social Support Survey. Additionally, social class was categorised into either professional, managerial, technical and nonmanual, or manual, partly skilled and unskilled. This referred to a person’s own social class or their husband’s if ever married.

5.2.6 Statistical analysis using SPSS 24

Chi-squared and Kruskal-Wallis tests were used to identify differences between the final included sample and those who died/refused/did not respond and were therefore not included in the analytical sample of timepoint 2.

Multiple linear regression allowed calculation of a prediction model to estimate the effect of exposure on outcome. Multiple linear regression measures the relationship between two or more independent variables and one outcome (Eberly, 2007). To adjust for potential confounders, multiple linear regression was the most appropriate choice of analysis. In this study, hearing loss, and confounding variables were independent variables and cognitive scores, and social isolation were dependent variables in two separate models. This type of linear regression did not allow multi-level measures to be combined to check the effect of time. Rather, they measured the correlation between the variables under study and predicted the outcome. The models were adjusted for confounders to identify if their presence modified the outcome. The final equation obtained from regression had a co-efficient for each variable based on how much of an effect it had on the outcome. The direction of the relationship was presented by + and – signs (Urdan, 2011).

The first analysis included the hearing threshold at time point 1 as the exposure, and MMSE cognitive score at time point 2 as the outcome, with other predictor variables used in the model to control for potential confounding. The second analysis included hearing threshold at time point 1 as the exposure, and social isolation score at time point 2 as the outcome, with other predictor variables used in the model to control for potential confounding.

The primary objective of these linear regressions is to establish a linear relationship between the response and the explanatory variable(s) for predictive purposes. A linear regression model has four assumptions: linearity, independence of observations (collinearity), homoscedasticity, and normality of data (Casson and Farmer, 2014). Verifying these assumptions is crucial for the validity and quality of causal inferences and predictions. One of the assumptions of multiple linear regression is that the dependent and independent variables have a linear relationship. The systematic literature review in chapter 4 confirmed that there is a linear relationship between hearing loss and cognitive decline.

Central assumptions were tested, and diagnostic tests were carried out before the data were analysed using a regression model. The independence of observations assumes that no independent variables are correlated with each other, also known as collinearity. Multicollinearity was assessed using the Variance Inflation Factor (VIF) and tolerance statistic. The VIF measures how much the variance (or standard error) of the estimated regression coefficient is inflated due to collinearity. The tolerance statistic is the inverse of VIF. A VIF value greater than 1 and a tolerance statistic less than 0.1 are considered to present high correlation within the predictors in the model (Johnston et al., 2018). The VIF and tolerance statistic values were calculated (table 10b), showing VIF values slightly greater than 1, and no

tolerance statistics less than 0.1. Therefore, indicating low or non-existent correlation between the predictors, except for heart attack and alcohol predictor variables.

Table 10b: Variance Inflation Factors and Tolerance Statistics for predictor variables

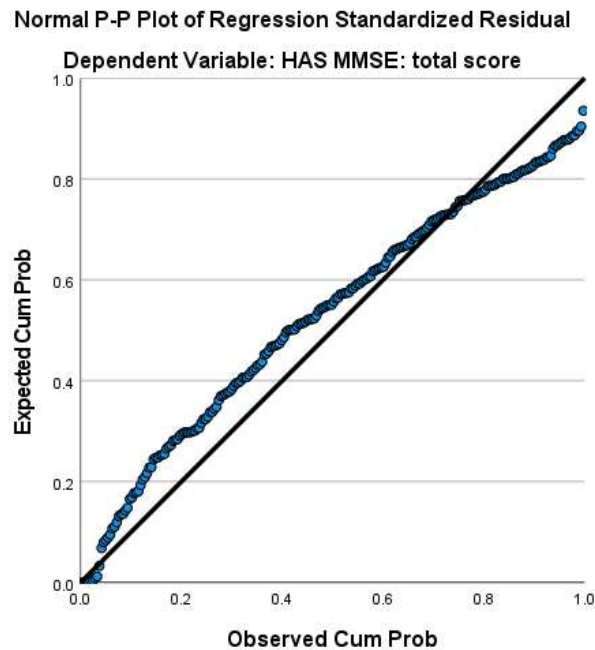
Variable	Variance Inflation Factor	Tolerance Statistic
Hearing Threshold	1.036	0.966
Gender	1.028	0.973
Age	1.016	0.984
Social Class	1.092	0.916
Diabetes	1.037	0.965
Stroke	1.055	0.948
High Blood Pressure	1.036	0.966
Heart Attack	1.380	0.725
Smoking	1.189	0.841
Alcohol	1.202	0.832

Table 10d demonstrates that none of the variables had high or strongly associated correlations with each other. Pearson's correlation for age was less than 0.6 (0.144; table 11). For other variables, t-tests were applied. The p-values were greater than 0.05, suggesting that the probability of any relationship between these variables was likely by chance rather than an actual relationship.

The Durbin-Watson test (Durbin and Watson, 1951) was used to assess independent errors. For any two observations the residual terms should be uncorrelated (or independent). A value of 1.908 was calculated within SPSS. A value of 2 means that the residuals are uncorrelated. The value reported for the Durbin-Watson test is very close to 2 and therefore there may be some positive correlation between residuals, but with minimal impact.

A normal probability plot was produced to assess normality of residuals as shown in Plot 1:

Plot 1: Normal Probability Plot of Residuals



The points on the normal probability plot do not fall neatly on the straight line. This indicates nonlinearity and confirms the need to log transform the hearing threshold variable, which is negatively skewed. Expected Cum Prob refers to the expected cumulative probability and Observed Cum Prob refers to the observed cumulative probability of the dependent variable data, which refers to the MMSE. This test of normality attempts to determine statistically whether the data deviate from normality or come from a random sample from a normally distributed population. Since large samples may be statistically significant even when the deviation from normal is relatively minor and small samples may not have enough power to find significance, the results of this test should be used in conjunction with other assumptions, rather than as a standalone finding (Lumley et al., 2002).

In addition, outliers in the data can also affect the normality of residuals. Outliers can cause the residuals to be skewed, leading to a curved normal probability plot. Influential outliers were assessed using standardised residuals. Standardised residuals are a measure of how far each observation is from the predicted value of the dependent variable. In general, values greater than 2 or less than -2 indicate potential outliers. There were 4 identified cases of influential outliers within the data, as indicated in the figures below.

Table 10c: Influential outliers identified within the data using standardised residuals calculations

Case Number	Std. Residual	MMSE Score	Predicted Value	Residual
177	-3.774	19	27.76	-8.757
200	-4.753	17	28.03	-11.027
208	-5.857	14	27.59	-13.588
291	-4.191	18	27.72	-9.725

Heteroscedasticity occurs when the variance of the residuals is not constant across all levels of the independent variables. Heteroscedasticity can cause the residuals to be skewed, leading to a curved normal probability plot. This may be evidenced from some of the higher VIF values for the heart attack and alcohol predictor variables. Non-normality of residuals does not necessarily invalidate the entire regression model, but it may affect the interpretation of the coefficients and the overall accuracy of the model.

The hearing threshold level was negatively skewed, so the median was used for descriptive statistics and then normalised using a log transformation to ensure normality for the linear regression analysis. A complete case analysis was used meaning that only comprehensive datasets were included in the analysis (van der Heijden et al., 2006). Multiple imputations or maximum likelihood methods are preferred when dealing with missing values. Still, lack of statistical knowledge and complex analysis is one major reason why researchers choose simpler methods like complete case analysis (Greenland and Finkle, 1995). It makes the sample size smaller, decreasing the reliability and validity of the study. Nonetheless, as the missing data accounted for around 20% of the data, complete case analysis was used, and any bias resulting from a reduced sample size may be meaningless (Ross et al., 2020).

There were three models used in each analysis. In the unadjusted multiple linear regression model (model 1), only the dependent variable and the independent variables of interest were included. There were no adjustments made for potential confounding variables, such as age or gender. This type of model was useful for exploring the relationship between the dependent variable and the independent variables without controlling for any other factors.

In the adjusted multiple linear regression model (model 2), adjustments were made for two potential confounding variables. Since age and sex were known to be associated with the dependent variable, they were included as independent variables in the model. This type of model allowed us the relationship between the dependent variable and the independent variables of interest to be assessed while controlling for the potential confounding effects of other variables.

In the fully adjusted multiple linear regression model (model 3), adjustments were made for all known confounding variables. In addition to age and gender, other relevant variables, such as, smoking status, alcohol units per week, social class, history of heart attack, high blood pressure, angina, stroke, and type 2 diabetes were included in the model. This type of model allowed the relationship between the dependent variable and the independent variables of interest to be assessed while controlling for the potential confounding effects of all known variables.

5.3 Results

5.3.1 Characteristics of the included sample

A total of 294 participants were included in the sample at timepoint 2. 58.8% were male, compared to 66.9% of males in the group who died prior to T1. In the final analysis, there were 254 participants for MMSE outcome and 231 participants for social isolation outcome included due to missing data of some variables. The samples with missing data were excluded from the analysis for accuracy (Greenland and Finkle, 1995). The cohort was followed 9–10 years from baseline. The median worse-ear hearing threshold level (referred as “hearing threshold”) was 27.50 dB HL at time point 1, worsening to 38.02 dB HL at time point 2. Therefore, there was an average decline of 10.5 dB. The rate of change between time point 1 and 2 in hearing threshold in dB per year was a maximum of 6.9dB, a mean of 0.76 and SD 1.17. The final included sample had better hearing thresholds (~4 dB) compared to those who died prior to time point 2 but there was no difference compared to those who declined or were untraced (*Kruskal-Wallis* 6.75, *df* 2, *p*=0.034). For the MMSE score (primary outcome) at time point 2, 92.9% of participants scored 25 or more (normal range), and 7.1% of participants scored 24 or less. Of the 294 in the final included sample, 254 participants had completed the MMSE data, and 231 had completed the social isolation survey.

Table 11 outlines the included sample characteristics, compared with those who were untraced or who declined and those who died. When compared to the final sample, those who died by time point 2 were distinguished by older age, male gender, worse average hearing threshold, current smoking status at time point 1, drinking >11 alcohol units per week, marital status of single/divorced/widowed, lower social class, diagnosis of stroke, and type 2 diabetes. Based on these variables, the population characteristics of the two groups were statistically different, demonstrated by p-values <0.05.

Table 10d: Correlations between included predictors and hearing loss for collinearity assumption

Confounding Variable	Number of Participants	Test and Reference Category (if applicable)	SPSS Output	P-Value
Age T1	293	Bivariate correlation	Correlation Coefficient = 0.144	<i>P</i> = 0.014
Sex	293	Independent <i>t</i> -test Ref Category = Female	Mean Difference = 0.057 Standard Error Difference = 0.024 Lower CI = 0.010 Upper CI = 0.104	<i>P</i> = 0.019
Smoking Status	292	One-way ANOVA Ref Category = Current Smoker	F = 1.41 (Between Groups) Mean Square = 0.059	<i>P</i> = 0.245
Alcohol Units per week	292	One-way ANOVA Ref Category = >11 units per week	F = 0.116 (Between Groups) Mean Square = 0.005	<i>P</i> = 0.890
Own Social Class	288	One-way ANOVA Ref Category = Manual and Unskilled	F = 3.920 (Between Groups) Mean Square = 0.164	<i>P</i> = 0.049
Heart Attack	291	Independent <i>t</i> -test	Mean Difference = -0.007 Standard Error Difference = 0.404 Lower CI = -0.087 Upper CI = 0.072	<i>P</i> = 0.860
Angina	291	Independent <i>t</i> -test	Mean Difference = -0.057 Standard Error Difference = 0.044 Lower CI = -0.144 Upper CI = 0.030	<i>P</i> = 0.195
High Blood Pressure	290	Independent <i>t</i> -test	Mean Difference = -.008 Standard Error Difference = 0.026 Lower CI = -0.059 Upper CI = 0.043	<i>P</i> = 0.756
Stroke	293	Independent <i>t</i> -test	Mean Difference = 0.013 Standard Error Difference = 0.145 Lower CI = -0.273 Upper CI = 0.299	<i>P</i> = 0.927
Type 2 Diabetes	278	Independent <i>t</i> -test	Mean Difference = 0.005 Standard Error Difference = 0.054 Lower CI = -0.102 Upper CI = 0.112	<i>P</i> = 0.922

Table 11: Population characteristics of included sample compared with non-responders.

	N (294)	Mean or Percentage	SD or IQR	Non-Responder – Died (121)	Non-Responders - Declined/Untraced (409)	P-value*
Exposure						
Average hearing threshold right ear T1 (dB)	293	21.25 (median)	15.00 (IQR)	(n=120) 23.75 (median)	(n=308) 22.50 (median)	0.150
Average hearing threshold left ear T1 (dB)	293	26.25 (median)	16.25 (IQR)	(n=120) 30.00 (median)	(n=308) 26.25 (median)	0.031
Average hearing threshold right ear T2 (dB)	252	32.90/30.00 (median)	14.73/17.50 (IQR)			
Average hearing threshold left ear T2 (dB)	254	34.08/31.30 (median)	14.83/18.70 (IQR)			
Maximum change in hearing T1-T2 (dB/year)	253	6.90 (0.76 mean)	1.17			
Worst average hearing ear T1 (dB)	293	27.50 (median)	17.50 (IQR)	(n=120) 31.25 (median)	(n=308) 27.50 (median)	0.034
Best average hearing ear T1 (dB)	293	20.00 (median)	13.75 (IQR)	(n=120) 22.50 (median)	(n=308) 21.25 (median)	0.070
Worst average hearing ear T2 (dB)	254	38.02 (median)	15.68 (IQR)			
Best average hearing ear T2 (dB)	254	29.23 (median)	12.66 (IQR)			
Cognitive Outcomes						
AH4 Score (follow-up 1)	290			115	294	
≤20	93	32.1%		58 (50.4%)	148 (50.3%)	0.000
>21	197	67.9%		57 (49.6%)	146 (49.7%)	
Change in AH4 Score T1-T2						
MMSE Score (follow-up 2)	281	-1.65	5.93			
Normal 25+	254					
Impaired ≤24	236	92.9%				
	18	7.1%				
Demographic and lifestyle characteristics						
Age at follow-up 1 (years)	294	66.97 (median)	3.55 (IQR)	67.96 (median)	(n=302) 67.39 (median)	0.006
Age at follow-up 2 (years)	294	76.43/76.30 (median)	2.22/3.70 (IQR)			
Gender						
Male	173	58.8%		81 (66.9%)	205 (50.1%)	0.002
Female	121	41.2%		40 (33.1%)	204 (49.9%)	
Smoking status at follow-up 1						
Never	108	36.7%		28 (23.1%)	150 (36.7%)	0.001
Ex-smoker	156	53.1%		69 (57.0)	184 (45.0%)	
Current smoker	30	10.2%		24 (19.9%)	75 (18.3%)	
Alcohol units per week at follow-up 1						
Non-drinker	100	34.0%		42 (34.7%)	167 (40.8%)	0.380
≤10 units	144	49.0%		56 (46.3%)	177 (43.3%)	
>11 units	50	17%		23 (19%)	65 (15.9%)	

Marital status at follow-up 1					
Single, Divorced, Widowed	76	25.9%	37 (30.6%)	127 (31.1%)	0.303
Married	218	74.1%	84 (69.4%)	282 (68.9%)	
Own Social Class^ at follow-up 1 (4 missing)			120	405	
I	133	45.9%	46 (38.3%)	161 (39.8%)	0.196
II	157	54.1%	74 (61.7%)	244 (60.2%)	
Years of Further Education (241 missing)			18	37	
1-10 years	50	94.3%	17 (94.4%)	36 (97.3%)	0.789
11-20 years	3	5.7%	1 (5.6%)	1 (2.7%)	
Diagnosed heart attack (2 missing)			121	402	
Yes	28	9.6%	15 (12.4%)	28 (7.0%)	0.143
No	264	90.4%	106 (87.6%)	374 (93.0%)	
Diagnosed angina (2 missing)			121	403	
Yes	23	7.9%	15 (12.4%)	51 (12.7%)	0.116
No	269	92.1%	106 (87.6%)	352 (87.3%)	
Diagnosed high blood pressure (3 missing)			119	403	
Yes	88	30.2%	44 (37.0%)	128 (31.8%)	0.411
No	203	69.8%	75 (63.0%)	275 (68.2%)	
Diagnosed stroke			119	406	
Yes	2	0.7%	7 (5.9%)	15 (3.7%)	0.008
No	292	99.3%	112 (94.1%)	391 (96.3%)	
Type 2 Diabetes (15 missing)			111	288	
Yes	15	5.4%	18 (16.2%)	25 (8.7%)	0.003
No	264	94.6%	93 (83.8%)	263 (91.3%)	
Low mood/depression			121	408	
Yes	39	13.3%	19 (15.7%)	59 (14.5%)	0.796
No	255	86.7%	102 (84.3%)	349 (85.5%)	
Emotional/Informational Support	229	3.97 (0.96)			
Tangible Support	233	3.96 (1.20)			
Affectionate Support	233	4.16 (1.11)			
Positive Social Interaction	230	4.05 (1.06)			
Additional Item	232	3.92 (1.16)			
Overall Support Index	223	7.93 (2.04)			

IQR: Interquartile range, SD: standard deviation. Figures in green denote p values less than 0.05.

*p-values correspond to the results of Kruskal-Wallis and chi-squared tests.

The average age of the study participants was 67 years at time point 1 and 76 years at time point 2. There were 67.9% of participants in the finally included sample who scored 21 or greater in the AH4 test at time point 1. This is greater than the 49.6% and 49.7% of those who died, declined, or were untraced, respectively ($p < 0.0001$). AH4 is a 65-item cognitive intelligence test with two subscales: verbal and numerical (Heim, 1970). Although this variable was not included in the final model, understanding the baseline cognitive scores of participants helps to support final interpretation.

There were 10.2% current smokers at time point 1 in the final included sample, compared to 19.9% of those who died and 18.3% of those who declined/untraced ($p = 0.001$). For alcohol units drunk per week at time point 1, 17% of participants in the final included sample reported 11 or greater, compared to 19% of those who died and 15.9% of who declined or were untraced ($p = 0.380$). At time point 1, there were 74.1% of participants who were married, compared to 69.4% of those who died and 68.9% who declined/untraced ($p = 0.303$). Social class was categorised into either professional, managerial, technical, and non-manual, or manual, partly skilled, and unskilled. This classification referred to a person's own social class or that of their spouse, if ever married (Syddall et al., 2010). There were 45.9% of participants in the social class I category, compared to 38.3% of those who died and 39.8% of those who declined or were untraced ($p = 0.196$). In terms of the number of years of further education, very small differences appeared between the final sample and those who died (0.1%) and declined or were untraced (3%) ($p = 0.789$).

Cardiovascular risk factors included diagnosed heart attack, angina, high blood pressure, and stroke. A greater percentage of people in the group who died who were diagnosed with these cardiovascular risk factors than in the final sample. Only differences in those with diagnosed stroke had a p -value of < 0.05 . For the group of individuals who had declined or were untraced, there was a lower percentage of those with diagnosed heart attack than in the final included sample, but a higher rate of diagnosed angina, high blood pressure, and stroke (p -value < 0.05). The final sample contained 5.4% of participants with diagnosed type 2 diabetes, compared to 16.2% of those who died and 8.7% of those who declined or were untraced. The p -value of these differences was < 0.05 . Participants were also asked about low mood/depression at time point 1. There was negligible difference between those in the final included sample compared to those who died, had declined, or were untraced (13.3–15.7% of participants answered "yes" to having low mood/depression).

The characteristics attributed to those who died prior to time point 2, compared to the final sample, included older age, male gender, a lower score on AH4 cognitive test, worse average hearing threshold, current smoking status at time point 1, drinking > 11 alcohol units per week,

a marital status of single/divorced/widowed, lower social class, diagnosis of stroke and type 2 diabetes.

Social isolation was assessed using the Medical Outcomes Study (MOS) Social Support Survey. Each question is rated from 1–5 on a Likert scale, with a lower score indicating greater social isolation. In the final included sample, the mean score for the emotional/informational support subscale was 3.97 (0.96 SD), the mean score for the tangible support subscale was 3.96 (1.20 SD), the mean score for the affectionate support subscale was 4.16 (1.11 SD), and the mean score for positive social interaction subscale was 4.05 (1.06 SD). The mean score for the overall functional support index was 7.93 (2.04). This was greater than 5 because the calculation included an additional item within the survey. Of the 294 participants in the final sample, 231 participants had complete data for the calculation of the overall functional support index.

5.3.2 Multiple linear regression

While the univariate analysis in table 12 (model 1) suggested that there may be a relationship between hearing threshold and later cognitive decline, age- and sex-adjusted (model 2) and fully adjusted models (model 3) indicate that no statistically and clinically significant associations were found between hearing threshold and later social isolation. The effect size for hearing threshold and later cognitive score in the unadjusted model was -1.476 95% CI (-2.992, 0.039), $p = 0.056$. For the model adjusting for age and sex, the effect size was -1.067 95% CI (-2.586, 0.453), $p = 0.168$. The effect size for the fully adjusted model was -0.923 95% CI (-2.471, 0.625), $p = 0.241$. This tells us that the relationship between hearing loss and cognitive decline is inverse. Still, the results are not statistically significant and may be explained, at least in part, by age, sex, and other confounders. After adjusting for age and sex, a 1 dB increase in hearing threshold will decrease cognitive score by 0.923, but an association does not exist because the lower and upper confidence intervals cross zero. The decrease in effect size with increased adjustment demonstrates the influence of confounding variables on observed associations.

The effect size for hearing threshold and later social isolation in the unadjusted model was -0.530 95% CI (-2.019, 0.959), $p = 0.483$ (table 14). For the model adjusting for age and sex, the effect size was -0.651 95% CI (-2.172, 0.869), $p = 0.399$. The effect size for the fully adjusted model was -0.595 95% CI (-2.083, 0.893), $p = 0.431$. Even though a negative relationship was observed between the samples, the p values of models and coefficients are not statistically significant. These findings suggest no association between hearing threshold and later social isolation.

Table 12: Linear regression models for hearing threshold (exposure) and cognitive scores (outcome)

Linear Regression Models	Adjusted R Square	Std. Error of the Estimate	F value¹	P value
Model 1 – Univariate	.011	2.338	3.683	0.056
Model 2 – Adjusted for age and sex	.041	2.303	4.280	0.006
Model 3 – Fully adjusted*	.026	2.320	8.417	0.111

* = Age, sex, smoking status, alcohol consumption, own social class, heart attack, angina, high blood pressure, stroke, type 2 diabetes. (n=254 in all models), ¹ = the f-value is the output of the f-test that compares the model with zero predictor variables (the intercept only model), and decides whether the added coefficients improve the model, which is denoted by a significant p-value.

Table 13: Regression coefficients for hearing threshold and cognitive scores

Linear Regression Models	Change in MMSE per dB HL increase	95% CI (Lower, Upper)	P-value
Model 1 – Univariate	-1.476	-2.992, 0.039	0.056
Model 2 – Adjusted for age and sex	-1.067	-2.586, 0.453	0.168
Model 3 – Fully adjusted*	-0.923	-2.471, 0.625	0.241

Table 14: Linear regression models for hearing threshold and social isolation scores

Linear Regression Models	Adjusted R Square	Std. Error of the Estimate	F value¹	P value
Model 1 – Univariate	-.003	2.05089	0.493	0.483
Model 2 – Adjusted for age and sex	-.008	2.05649	0.466	0.707
Model 3 – Fully adjusted*	.039	2.00754	1.921	0.051

* = Age, sex, smoking status, alcohol consumption, own social class, heart attack, angina, high blood pressure, stroke, type 2 diabetes. (n=231 in all models), ¹ = the f-value is the output of the f-test that compares the model with zero predictor variables (the intercept only model), and decides whether the added coefficients improve the model, which is denoted by a significant p-value.

Table 15: Regression coefficients for hearing threshold and social isolation scores

Linear Regression Models	Change in Social Isolation score per dB HL increase	95% CI (Lower, Upper)	P-value
Model 1 – Univariate	-0.530	-2.019, 0.959	0.483
Model 2 – Adjusted for age and sex	-0.651	-2.172, 0.869	0.399
Model 3 – Fully adjusted	-0.595	-2.083, 0.893	0.431

5.4 Discussion

5.4.1 Key findings

This study aimed to investigate the longitudinal relationship between hearing threshold and later cognitive score and hearing threshold and later social isolation among community-dwelling older adults. Over a period of 10 years, the hearing of the cohort worsened by 10.5dB on average. In contrast to previously published research findings (Gallacher et al., 2012; Lin et al., 2013; Mick et al., 2014), the regression analysis of hearing loss with cognitive score and hearing loss with social isolation score did not suggest an association between the exposure and outcome variables of interest. The sample size of the reported study was considerably less than previous studies (Gallacher et al., 2012; Lin et al., 2013; Mick et al., 2014), and therefore the study may have been underpowered. Furthermore, the central assumptions for the regression model were not entirely met, which may have lowered the internal validity of the results. The outcome measures could have also been inappropriate for the sample population, and not sensitive enough to detect changes in cognition and social isolation. Although no statistically significant associations were found in the analyses, the direction of the exposure-outcome relationships was inverse, like in other studies (Hong et al., 2006; Fischer et al., 2016). What's more, a recent study prospective cohort study investigating hearing threshold and later cognitive decline also found no significant effect on accelerated cognitive decline when controlling for age (Croll et al., 2021). Therefore, emphasising the importance of controlling for confounding variables, and ensuring appropriate outcome measures are used with a long enough duration from the exposure measures.

What this denotes is that hearing-cognition and hearing-social isolation patterns may not be as evident in epidemiological data as they are using individual and community-level observations. What's more, the MMSE may not be the most sensitive measure to detect changes in cognition for older adults in their 70s (Arevalo-Rodriguez et al., 2015; Jia et al., 2021). It also tells us that there are not enough multifactorial measures of social isolation in the literature to accurately compare to when trying to understand whether the association truly does not exist or has not been shown in the data. It is important to note the characteristics of the participants who were not included in timepoint 2 because of death or other reasons. Perhaps these participants were the ones who were more likely to have accelerated cognitive decline or social isolation.

An average of 10.5dB decline in hearing thresholds over a maximum of 10 years is not clinically significant (Wiley et al., 2008). A decline of 15dB or more in pure-tone thresholds at 2,000, 3,000, and 4,000 Hz may be considered clinically significant in older adults (Lin et al., 2011; Chien and Lin., 2012). However, it's important to note that these values can vary

depending on individual factors such as baseline hearing levels, comorbidities, and overall health. Age-related hearing loss occurs over many years, and individuals are very good at compensating for hearing difficulties. Therefore, a decline in hearing sensitivity of this value, over a 10-year period is unlikely to be considered significant to most people. Furthermore, this population were community-dwelling adults and therefore had a lot of control over their acoustic environment to ensure it was optimal for any changes noticed in their hearing. It is also important to note most participants had MMSE scores that were considered within the normal range.

To understand the causal pathway of hearing loss, social isolation, and cognition, mediation analysis is the preferred choice, and it has been used extensively in researching the relationship between a wide array of variables related to health sciences (Fairchild and McDaniel, 2017). This is where a mediator, or intermediate variable, evaluates an exposure's direct and indirect effect on the outcome of interest (Hafeman and Schwartz, 2009). Ergo, the exposure (independent variable) causes the mediator, which in turn causes the outcome (dependent variable). Traditionally, mediator variables have been investigated in observational studies through adjustment as part of a regression model (Richiardi et al., 2013). Unadjusted and adjusted models are then compared to identify the effect of the mediator. This method is prone to different types of bias because confounding variables related to both the mediator and to the outcome are not conditioned upon. Specifically, selection bias can lead to inaccurate estimates of association because of the introduction of collider variables (Munafò et al., 2017). Due to the timepoint at which social isolation was measured, it was impossible to conduct mediation analysis within this dataset. However, in this study associations between the exposure and the outcome, and exposure and mediator (both essential steps in mediation analysis), indicated no significant association. This does not necessarily mean that an association does not exist, but it supports the early signs of no evidence of social isolation as a mediator in this analysis. There was great value in doing two separate regression analyses: hearing threshold and later cognitive score, and hearing threshold and later social isolation score because I also noticed in my systematic review that there was a lot of selection bias in the included studies, so I wanted to see what the results were in my supposedly representative cohort. Also, there are very few studies using appropriate measures of social isolation.

5.4.2 Strengths

The characteristics of the HAS participants are not dissimilar from those of nationally representative data in England and Wales. As such, it is reasonable to generalise the findings to the wider population. Nevertheless, the participants were community-dwelling adults who were in good health and able to attend follow-up visits at a clinic. This situation is perhaps not

representative of older adults who experience hearing loss, cognitive decline, and social isolation simultaneously, so may present some selection bias within this study dataset. In order to prevent this bias in future, appropriate inclusion criteria within a study should be considered, ensuring that the exposure and outcome of interest do not drive inclusion or selective retention within the study (i.e., promoting selection and attrition bias, respectively). This can also result in a subset of participants being more likely to be included in detailed analyses because they have provided more data or volunteered for follow-up visits (Relton et al., 2015).

Additionally, another strength of this study was the use of pure tone audiometry to measure hearing loss. Subjective, categorical, and self-reported data on hearing loss can be inaccurate and does not allow a comparison between the studies as we do not know how the hearing loss was defined, what the participants perceived, and whether the measures were accurate. Self-reported hearing loss is also common in participants with normal audiometric threshold (Kamerer et al., 2022). Thus, use of self-reported hearing loss to measure the association between cognitive decline or social isolation can lead to misleading results.

Additionally, use of the MOS social survey, as a validated questionnaire, is a strength of this study. The MOS social survey captures the multifaceted nature of social isolation with more validity than the single, proxy measures used in most of the previous research. The definition and measurement of social isolation also varies in the research with most studies using marital status, social circle, living alone or loneliness as a proxy measure for isolation (Alattar et al., 2020; Ray et al., 2018, Hong et al., 2016). The inappropriate measurement of social isolation can also lead to biases in the research.

5.4.3 Limitations

There were several notable limitations to this study. The sample size limits the study and may account for the lack of association demonstrated. Whilst the sample size was fixed because the dataset was acquired after all data had been collected and the study completed, the study was underpowered according to the sensitivity table of effect sizes and power levels. The high attrition rate from time point 1 to time point 2, and the missing data within the predictor variables are responsible for the low sample size included in the final regression analyses. Those who died or declined further participation were compared in the descriptive statistics to consider the attrition rate and to identify selection bias, but this does not replace having data for those participants available.

Another limitation of this study was potential selection bias from multiple sources. The follow-up interval was too long, and a huge percentage of sample was lost to death or lack of participation thus, attrition was high. The population characteristics of the sample analysed,

and non-respondents were also significantly different in age, smoking level, hearing threshold, cognitive scores, etc. (table 11). This bias resulted in only the respondents with better outcomes and better hearing being included in the analysis, yet an association in both analyses was not found. If those with the highest social isolation or hearing loss were more likely to die or be non-responsive, those for which there may have been in fact a relationship may have removed those from analysis.

Selection bias can lead to inaccurate estimates of association and can distort the association between the exposure and outcome when none exists (Munafò et al., 2017). To prevent selection bias, appropriate inclusion criteria within a study should be considered, ensuring that the exposure and outcome of interest do not drive inclusion or selective retention within it (i.e., promoting selection and attrition bias, respectively). This can also result in a subset of participants being more likely to be included in detailed analyses because they have provided more data or volunteered for follow-up visits (Relton et al., 2015). Furthermore, using a complete case analysis could have introduced selection bias because of the characteristics of the group of people who were available for the entire duration of the study, to complete all measures, compared to those with missing data. They may have been sicker, poorer, or less willing to attend research appointments, and these reasons could be a factor in the presence or absence of an association.

Additionally, the change is measured at relatively small intervals, and so the loss of hearing noted is often small. This could be avoided by employing larger time frames in the future but more frequent follow-ups. It is also possible that the present study was underpowered to identify the small effect sizes that were observed. Finally, as explained earlier, this study could not measure the mediation effect of social isolation due to lack of data at appropriate timepoints. Nevertheless, the analyses have been instrumental for future work in this topic area.

There is sufficient evidence to suggest that positive and statistically significant results tend to be over-reported in the literature (Chisolm et al., 2007; Joober et al., 2012; Yang et al., 2022). A survey of 4600 publications showed a significant increase in publication bias over the years. Journal editors tend to favour statistically significant results that conform with the general trend in a topic area as it brings more citations for the journal thus increasing its prestige in the form of impact factor (Joober et al., 2012). Therefore, challenging widely accepted results in a research field is more difficult than supporting it. This could be the reason for lack of data on no association between hearing loss and cognitive decline.

Another reason for observed associations in other studies may be because of the inclusion of measures such as depression. Depression is strongly associated with hearing loss, social isolation, and cognitive decline but few studies have controlled for depression which might have overestimated the effect of hearing loss on cognitive decline in some studies (Anstey et al., 2003; Lin et al., 2013; Alattar et al., 2020). There may be an argument for depression acting as an outcome to hearing, cognition, and social isolation therefore introducing collider bias into the model (Tennant et al., 2021).

5.4.4 Novel contribution and future directions

In summary, this study has contributed to the existing literature on hearing loss, cognition, and social isolation, using appropriate longitudinal methods and analyses. The results may indicate more sensitive cognitive and social isolation measures are required to demonstrate meaningful associations. Specifically, for social isolation there may not be enough precision in the language used to capture the essence of someone feeling social isolation within prospective cohort studies.

The above discussion indicates a need for better designed studies to evaluate the relationship between hearing loss, cognitive decline, and social isolation. The mediation effect of social isolation on cognitive decline due to hearing loss should also be studied in well-designed studies using cross-lagged panel or latent difference score models (Maxwell et al., 2011). What's more, there needs to be greater understanding of social isolation at an individual level to better define the terms that should be used in prospective cohort studies. This will increase the sensitivity of these measures and capture the essence of what it means to be socially isolated.

From a public health point of view, the conditions discussed will continue to affect a greater number of people due to the veer towards an increasing ageing population. Therefore, healthy ageing initiatives such as hearing screening, cognitive screening, and socially interactive programmes for older adults to engage in will be key to curbing the issue of cognitive decline and social withdrawal in older adults.

CHAPTER 6

PREPARING TO CONDUCT ETHNOGRAPIC WORK IN RESIDENTIAL CARE SETTINGS

6.1 Introduction

This chapter details the extensive planning and engagement work that was conducted to prepare for the ethnographic research. There are also details provided on the ethical approval process obtained from the Health Research Authority, and the Mental Capacity Act 2005 training that I undertook in preparation for the ethnographic research. So far, there has been a focus on a positivist approach toward hearing, cognition, and social isolation and investigating how these conditions interact at a population level. The systematic review identified the need for more longitudinal studies to investigate social isolation as a mediating factor between hearing and cognition. The epidemiological analysis has shown that any associations that exist in older adults with unmanaged hearing loss and later cognitive impairment and unmanaged hearing loss and later social isolation hugely depend on the sample of participants and the outcome measures used.

The language used in describing social isolation is crucial for capturing the lived experience of the phenomenon, and the positivist work described in this thesis helped to shine a spotlight on how social isolation is labelled and measured. This part of the research focussed on an interpretivist approach toward hearing, cognition, and social isolation. Specifically, the micro level aspect of living with hearing loss and dementia in a residential care setting, and social isolation's role in this scenario.

Approximately 39% of adults aged over 65 who are living with dementia, reside in care homes in England, according to the Social Care Institute for Excellence (2020). Of all older adults residing in care homes in England, an estimate 80% are living with dementia (Prince et al., 2014), and up to 90% with hearing loss (Tolson, 1997). These reported figures are highly significant and will continue to rise with an ageing population and greater demand for social care. This is the reason for choosing care homes as the setting for exploring social isolation in residents living with hearing loss and dementia.

Conducting research in care homes is important for several reasons. The population in England is ageing, and the number of people aged 65 and over is expected to increase by over 40% in the next 20 years. (ONS, 2020) As such, there is a growing need for care homes that provide safe, high-quality care for older adults. Research can help identify effective ways to support the care home sector and improve the quality of care for residents who are living with dementia and associated comorbidities. Care homes in England have faced significant challenges in recent years, including staffing shortages, financial constraints, and regulatory changes (Age UK, 2021). Research can help identify strategies to address these challenges and support the sustainability of the care home sector. The COVID-19 pandemic has highlighted the vulnerabilities of care home residents and staff, and the need for effective

infection prevention and control measures in care homes (Upshaw et al., 2021). Care homes in England provide care to a diverse population with complex health and social care needs. Research can help identify effective ways to address the complex needs of care home residents, including those with dementia, hearing loss, and multiple long-term conditions. Finally, research on care homes can inform policy and practice in England, including the development of guidelines, standards, and regulations that support the provision of high-quality care in care homes (Spiers et al., 2021).

Residential care settings are highly complex and unique. Communication practices between residents, residents and staff members, and residents and their visitors vary greatly depending on the environment, existing medical conditions, and one's ability to communicate verbally and non-verbally (Cross et al., 2022). Therefore, the preparatory work to conduct research in those settings is vital, and naturally led to a co-operative inquiry approach. This chapter provides a detailed overview of communication in residential care settings, which acts as the founding principle of the ethnographic work. There is also an outline of the barriers and facilitators of service user involvement in residential care research, highlighting the need for such preparatory work. This is followed by the steps I took to build relationships and knowledge prior to the ethnography.

6.2 Communication in residential care settings

Hearing loss and dementia are both highly prevalent among care home residents. Prevalence rates are as high as 90% for hearing loss (Tolson, 1997), and 80% for dementia (Prince et al., 2014). In addition to other chronic illnesses that exacerbate frailty, a significant portion of residents will also have both problems. The staff of residential care facilities will regularly encounter communication barriers since both conditions impair communication, which can adversely affect the care given to residents and their quality of life. When communication breaks down, staff members can have difficulty differentiating the relative contributions of hearing loss and dementia. Nevertheless, knowing the individual enables them to differentiate these two factors through observing body language, facial expressions, and attempting to “read between the lines” (Rapaport et al., 2018).

Social isolation is exacerbated in marginalised communities such as residential care settings (Grenade and Boldy, 2008). What's more, if adults are not provided with information and tools to interact, the isolating nature of hearing loss may also be exacerbated (Hay-McCutcheon et al., 2017; Zaidman-Zait et al., 2015). People with hearing loss often find social interactions less gratifying because they find it difficult to discern between background noise and dialogue (Shukla et al., 2020). Hearing loss makes it harder to communicate, leading to social retreat and isolation, which increases the risk of cognitive impairments, low levels of mental

stimulation, and possibly depression (Lara et al., 2019b). Residents in nursing homes and community settings with significant hearing loss have up to twice the chance of becoming socially isolated, which is indicative of these detrimental effects (Mick et al., 2014).

6.3 Importance of service user involvement

Research in residential and nursing care environments is often conducted for the purpose of intervention development or implementation (Lawrence et al., 2016). Yet the people whom the interventions are designed for are seldom included in key decisions about the research (Sampson et al., 2019, Bayer and Tadd, 2000). The needs of care home residents and staff have largely been ignored in past research, especially where randomised controlled trials and other experimental studies have been conducted (Forster et al., 2017). Here, participants have been “done to” rather than “worked with” (Dewar, 2005), and this has reinforced the marginalisation of care home residents and staff. Similarly, qualitative research that has been carried out in care homes has highlighted the power imbalance between researcher and participant during interviews and focus groups (Råheim et al., 2016). This can occur despite the researcher having the intention to minimise any feelings of authority between themselves and the participant. In practical terms when working with people who have fluctuating capacity and compromised cognitive abilities, there are areas in which the researcher must take the lead for the activity, whilst still respecting and dignifying the individual’s opinions, voices and lived experience (Roberts et al., 2020).

Previous research has suggested that care home residents and staff view the role of the researcher as somebody entering their environment solely to collect data (Luff et al., 2011a). Therefore, a lack of follow-up and maintaining relationships between the researcher and participants does not allow for meaningful change. Furthermore, the lack of co-produced research conducted in care homes (Backhouse et al., 2016) highlights either the lack of willingness of researchers to address the power imbalance or the unfortunate reality of the pressures to produce “discovery research” that so many researchers face. Either way, participants whom the interventions could benefit from most are not reaping the rewards of their participation.

Care home staff may be reluctant to participate in research due to high work pressures (Hall et al., 2009). However, the lack of engagement from researchers towards care staff may be the driving factor in their unwillingness to participate. Building relationships (and trust) between different stakeholders of a care home should enable the research process to be more efficient and valuable (Froggatt et al., 2009). However, constant re-negotiation with the “gatekeepers”

of research within those homes (e.g. care home managers and duty supervisors) can delay the process (Luff et al., 2011a). Thus, investing time and effort into understanding the culture and context of the homes in which research is planned can provide solid foundations for developed relationships, and should be standard practice in qualitative research. One approach towards this is using a relational skills model based on well-established psychotherapeutic theoretical models (Rogers, 1961, Egan, 2013). The value of using a relational skills model in proposing stages of relationship development and maintenance enables richer and fuller engagement. There is also an opportunity to positively manage the power imbalance between researchers and participants via good communication practices and transparency. When done well, the researcher can understand the perspectives and ethos of the care home and retain a long-term relationship with residents and staff. Without this effort, there is a strong tendency to lose contact with the home once data collection is complete, and there is no desire for care staff to retain relationships if researchers have been overly critical of their practice throughout the research.

The culture of a care home can have a great influence on the type and extent of research conducted within that home (Dewing, 2009). In this context, culture refers to the ambience within the home, the personalities and attitudes of staff members, the level of interaction between residents, and between staff members and residents, the ability of visitors to come and go as they please, and the amount of transparency from senior management about the day-to-day running of the home (Dewing, 2009). Strong leadership that is complemented by transparent and effective communication throughout the home has led to successful research delivery, compared with homes lacking these traits (Wilson et al., 2009). This is further enhanced by the researcher allowing adequate time to become familiar with the environment and culture of the home, which often leads to increased study support from stakeholders (Evans, 2008). There are examples of very good practice within this area. For example, when Johnson et al. (2012) revisited the care homes that Townsend (1962) researched, they used innovative methodological techniques to understand the lived experience of residents. This included using older adult volunteer researchers to trace the homes and utilise their knowledge and experience of the local area and culture. They also used a combination of surveys, interviews, and diaries with care home staff and residents to understand the realities of life in the homes holistically.

6.3.1 Co-operative Inquiry

Most residents of care facilities are physically dependent, and many are close to the end of their lives (Gordon et al., 2014b). Hence their stay is generally short (Forder and Fernandez, 2011). Compared to individuals living in the community, these older people are usually frailer,

have more health problems, and have more severe disabilities (Matthews et al., 2016). Care facilities are unique research settings, and individuals need specific consideration regarding their prospective research involvement. It is crucial to arrange involvement activities carefully and thoughtfully if we are to more fully and successfully include this underrepresented population in studies, give them a voice, and encourage active participation.

Co-operative and participatory initiatives in healthcare research are encouraged (Dewar, 2005), but the tools to involve marginalised members of society are not readily available (Baur et al., 2010). As described by the World Health Organisation (2000), institutions have a social responsibility to use education and research to address the “priority health concerns of the community.” This can lead to an increased sense of ownership by community members and focused healthcare needs that are wholly relevant to the community of interest (Ramsden et al., 2010). However, for several reasons, marginalised communities, such as older adults living in residential care, may not be willing to engage in research. For example, their residential life's physical and social construction is very much centred around a schedule of mealtimes, communal activities, and sleep (Baur et al., 2010). It may be challenging for individuals to participate in activities that do not fall within their usual schedule. The reasons for this could be the fear of the unknown, medical conditions preventing participation, or simply no desire to get involved (Backhouse et al, 2016). Thus, participatory initiatives can prove challenging.

6.4 Planning and engagement phase

The project aims and objectives outlined in 6.4.1 were developed using the theoretical framework for co-operative inquiry.

6.4.1 Aims and objectives

I aimed to use patient, and public involvement activities based on the NIHR INVOLVE framework to help inform research priorities and methods for the ethnographic work. This was mainly achieved through developing relationships with multiple stakeholders.

Specific aims were as follows:

- To determine whether approached care homes have the willingness and infrastructure to be part of the ethnographic research
- To ascertain variation between care home residents for an adequate sample of participants
- To build and develop trusting relationships with care home managers to enable the ethnographic research to be carried out successfully

- To determine the importance and relevance of the proposed projects to care home staff, residents, and their relatives, and to gain insight into social isolation that could be explored throughout the research

Specific objectives were as follows:

- To establish willingness to participate from a minimum of four care homes (for a substantial sample of 30 participants) within Birmingham that specialise in dementia care, with contrasting sociodemographic features
- To develop an understanding of staff and relatives' attitudes towards proposed research
- To conduct discussions and observations with staff, residents, and relatives to determine whether amendments to proposed projects are required
- To identify and interview appropriate experts in the field of residential care research for guidance on proposed projects and study design

The planning and engagement work was achieved by acclimatising to the care home settings, building relationships with the managers and care staff, and becoming a known quantity in the homes in preparation for the start of the projects.

6.4.2 Relational Skills Model

When people who live with a particular health condition are involved in research for that condition, there is meaningful focus and direction to projects. I was informed by the relational skills model developed by Midwinter and Dickson (2015) to facilitate good communication with the care home residents and employees. The model seeks to explain the five phases of developing a helper relationship. This follows a continuum of setting up the relationship to ending and maintaining the relationship. The philosophical underpinnings of this model are derived from the Rogerian approach of person-centred therapy (Rogers, 1986). In this approach, the core conditions needed for free exchange and expression of information, especially aimed at change, require congruence, empathy, and unconditional positive regard. Expressing these qualities can lead to a person feeling empowered to contribute meaningfully to a situation based on their life experiences (Rogers, 1986). Empowerment is at the core of this model and therefore fitting for use with marginalised communities (Egan, 2002). However, some criticisms of Rogers' (1986) approach include the lack of focus on specific techniques and interventions to address psychological problems. It can be argued that the client-centred approach may not be effective for clients with severe mental health conditions or those who require more structured and directive therapy. Therefore, when working with people with

fluctuating capacity, there is a need to take a more directive approach as with the participants involved in the planning and engagement phase. Furthermore, the emphasis on the therapeutic relationship may overlook the role of social, cultural, and environmental factors that contribute to psychological distress. By focusing solely on the individual's subjective experience, the approach may ignore the larger systemic issues that contribute to specific health problems.

There is insufficient representation and encouragement for diverse groups to participate in PPI activities (Tierney et al., 2021). When PPI activities have been reported in the literature, they are often described as “round-table” discussions with able-bodied and healthy older adults (Morgan et al., 2016). This is wholly inappropriate for the participant demographics of my study. Therefore, a round table approach was not used. Instead, a person-centred approach was used, guided by the relational skills model (Midwinter and Dickson, 2015). The person-centred nature of the model provides support in relationship development with the important stakeholders of a care home, i.e., care home residents and care staff. By giving these marginalised communities a voice, the proposed research can be designed and disseminated in a relevant and respectful manner (British Geriatrics Society, 2021).

6.4.3 Identification of opinion leaders

An information search was conducted to determine experts in the field of residential care research who had experience working with people living with hearing impairment or with cognitive decline or dementia. Action on Hearing Loss (AoHL) was identified as an “expert” group that had recently completed a hearing-aid awareness and training programme within care homes in the Northwest of England (AoHL, 2018a). As Action on Hearing Loss (now Royal National Institute for Deaf People) is a prominent charity for hearing-related conditions, discussing the training programme and proposed studies with relevant staff was beneficial. After initial communications, I met with two Development Project Managers responsible for the care home training programme. I asked them questions on the following topics:

1. The identification and sampling techniques for the chosen care homes
2. The initial approach used to contact care homes
3. The appropriate number of care homes I would need for the proposed studies

A second expert stakeholder identified from the literature searches was a University of Birmingham lecturer specialising in Deafblindness. Dr Liz Hodges was involved in research evaluating residential care settings for older adults with hearing and vision impairment. Her opinion was sought concerning the feasibility of the proposed studies.

6.4.4 Sampling of care homes

An online search of care homes (nursing and residential) within Birmingham was conducted to identify those specialising in dementia care or having residents living with dementia. The original search for homes was inspired by the care home organisations used in the AoHL training programme. Next, care homes located within Birmingham which specialised in dementia care were contacted either by email or telephone to bring the research to the attention of the care home manager. A total of 20 care homes were reached, of which four responded positively. The four homes strongly contrasted in socioeconomic and demographic status within Birmingham, determined by Acorn profiling of residential postcode (Acorn, 2019).

Initial meetings were arranged with each care home manager by telephone, following an email summarising the purpose of the research and a request to meet in person to discuss the project in more detail.

6.4.5 Determining suitability of care homes

At the initial meeting with each care home manager, I sought to determine an overview of the type of residents, attitudes, staff, and general culture of the home. Following the aims and objectives of the PPI work, I asked questions that aimed to identify the amount of variation within and between care homes to determine a suitable range of potential participants. If they seemed engaged, I could get a sense of the care home manager's willingness to participate and focus on relationship-building.

6.4.6 Observations and conversations with residents and staff

The relational skills model (see figure 9) (Midwinter and Dickson, 2015) was used as a guide to building relationships within the home. Initial communications with care home managers were formal via email or telephone and were used to "set-up" the relationship. This process involved contacting and meeting the person using attending, active listening, and contracting skills. Care home managers were viewed as the "gatekeepers" to conducting the proposed research. I used the first meeting with each care home manager to summarise my previous employment and qualifications, current job role, and rationale for the ethnographic research. Thus, I began developing the relationship (second stage of the relational skills model) using presence and effective communication. The background summary proved helpful when care home managers introduced me to other staff members within the home and provided an overview of my role. Following this first meeting, subsequent meetings became familiar and relaxed.

I introduced and described the research to care home managers using the following text:

“It is not unusual for individuals living in residential care to have multiple health conditions. They are usually required to adapt to living in a new environment as well as manage their health within a short space of time. Furthermore, there is much irony placed in the context of residential care, which encompasses all the features of a community, yet can be most isolating and lonely for some individuals. There is often a high proportion of individuals living in residential care who are living with dementia. I am interested in the relationship between hearing loss and dementia because often somebody with even mild hearing loss can reduce the number of social interactions they have simply because it is too much effort to listen and concentrate on speech especially if the listening environment isn't optimal. Overtime this reduction in social contact may lead to certain areas of the brain no longer being stimulated and this could trigger a decline in our cognitive skills which may or may not lead to dementia. There is lots of research that shows how beneficial social interaction and engagement is to a person's quality of life regardless of whether they are living with any health conditions or not. I would like to work with residents who are living with dementia to find out what sorts of activities they would like to be involved in that would help them to interact more. If they also have some hearing loss, I would like to suggest ways that their listening environment could be improved within the home and bring the local NHS Audiology service provider on board as well. As well as working with the residents themselves I would also like their friends and families to be involved, and staff members too. At this stage I am gathering as much information as possible from people who will potentially be involved so that the direction of my research can be influenced. I am hoping to apply for ethics approval in the spring so that the research can formally begin early next year. Once the suggestions for increasing social engagement have been agreed, I will allow time for the interventions to be put into place before returning to monitor and evaluate them. This will be an inclusive research process where all those involved have equal input and value to the project. I welcome any questions or suggestions. Just to note that I am fully aware that there is currently a great amount of social interaction activities taking place within this home. My aim is not to replace or reduce these, I am interested in seeing whether the listening environment and other therapies can help to improve social isolation for those living with dementia.”

The relationships I built with the care home managers were based on respect and admiration for their roles and the sector. It was essential to emphasise that I did not intend to judge or criticise but instead observe and listen. This pledge visibly made them feel at ease as there is often apprehension about external visitors watching the day-to-day running of residential care settings, which usually equated to inspections such as from the Care Quality Commission. The relationship became more substantial and more developed when they realised that I was transparent about my agenda and willing to adapt my research methods to suit the needs and

requirements of the home. The honesty and transparency led them to willingly advocate my research to staff members and encourage them to engage with me. As a result, I could understand the numbers of each type of staff member within the homes and calculate proposed recruitment figures.

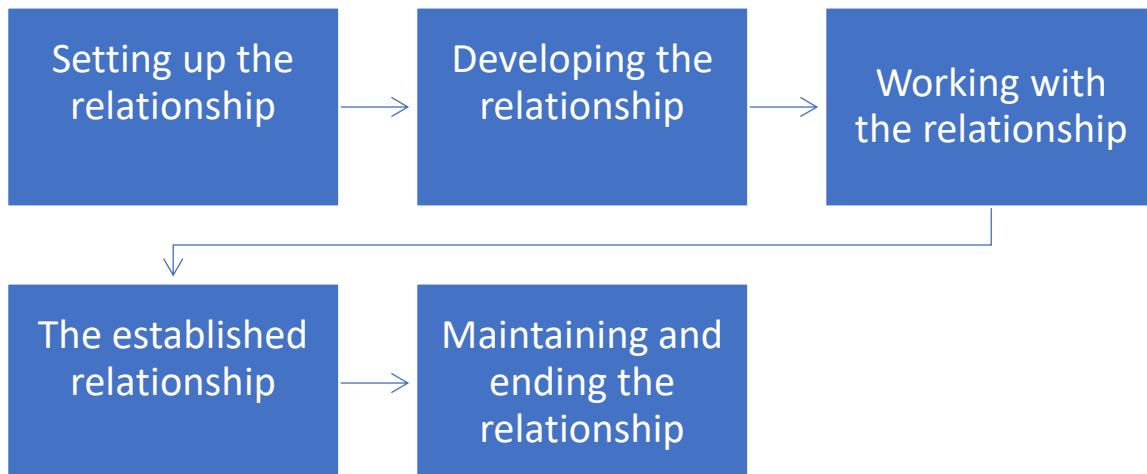


Figure 9: Relational skills model (Midwinter and Dickson, 2015)

The care staff were the next group of people I spoke with. It was more difficult to provide them full details of my purpose for being at the homes because they were constantly moving from one part of the home to another, carrying out various tasks. I decided to keep my conversations with them as brief, positive and light-hearted as possible in order to set-up the relationship well. I initially focussed the conversations on topics about them such as how they came to work in the care sector, how long they had been a member of staff, what they enjoyed about the role etc. This led to an invitation to join them for tea during their breaks, which gave me an opportunity to share my research aims and objectives and ask them questions (see table 16).

Table 16: Questions directed to care home staff in relation to aims of project

Aim of Project	Questions Asked
To establish willingness to participate	<ul style="list-style-type: none"> • How would you feel about being observed? • What is the level of involvement of relatives in the care of residents?
To establish knowledge on the relevance and importance of the proposed projects	<ul style="list-style-type: none"> • What have you noticed about the interactions of residents with hearing loss and dementia? • What are your thoughts on improving social isolation within the home? • What were the main barriers to improving social isolation? • Have you noticed any hearing difficulties in residents living with dementia?
To establish an understanding of staff attitudes towards the proposed projects	<ul style="list-style-type: none"> • What type of training have you received to effectively communicate with residents who have hearing impairment and/or cognitive impairment/dementia? • What would you like introduced within the home to help you to communicate more effectively with residents?

I spoke with staff members about the proposed research to discern their views on its relevance and importance and to understand what was currently in place to help residents engage. I also spoke with residents informally about their experiences of living in care homes and their daily activities, aiming to understand their current level of social interaction and general satisfaction. This stage was very much ‘working with the relationship’ and practising healthy boundaries and behaviours in terms of how much of their time I took and the level of detailed questioning. At one care home, I attended a “friends and family” monthly meeting in which I formally discussed the proposed research to seek the views of residents’ family and friends. This home was particularly proactive in involving relatives in their practice, as they invited them to monthly staff meetings to discuss changes in care to residents and new initiatives that may be implemented. Attendance at this meeting catalysed the established relationship stage of the model because I began to feel a connection to the team as an external researcher. As the developing relationship with staff members became stronger, I tried to incorporate as much flexibility as possible into the research design by agreeing to interview staff members only at times that were convenient for them i.e., the beginning and end of their shifts. Even without this use of a relational skills model, it is standard practice in qualitative research to be as accommodating to participants as possible.

Following the initial meetings, I arranged monthly visits during which I spent time observing the routine functioning of the care home to see whether any prominent examples of social isolation could be identified and to better understand the role of carers. I attempted to determine the amount of unaddressed hearing loss amongst the residents and the proportion of residents living with some degree of dementia. Most importantly, I sought to understand whether any measures were in place to address the communication needs of residents. This

helped to justify the need for an environmental audit in each home, to understand the contextual factors related to hearing and communication.

I approached residents only in the communal areas of the homes. My initial observations led to assumptions about which residents would more likely speak with a stranger. I presented as friendly and professional, extending my hand to shake their hand or placing it on their shoulder to greet them. I was anxious about this initially. I had only ever visited care homes in a clinical capacity, where there was a specific task and finite duration. This experience was much more fluid, which made me nervous. After introducing myself and asking if I could sit next to them for a conversation, I allowed the residents to lead the discussion. This was very helpful in setting up the relationship and allowing me to assess their hearing and communication abilities informally. If the resident wanted to engage in conversation with me, I often asked if we could sit somewhere quieter to discuss more. This would be either the dining room (avoiding mealtimes of course) or the library. There was often a natural opening for me to discuss the purpose of my visit because the residents were very polite and well-mannered so would ask who I came to see and why I was there. Having done a Mental Capacity Act (UK Public General Acts, 2005) course, I was able to assess if a resident understood my reasons for talking with them and therefore had informed choice about whether to continue. The Mental Capacity Act training course adequately prepared me for determining the level of capacity residents had and whether it fluctuated. I made a conscious effort to repeat my reasons for being in the home and speaking with them, and only discussed the research if I felt they had the capacity to understand. If they did not, then I engaged in general conversation using positive communication strategies.

Over the next 3 months, I made weekly visits to the homes and the residents began to recognise me. The relationship was developing, and I started to become a familiar face within the settings. This meant that I could start to ask specific questions about the research to individual residents who chose to contribute to the planning and engagement. For those residents who were not interested in discussing the research but simply wanted a conversation, I happily obliged because these experiences enlightened me to the needs and wants of the residents.

6.5 Planning and engagement phase findings

6.5.1 The makeup of care comes

Approximately 160 people were living with dementia across the four care homes, and 100 of these persons could consent at any one time according to care staff assumptions (see table 17). A report evaluating a network of research-ready care homes has found that recruitment

rates in residential care account for approximately one-third of all potential residents eligible for participation (Davies et al., 2014). Therefore, 30 participants out of a potential 100 was deemed a reasonable number for recruitment to ensure sufficient variation, with approximately 7–8 participants from each home, if every home chose to participate in the ethnographic research. The aim was to provide a sample large enough to cover age, gender, and ethnic variations, using purposive sampling methods, within the realistic recruitment rate of 30 participants across the four homes (Davies et al., 2014). A priori maximum variation could not be achieved because I excluded participants without capacity to consent. Nonetheless, the contrasting postcodes of the homes would provide socioeconomic variations between participants, and within each home I would seek to recruit a diverse sample of participants via purposive sampling. The AoHL team discussed the practicalities of recruitment and stated that it would be unrealistic to expect more than 10 residents to consent for research participation in any one home. They also suggested approaching 15–25 care homes within Birmingham with an aim to include 3–5 in the ethnographic research.

Across the four homes, there were approximately 45 residents with diagnosed hearing impairment and who wore hearing aids. The care home managers felt that there were far more than this who had some level of hearing impairment but had not yet been referred to appropriate services. Up to 75% of individuals living in residential care may have undiagnosed hearing loss (Escalier, 2012), equating to a potential of 120 people across the four homes without a hearing diagnosis or management plan.

There were approximately 25 staff members within each home, with a general hierarchy consisting of care home manager, deputy manager, team leaders, care staff, and housekeeping, laundry assistants, and handymen.

In addition to residents, I also invited staff members to participate in the studies. There was a recruitment aim of three staff members per home, preferably of differing roles, to provide variation and a range of rich viewpoints to the data. This provided the capacity for a suitable number of individuals to participate and contribute substantially to the ethnographic research within each home. Furthermore, as the care staff make up most staff within the homes and have the most contact with residents, they could provide important and relevant information on which residents to approach for recruitment purposes, easing the recruitment process. Nevertheless, the desired participants for the proposed projects are described as “hard to reach” groups (Chamberlain and Hodgetts, 2018), so creative processes for research interest and participation are required to reduce health inequalities (Nutbeam, 2004). For example, empathising with the attitudes of staff and residents, allowing flexibility in the timing and

duration of research activities, and working in partnership with stakeholders (Flanagan and Hancock, 2010).

Table 17: Summary of findings and implication for research design

Planning and Engagement Findings	Implications for Research Design
Four care homes of contrasting sociodemographic status have the infrastructure to allow ethnography and interviews to be conducted	These four care homes will be used in the proposed research (only two homes were used because of Covid-19 lockdown March 2020)
100 residents across four homes with capacity to consent at any one time, approximately 25 staff members in each home, and varying numbers of engaged relatives	30 residents, 10 care staff (senior and junior), 4 team leaders, and 6 relatives will be sampled across all four care homes
Expert suggested conducting an environmental audit to help identify auditory recommendations within care homes	Environmental audit will be incorporated into ethnography
Care staff have very limited “free” time whilst on duty so participating in research might be difficult	Care staff will be interviewed at the beginning and end of shifts, and provided with gratitude for their participation
Care staff may feel obliged to participate by managers or not understand the voluntary nature of research participation	Re-consenting will be factored into research activities for both staff and residents

6.5.2 Intent to facilitate communication

The informal observations and interviews with care home managers and staff highlighted an overall willingness and strong intent to facilitate communication that is often unguided and confused. Care home staff reported that there was no formal training offered in any of the care homes in how to communicate with people who have hearing impairment, or basic use and repair of hearing aids. Therefore, willing staff made an effort to adapt their communication or learn about hearing aids on their own accord. Rocks and Ferguson (2013) suggested that up to 72% of care staff assisted residents with hearing aid use and maintenance in their sample of 25 carers across three homes. It may be that these carers had also received no formal training but were particularly motivated to learn how to use and maintain the hearing aids to benefit residents, and therefore learned ‘on the job’.

With regards to communication training for people with cognitive impairment or dementia, great variation was reported from care home staff. For example, at one care home, care home staff spend an entire working day on memory care training, and staff are required to refresh this training annually. At another home, the shadowing of senior staff as part of the induction process was the extent of their training. Figures suggest that only 51% of care homes provide training on dementia to care staff (Eggenberger et al., 2013), which fits with the four care homes I visited.

I planned to gather information about the different levels of training provided to carers via observations and interviews. Those who have undergone more training may communicate with residents more effectively and have more insight into the needs of people living with dementia or cognitive impairment. This identified variation in training allowed me to compare communication behaviours between homes and to establish whether training improves communication between staff and residents. This information has led to the following research question that will be used in participant interviews and observations: What evidence is there in daily communication with residents that training is of benefit? The ethnographic work and interviews will allow deep insight into day-to-day communication behaviours, and the impact of this on a resident's mood.

Being aware of the current practice around activities for residents informed how and when to involve care staff in the research. For example, interviews were scheduled at the beginning of a shift when there was generally more time available, but as a researcher, I was flexible to the needs of the participant. Furthermore, the initiation of an activity is almost always provided by a carer, reinforcing the passive relationship between caregiver and receiver that is so often seen. From the enquiries made, carers reported that some residents are more willing to participate in an activity if their "friends" or acquaintances are also taking part, but even when this is the case there is often no conversation between the residents during the activity, perhaps because it is too cognitively demanding, or the environment is inappropriate for meaningful conversation. Therefore, activities formed a focal point in the data collection during the ethnographic observations, to better understand the interactions that take place.

One-to-one interactions between staff members and residents were useful data gathering points for observations. However, these interactions were guided by the acoustic environment of the home. For example, care homes with low ceilings, carpeted floors, and soft furnishings provide an environment in which it is easier for individuals with hearing loss to communicate, as compared to the setting of a home with a high ceiling, hard floors, or wooden furniture. This was especially true during mealtimes and medication rounds. During my visits, I was overwhelmed by the conflicting sound sources in the communal areas of the home. This is likely to discourage individuals with hearing loss from wanting to engage in conversation and generally interact. These findings facilitated discussions with care home staff on the importance of providing an adequate hearing environment for residents.

6.5.3 Accessing hearing care

Most of the care staff members in all of the homes explained that they felt that the greatest issue with accessing care was the difficulty in arranging travel and assistance for residents to

attend healthcare appointments. This is a huge issue, especially in the context of these homes situated in the second largest city in England, all with hospitals within a 15-minute distance.

All of the care staff members in all of the homes also mentioned the difficulties with residents being referred to outpatient services, as the appointment times were often inflexible and unsuitable. All four care homes reported that their links with NHS Audiology services were virtually non-existent. In some instances, residents had appointments to undergo a hearing assessment or get their hearing aids checked, but this usually resulted in a missed appointment because of the time and effort required to prepare for travel and assistance to the appointment, or the hospital cancelling the appointment at short notice. Therefore, a gap in service provision from both primary and secondary care has been highlighted.

The care home managers in all homes reported that their preference was for domiciliary visits to be arranged so that the healthcare professionals could visit the residents rather than the other way around. This wasn't easy to arrange, and when it was, the wait time would be too long to be worthwhile. Therefore, they felt that the residents suffered as a result and continued to have ongoing communication difficulties. These realities were frustrating for care staff because they witnessed domiciliary services working so well in other healthcare professions, such as optometry and podiatry. These findings alone highlighted the need for ethnographic work.

The time and effort put into developing relationships with care home managers and care staff was what led to honest and transparent answers from them. If those relationships had not been fostered, I would have received a great amount of socially desirable responses to the questions asked in table 16. As an example, in one home, all care staff revealed details of recent changes to their job description because activity coordinators were being made redundant. Therefore, the onus was on the care staff to design and lead group activities for residents, among their usual physical caring duties.

6.5.4 Participation in research

When senior carers in both homes were asked about being observed, they reported that they were well accustomed to working under observation, as new and junior members of staff had often watched them as part of their training. Others verbally stated that they would be happily observed but showed signs of reluctance, such as with facial cues of hesitation or with closed body language. Therefore, it was my responsibility as a researcher to ensure that the care staff participating in the projects fully understood the voluntary aspect of the research process. This process was emphasised to managers, who could imply that participation in research interviews is compulsory, when in fact participants were wholly free to decline to participate,

according to Good Clinical Practice (Otte et al., 2005) and Declaration of Helsinki (2013) ethical principles. I periodically took consent for their continued participation. This will mean that extra time will be allocated for data collection to ensure the consenting and re-consenting process is not rushed, and participants are aware of their requirements and rights.

Some of the staff members across all homes informed me that the reason others were not keen on my presence was because they felt any kind of research being conducted in the home would have a direct impact on their workload. Therefore, their perceived negativity about the research was instilled through fear of increased workload upon an existing highly pressured role. I sought to overcome this by speaking with them on a personal level, and casually mentioning the impact that the research would have on their workload should they wish to take part or not. This seemingly helped ease concerns, but it was clear some staff members were averse to any kind of change within the home (either additional people or additional tasks). Nevertheless, relationships had been established at this point, which had allowed the researcher to gain meaningful insight into the views of care staff.

Relatives are an important communicative partner and must be included in the interviews. Based on the reported involvement of relatives, I can expect to recruit 1–2 relatives from each home. As such, I must sample 30 residents, 10 care staff (senior and junior), 4 team leaders, and 6 relatives across all four care homes.

Dr Liz Hodges (expert stakeholder) suggested that the ethnography could encompass an environmental audit, which would encourage focus on the auditory environment in which residents live. The findings from the audit could then inform the interview questions. Overall, Liz felt that the proposed projects were highly feasible and specifically noted the sociodemographic contrasts of the included care homes as a strength of the study.

6.5.5 Implications for ethnographic research

This preliminary work led to the following refined research questions:

1. What is the impact of hearing loss and/or dementia for residents living in residential care?
2. What impact does training have on the communication behaviours between staff and residents? And does this impact vary between staff of different grades and roles?
3. What are the opportunities for residents to socially engage within the homes?

It was feasible to address these questions because care homes with the appropriate infrastructure had been chosen according to a suitable number of residents to sample from, a substantial number of willing staff members, and sufficient variation in the sample. The

guidance received from AoHL informed my searches of appropriate care homes, resulting in four successful meetings and their inclusion in the planning and engagement phase.

The contrasting socioeconomic locations helped determine the extent of differences that currently exist in care homes. This is useful for transferring the findings to other care homes that may have similar demographics and socioeconomic status to the four proposed sites.

The views of potential participants were largely considered and helped to shape the methods and design of the ethnographic work. Importantly, potential participants spoke positively of the work and felt the findings would be highly beneficial to them. Similarly, most staff members said they would be happy to be observed as long as the observations did not disrupt their usual work routine or delay their duties. Being discreet and self-contained during the observations reduced the potential of reactivity from those in the research setting (Sangasubana, 2011) and put care staff at ease. Furthermore, interviews were arranged at the beginning or end of a shift, or during a period of low activity in the home, for minimal disruption to care staff duties, especially as time was mentioned as a barrier to participation. When asked, the staff members who appeared reluctant to participate were assured that their participation in the research was wholly voluntary and that they could leave the study at any time without being questioned. This was written clearly on the participant information sheet and reiterated verbally to them multiple times.

The established working relationships with care home managers and some care staff are a further indicator of feasibility. Through regular visits, emails, and telephone conversations, I was able to keep staff updated on my research plans and timeline and became a part of their community in the process. Having been invited to take part in memory care training at one home, and a Christmas party in another home, I felt truly welcome in the homes and very comfortable to spend long periods of time with the staff and residents. I endeavoured to become a part of the team at each care home, and therefore ensured that the research being conducted was not forgotten about by staff members, as this was an essential element of the ethnographic work. The working relationships allowed the research projects to be undertaken with minimal difficulties, as a strong sense of trust had been built between myself and the care home managers. Throughout the process of obtaining ethics approval and preparing for the proposed studies, I ensured I maintained these relationships through honesty and transparency in my progress.

The consistency in findings from the care home staff and guidance from local experts provided me with assurance that studies were both feasible and of value to care home residents experiencing social isolation. The range of activities conducted were vital to the future success of the proposed projects. Not only did they inform the design of the study (table 17), but they

have facilitated the working relationships I developed and nurtured with care home staff and residents, and my familiarity within each home.

6.6. Obtaining Ethical Approval

A research ethics application was submitted through the Integrated Research Application System in July 2019. The Integrated Research Application System (IRAS) is an online platform used to apply for research ethics approval in England. The process of obtaining research ethics approval through IRAS for qualitative research involved the following steps: registering with IRAS, creating an application to provide detailed information about the research project, research question, methodology, data collection methods, and ethical considerations. Next, was completion of the ethics form which was a crucial aspect of the application process. I was asked to provide information about the potential risks and benefits of the research, the steps I will take to protect participants' confidentiality and privacy, and the plan for obtaining informed consent. I was also asked to describe any potential conflicts of interest or other ethical issues that may arise during the research. I submitted the completed application through the IRAS system and uploaded relevant documents such as the research protocol, consent forms, participant information sheets, research advertisements, and the interview schedules.

After the initial application was submitted, I was invited to a research ethics committee meeting to answer further questions about the proposed research. I attended the meeting with my primary supervisor who acted as the chief investigator of the study. There were approximately 10 panel members who were lay members/Patient and Public involvement representatives, clinicians, and qualitative research methodology experts. I was asked about my interest in the topic area and clinical experience of working with older adults who had hearing impairment.

I have included some examples of questions and answers below:

How did you select the care homes and participants for your study?

Answer: I selected care homes based on their reputation for providing high-quality dementia care and their willingness to participate in the study. Within each care home, I will work with staff members to identify potential participants who are willing and able to participate in the research, based on my knowledge of the MCA. Participants will be selected based on their level of cognitive impairment and ability to provide informed consent, as well as their willingness to participate.

How did you obtain informed consent from participants, and how did you ensure that they understood the purpose and nature of the study?

Answer: I will obtain informed consent from participants by explaining the purpose and nature of the study in plain language and providing them with an information sheet and consent form to review. I will use visual aids and other communication techniques to help ensure that participants with cognitive impairments understood the study and their role in it. I obtained written consent from participants who were able to provide it, and verbal assent from participants who were not able to provide written consent.

How will you ensure the privacy and confidentiality of participants, and how will you handle sensitive or personal information?

Answer: I will ensure the privacy and confidentiality of participants by using pseudonyms and other measures to protect their identities. I will store all data securely and ensure that only authorised individuals have access to it. I will handle sensitive or personal information with great care and sensitivity, and only disclose it to other members of the research team such as my supervisor on a need-to-know basis.

How will you analyse the data that you collect?

Answer: I will analyse the data using Grounded Theory analysis, which involves different levels of data coding and categorising to produce a model that explains the context and mechanisms of how and why social isolation is created and maintained.

6.6.1 Ethical considerations

The following ethical considerations were considered and acknowledged as part of the ethical approval process prior to the beginning of the ethnography study:

1. No data will be gathered on persons who have not consented to take part in the study. Therefore, field notes will only refer to participants who have consented to be observed. Any persons observed who have not consented to participate in the study, will not be included in the field notes or findings.
2. Recruiting from a vulnerable population i.e., participants who are living with dementia and who may have fluctuating capacity. I have undertaken training to take informed consent for persons with limited capacity under the Mental Capacity Act 2005, in addition to Good Clinical Practice Training. I will only recruit participants who have capacity to consent at the time of initial consent and during re-consenting.
3. To conduct research within care homes where vulnerable adults living with dementia and hearing loss reside, the Chief Investigator (Nisha Dhanda) will undergo a full DBS check. The completed DBS report will be presented to each care home manager for their assurance.
4. Participants may be uncomfortable with being observed, and later being interviewed. This will be overcome by ensuring ongoing consent is provided and withdrawing participants who

no longer want to be involved in the research. Participants will be reminded of the voluntary nature of research and their freedom to withdraw without reason.

5. Local safeguarding procedures of the care home will be followed in relation to any observations or recordings that may lead the Chief Investigator to have concerns about the welfare of a participant or resident within the home.

6. Care home staff may feel burdened by the amount of time required for participation in the interviews. This will be overcome by providing an accurate estimate of the time required by them to participate in the participant information sheet that will be provided during the recruitment stage. Interviews will take place at the beginning or end of their shifts to ensure their usual work duties are not disturbed, as identified from the Patient and Public Involvement preparatory work.

7. Choice of observation and interview - in order to capture rich data on the lived experience of people living with hearing loss and dementia, and to understand the role of social isolation within a residential care setting context, observing and interviewing participants is much more appropriate than one-off interviews or survey questionnaires that do not capture depth of information.

8. Participant confidentiality will be retained by de-identifying participants using pseudonyms during observations, analysis and dissemination. Interview transcripts and field notes will be kept secure at the university in a locked cabinet that only the Chief Investigator and Supervisor will have access to.

Resident and relative participants will be recruited with the assistance of care staff. At the beginning of the study, all care staff will be briefed on the inclusion and exclusion criteria, not only for their potential participation but to advertise the study to resident and relative participants. A Participant Information Sheet (PIS) and research poster will be placed in the communal areas of the home, entrance notice boards, and in staff rooms/offices (see appendices 4, 8-10). This gives residents and relatives the opportunity to approach the researcher directly if they are interested in participating. Contact details of the researcher will be clearly displayed on the PIS and research poster. The researcher will make regular weekly visits to each home to advertise the study and allow potential participants to ask questions. Details of the study will also be included in any newsletters published by the home and put as an agenda item for staff meetings.

Written informed consent will be undertaken with each participant. This will be supported by verbal information. Both forms of consent will be delivered in plain English as well as summarised and explained appropriate to the level of language and understanding of the participants. Non-English-speaking persons will not be included in the study due to the limited

resources available for hiring interpreters or translation services. During this process, potential participants will be given a detailed description of the study and what their participation will involve. This will be an opportunity for them to ask questions and clarify concerns or issues. The voluntary nature of participation will be emphasised, as well as the ability to withdraw from the study at any time, for any reason.

Potential participants will not be required to make an immediate decision for participation, and indeed will be encouraged to discuss the study with others before deciding. Participants will initially accompany the researcher to a private room/office within the home so that the researcher can discuss the details of the study. They will have the choice to discuss participation with their friends and family, and reapproach the researcher, or give their consent to participate. The researcher will verbally read out the participant information sheet and give the participant time to read it for themselves. They will also answer any questions the person may have. The researcher will also read through the consent form and ask the participant to initial and date the consent form, and sign and date the participant information sheet. Separate participant information sheets and consent forms will be provided depending on whether the participant is a resident, relative or staff member. The participant will be told that they will be observed and interviewed for up to two weeks, during the hours of 7am-7pm.

Each time the researcher begins an observation, they will check that the participant is still happy to continue their participation. Care staff will assist with the identification of suitable resident participants based on mental capacity. I had undertaken training on the Mental Capacity Act (UK Public General Acts, 2005) prior to study commencement (see section 6.7). Residents who could consent at any one time as determined by me, could participate in the study observations and interviews. It would be deemed unethical to include participants lacking the capacity to consent and required a proxy decision-maker, where those with capacity are available (Shepherd et al., 2019).

Residents and care staff will not be asked to do anything different to their normal daily activities, apart from taking part in short interviews privately. Relative participants will be asked to undertake a one-off interview that may last up to an hour and may also be observed during their visit with their relative at the home, within a communal space.

Potential risks and burden for research participants and how they will be minimised are outlined below:

Intrusion - participants may feel uncomfortable to be observed for long periods of time. This will be minimised by ensuring that I remain discreet in my observations and do not disturb daily activities or routines.

Inconvenience - participants may feel inconvenienced by the time spent on consenting and interviews. This will be minimised by explaining the importance of these processes to the study and arranging research activities at times convenient to the participants.

Distress - the sensitive and emotive topic of social isolation may cause distress to participants during interviews. This will be minimised by actively listening and allowing participants the space and opportunity to reveal their feelings on the topic, which may be relieving. As a qualified Audiologist, I can demonstrate person-centred care and listening skills. In addition, I have undertaken a MSc level module in the Psychology of Dementia Care to understand the communication skills of persons living with dementia to a greater depth.

Finally, the potential risk for myself as the researcher is that I may observe or hear distressing information during the ethnography and interviews. This will be overcome by regular debriefing sessions with my supervisor.

6.7 Mental Capacity Act 2005 Training

There was also a detailed discussion about how I would identify eligible residents who had fluctuating cognitive capacity to make an informed decision about participation. The Mental Capacity Act 2005 provides a legal framework for making decisions on behalf of people who lack the capacity to make decisions for themselves. Researchers who are working with individuals who may lack capacity to provide informed consent are required to receive training on the Mental Capacity Act 2005 to ensure that they are aware of their legal and ethical obligations in relation to informed consent. The key components of the Mental Capacity Act 2005 course for researchers that I attended were:

Overview of the Mental Capacity Act 2005: The course provided an overview of the key principles of the Act, including the presumption of capacity, the importance of promoting autonomy and decision-making, and the role of the Independent Mental Capacity Advocate (IMCA).

Assessing capacity: The course provided guidance on how to assess capacity in the context of research, including the importance of conducting capacity assessments on a case-by-

case basis and the role of the research team in ensuring that participants have the capacity to provide informed consent.

Best interests: The course provided guidance on how to determine what is in the best interests of individuals who lack capacity, including the importance of considering their wishes and feelings, their beliefs and values, and their social, cultural, and religious background.

Obtaining informed consent: The course provided guidance on how to obtain informed consent from individuals who lack capacity, including the importance of using appropriate communication strategies and ensuring that participants understand the nature and purpose of the research.

Legal and ethical issues: The course provided guidance on the legal and ethical issues related to informed consent in research, including the importance of ensuring that participants are not exploited or subjected to undue influence, and the importance of respecting their privacy and confidentiality.

Practical considerations: The course provided guidance on the practical considerations related to obtaining informed consent, including the importance of involving family members or other advocates, ensuring that consent is obtained in a timely manner, and ensuring that the consent process is documented appropriately.

Overall, the course provided me with a thorough understanding of the Mental Capacity Act 2005 and the implications for obtaining informed consent in the context of research with individuals who may lack capacity. It also provided practical guidance on how to ensure that informed consent is obtained in a manner that is respectful, ethical, and legally compliant.

The Research Ethics Committee were clear that they did not want me to use Independent Mental Capacity Advocates (IMCAs) in the care home research. The Act allows for the use of IMCAs to support and represent individuals who lack capacity to make decisions about their participation in research. Researchers may need to involve an IMCA to help determine whether an individual has capacity to provide informed consent or to support the individual in making decisions about their participation in the research. However, for the ethnographic research I conducted, I used my own judgement and the support of care staff to identify eligible participants and obtain appropriate data.

The purposive sampling method allowed for a diverse range of participants to be included in the study but those lacking the capacity to consent were excluded from the research.

Therefore, the diversity of those included was even more important to ensure adequate

representation across the homes, and substantial data to be collected and analysed for the development of the model.

The process of attending a Research Ethics Committee to justify my research approach and answer questions about the research was wholly useful to me as an early career researcher. The process reinforced the importance of the work and highlighted ways in which care home research could be improved and more inclusive such as consistent use of IMCAs.

The Mental Capacity Act 2005 training informed my understanding of ethical research practice with people lacking capacity living in care homes in the following ways:

Assessment of capacity: The Act requires that researchers assess the capacity of participants to provide informed consent to participate in the research. This assessment must be done on a case-by-case basis and should consider the individual's ability to understand and retain information, weigh the information in the balance, and communicate a decision.

Best interests: The Act requires that decisions about an individual's participation in research be made in their best interests. This requires researchers to consider a range of factors, including the individual's wishes and feelings, their beliefs and values, and their social, cultural, and religious background.

Communication: The Act requires that researchers communicate in a way that is accessible and understandable to the individual. This may require the use of alternative communication strategies, such as visual aids or simplified language.

Documentation: The Act requires that researchers document the decision-making process and the reasons for their decisions. This documentation should be kept in the individual's care record and should be available for review by the relevant authorities.

Overall, the Mental Capacity Act 2005 required me to take a careful and considered approach to qualitative data collection in care homes, particularly when working with individuals who may lack capacity to make decisions about their participation in research. Researchers must ensure that they comply with the Act and take steps to protect the rights and interests of the individuals they are working with.

Once my application was approved by the West Midlands – Coventry and Warwickshire Research Ethics Committee, I received a formal letter of approval from the ethics committee (appendix 11). The approval allowed me to start data collection in January 2020.

6.8 Summary

The use of the relational skills model for co-operative inquiry was novel and innovative. The model helped me to set-up and maintain key relationships with the care home managers, carers, and residents. This led to appropriate modifications for the ethnographic research. I was satisfied that the careful preparations I made provided the participants with maximum choice and maximum comfort in their experience of interviews.

The involvement of service users can be considered a form of empowerment. The notion that service users will be “empowered” by participating in a particular research project may be an oversimplification of the processes involved (Gray et al., 2000). Some aspects of service user participation in research may feel empowering, while others may feel disempowering (Hudson, 2003). Service users have diverse perspectives, experiences, expectations, and interests is fundamental, but this is often overlooked (Smith et al., 2008). Regarding the purpose, objectives, and context of any proposed research, the participation of service users must be evaluated. Whenever possible, such decisions should be discussed with service users. Service users require assistance and information regarding participation, such as direction regarding what will be expected of them and their potential contribution to the research process. Similarly, Boote et al. (2002) reported that some professionals are concerned that service users will not comprehend the complexities and rigour of research or possess the necessary skills to participate. However, it is lived experience and voice of participants that is often most meaningful, where specific skills are not required. Rather, an ability of a researcher to listen without judgement and give the space and freedom for somebody to talk.

Having the opportunity to speak with residents was the most fulfilling and valuable aspect of the planning and engagement phase. They did not appear to be curious by my presence. Instead, they accepted me as another member of staff and spoke to me about their day, any wants or needs they had in that moment, and recollected life experiences with me. Therefore, setting up and developing the relationship with residents went very well largely due to their early acceptance. This positive experience contributed to the success of the ethnographic research.

CHAPTER 7

ETHNOGRAPHY

7.1 Introduction

This chapter describes the ethnographic research conducted within two care homes in Birmingham UK. The grounded theory model developed from the ethnographic research is outlined. The purpose of the model was to describe and detail the factors contributing to the phenomenon of social isolation in residential care settings for older adults living with hearing loss and dementia.

In residential settings, interactions between care personnel and residents are essential (Burgio et al., 2002). Care staff can effectively communicate each resident's needs and provide individualised care (García de Lucio et al., 2000). Even though communication is important in the delivery of care, both residents and carers frequently express dissatisfaction with this component of care (Nay, 1998). Residents often feel disempowered, dehumanised, and undervalued because they believe the carers are not readily available to address their concerns or fulfil their demands (Hayward et al., 2022). Section 2.7.1 and 2.8 provide details on communication in residential care settings and previous care home research that has informed the work.

A person-centred care approach (Kitwood, 1998) puts the person's needs first and supports them in taking charge of their own treatment. Instead of the person's illness or impairment, the emphasis is on what they are capable of. Support should be targeted to the individual's requirements and specific situations with an emphasis on helping them achieve their goals (Levy-Storms, 2013). For individuals living with hearing loss and dementia, where communication may be severely affected, this approach would put a person's identity and values at the core of their care, instead of their health condition(s). The ethnographic work will seek to explore the extent to which person-centred care is adopted within residential care settings. Section 2.7 provides a critical commentary of person-centred care.

The mechanisms of how and why social isolation occurs in individuals living with self-reported (with or without a formal diagnosis) hearing impairment and cognitive impairment in two residential care settings were investigated in this study (see section 3.7). In keeping with the social identity approach to health, I began with the assumption that social engagement and social connectedness among individuals is the foundation of meaningful relationships. This is the subject of my investigation and the phenomenon I have set out to investigate.

7.1.1 Social Identity Theory

Social identity theory is considered a key component of this work. The premise of this approach is that the nature of the social groups you belong to influences how you see yourself (Tajfel and Turner, 2004). As a result, rather than their 'personal identity,' a person's defined

'sense of self is primarily influenced by their membership in social groups (Turner, 1982). We evolved to live in social groups, which provides us with a sense of direction and purpose (Dunbar, 1998). Social identity is at the heart of group behaviour and can be considered necessary for our survival (when group participation is positive) (Haslam et al., 2018). The identification hypothesis, when applied to health and wellness, states that a person will experience health-related benefits based on their group membership and the amount they identify within that group (Haslam et al., 2018). While many researchers have recognised the value and importance of the social identity approach in terms of interactions within social groups (Tajfel and Turner, 1986; Ellemers, 1993; Holt-Lunstad et al., 2017), the amount of meaningful engagement and identification within those groups has been overlooked.

I used the social identity theory to explain the community culture people feel comfortable with and connected to. The social identity theory was used as part of the analysis to understand social interaction. Social identity theory provides a useful lens for analysing social interaction by highlighting the importance of group membership, the role of social norms and values in guiding behaviour. By applying this theory to real-world situations, I can gain a better understanding of how social identity influences residents' interactions with others, and how positive intergroup relations can be promoted to help reduce the occurrence and maintenance of social isolation. The nuances and complexities of a residential care home community lend itself well to this theory. The circumstances in which a resident has arrived at a care home may determine how connected they feel to that community and how engaged they are with those around them or may not have any influence at all. Nevertheless, the level of connectedness and engagement can be enhanced or reduced depending on several factors. For example, the acoustic environment of a home presents assorted barriers to residents that would impact their sense of identity. Moreover, when considering connectedness, there is a distinction between residents feeling a connection with their physical environment and the familiar routine processes within the home, as opposed to a connection to those around them.

I define social isolation as an individual's level of social connectedness and meaningful engagement within their social context (see section 1.3 for a detailed definition and account of social isolation). Hearing loss can exacerbate actual or perceived social isolation (Heffernan et al., 2016), reducing the number and quality of social connections (Barker et al., 2017). If an individual has a sense of identity within a group, active management of hearing loss may reduce social isolation (Sani et al., 2012). As a result, contact frequency is less important than the quality of social interactions and the importance of one's social identity within the group. When hearing loss is combined with cognitive impairment, the lack of a social identity can lead to social isolation (Mick and Pichora-Fuller, 2016). This is especially so where social isolation

exists as both an outcome and moderator of worsening cognitive function (Cacioppo and Hawkey, 2009; Lara et al., 2019b).

7.2 Methods

7.2.1 Design

Based on the participants' lived experiences, I used a multi-method realist approach to investigate the mechanisms of social isolation. A realist framework seeks to determine how a phenomenon's context, mechanisms, and outcomes can help explain its social construction (Pawson, 2006). The topic of discussion was social isolation. I used an ethnographic approach, beginning with a planning and engagement phase (see chapter 6) to determine the values and access that would influence research conduct and feasibility (see chapter 6). The ethnographic empirical work used an environmental audit, observations, informal discussions, and formal interviews. The environmental audit aided in the description of pertinent contextual features. Mechanisms and outcomes were determined through a set of ethnographic observations that provided insight into the culture of communication and inclusion. The informal discussions and formal interviews provided insights into perspectives of the community including residents, staff and family members, and contributed to the identification of mechanisms and outcomes. This pluralist approach allowed for triangulation of data within a context-specific realist framework (Greenhalgh and Manzano, 2022).

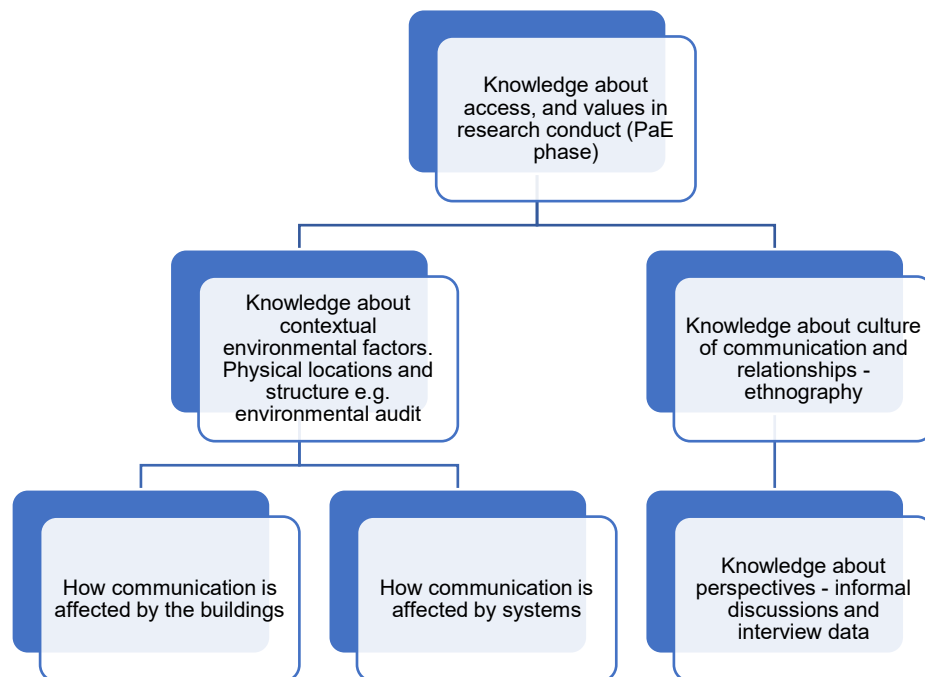


Figure 10: A diagram outlining the design components of the study and their relationship to one another. The richness of data generated from this type of multi-method approach can provide a

meaningful interpretation and explanation of social isolation mechanisms that exist within a care home setting.

7.2.2 Setting

I spoke to or observed approximately half of the final sample during the planning and engagement phase. The collected data were evaluated to determine the feasibility and appropriateness of each care home. Pragmatic issues were resolved through discussion and understanding of the care home routines and schedules. This included staff requesting that observations not be disruptive to their duties and for interviews to take place at the beginning or end of shifts. Additionally, due to safeguarding policies, observations and interviews were held in communal areas only. This phase provided me with the opportunity to become a familiar presence to staff and residents. As a result, I was integrated into the community as a frequent visitor ahead of data gathering. This allowed staff and residents to feel relaxed in the researcher's presence.

The ethnographic work was conducted in two of the four homes that were involved in the initial planning and engagement phase. They were part of the same private company and specialised in Dementia care. Care home A was located in a deprived area of Birmingham, categorised within "urban adversity", and care home B was in a more affluent area, categorised within "comfortable communities" according to Acorn postcode profiling (Acorn, 2019). Each home caters for up to 40 residents living with or without dementia, who require personal or nursing care.

7.2.3 Sampling and participants

Purposive sampling was used to select participants based on their characteristics: namely, residents with self-reported hearing loss and dementia diagnosis, willing staff members, and engaged relatives of residents (see tables 22-24). I aimed for maximum variation between participants to gain as widespread experience as possible.

Of the 100 eligible residents across both homes, 16 consented to participate and could provide fully informed consent. Residents were approached directly and informed about the purpose of the research. A total of 11 staff members and 6 relatives consented to take part and were approached directly by me. Levels of participation involved observation, interview, or both. Field notes were recorded only for participants who had consented to participate in the research. These notes were written by hand, during or immediately after observations. To ensure their anonymity, all participants are given pseudonyms in reporting results.

Table 18: Inclusion and exclusion criteria for residents, staff, and relative participants.

	Inclusion Criteria	Exclusion Criteria
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Residents	Male and female residents were included in observations and interviews if they were i) permanent residents of the care home, ii) 60 years or older, iii) had self-reported hearing difficulties, iv) had a dementia diagnosis or reported cognitive decline.	i) individuals who occupied a nursing care bed and were too ill to take part, ii) those with significant language difficulties, iii) individuals unable to provide written informed consent
Staff	Permanent members of staff who had enough time to participate.	
Relatives	Relatives who had a family member that was a permanent resident of the home and who had enough time to participate.	

7.2.4 Ethical approval

The study received a favourable ethical opinion from the West Midlands — Coventry and Warwickshire Research Ethics Committee, reference number 19/WM/0294.

7.2.5 Data collection

The environmental audit was completed during the day when most residents were seated in the communal lounges, and care staff were busy with their daily tasks. It followed a template that included sections on lighting, sound resources, echo, noise reduction, and internal/external noises. The research planning and engagement phase aided in the creation of the environmental audit proforma (see appendix 3). The environmental audit reported on each home's physical features and structures. On the first day of data collection, I walked through each home's communal areas (lounges, dining rooms, main corridors) and completed the proforma. This process provided context information for each home, which was used to support the realist framework. This determined the approach for subsequent activities within the research and enriched the interpretation of observations and interview transcripts in relation to environmental factors that contributed to the presence of social isolation.

Fieldnotes were taken with a pen and paper during observations, and interviews were recorded with an encrypted dictaphone. I spent two weeks in each home, visiting for an average of four hours a day between 7 a.m. and 7 p.m. During this time, I was able to observe participants' daily routines, mealtimes, and structured activities. As evidenced by the planning and engagement phase, this is where the majority of communication interactions would take place. As a result, it was an excellent opportunity to document the types of interactions that occurred among residents, between residents and staff, and when relatives were most likely to visit. There was thought given to how residents used the space and furniture, how furniture placement hindered or facilitated interactions, and how residents interacted with one another, and with staff, and with family members. Observations occurred only in communal areas of the homes, such as dining rooms, lounges, and libraries.

Following observation and informal discussion with participants, interviews were conducted. Three distinct interview schedules were created to represent the various interests of the three participant groups (see tables 19-21). The questions covered current activities in the home, residents' communication experiences with other residents and with care staff, ideas for improving social isolation in the home, factors that contribute to social isolation, the home's listening environment, access to sound and conversation, and opportunities for social interaction. Because the interviews were intended to be semi-structured, the questions on the interview schedules were used as a prompt rather than a script. The interview schedules were determined by the responses of the participants, ensuring that I gained valuable insight into their experiences. Questions were asked in a different order to those listed on the schedules or omitted if not appropriate/covered elsewhere. I began by asking about the participant's background and current interests to build rapport, before moving on to their communication experiences. The interviews with residents and care staff occurred in between ethnographic observations, and participants were advised that further questions would be asked following another period of observation. Relatives underwent a one-off interview that lasted up to one hour.

The interviews questions broadly covered the following topics:

- Current activities carried out within the home
- Communication experiences of residents with other residents and with care staff
- Ideas for reducing social isolation in the home
- Factors that contribute to social isolation
- The listening environment of the home
- Access to sound and conversation
- Opportunities for social interaction

Tables 19-21 describe the types of questions asked to each participant group.

Table 19: Interview schedule for resident participants

Questions for resident participants	Rationale for asking the question	Prompts
<p>INTRODUCTORY QUESTION: Can you tell me a bit about yourself?</p>	<p>To gain a sense of context about the individual, and their family, and friends</p>	<p>How long have you lived at this home? Do you have family and friends close by? How often do you see them? What are your interests?</p>
<p>INTRODUCTORY QUESTION: Can you describe a typical week – the sorts of things you do day to day?</p>	<p>To gauge the participant’s level of social engagement within the home</p>	<p>What kinds of activities do you enjoy? How often do you see your family and friends?</p>
<p>How well do you hear in this environment?</p>	<p>To gauge the participant’s current access to sound and conversation within the home</p>	<p>What allows you to hear well? What allows you to have meaningful conversations? Which part of the home gives you the best access to sounds?</p>
<p>OBSERVATION FOLLOW-UP QUESTIONS:</p> <ol style="list-style-type: none"> 1. What are your thoughts on what has just occurred? 2. How does that make you feel? 3. What would you have liked to have happened? 4. Tell me more about... 5. Is there anything else you would like to add? 	<p>To gain depth and insight into observed communication experiences between the resident and other residents, and the resident and care staff.</p>	<p>How often do you speak with XXX? What sorts of things do you like to speak about? How connected do you feel to other residents in this home? Are there people you can confide in within this home?</p>

Table 20: Interview schedule for staff participants

Questions for staff participants	Rationale for asking the question	Prompts
<p>INTRODUCTORY QUESTION:</p> <p>Can you tell me a bit about yourself?</p>	<p>To gain a sense of context about the individual and their role</p>	<p>How long have you worked at this home?</p> <p>How would you describe your role at the home?</p>
<p>INTRODUCTORY QUESTION:</p> <p>Can you describe the sorts of activities that are arranged for residents to help them socially engage?</p>	<p>To understand the current range of activities and programmes provided within the home that encourage social engagement of residents</p>	<p>Who is responsible for organising the activities?</p> <p>What strategies are in place to encourage residents to engage who do not want to?</p> <p>How often do care staff have one-to-one conversations with residents?</p>
<p>How well do you think residents hear within this home?</p>	<p>To understand the care staff member's views on the listening environment of the home</p>	<p>Do you think residents are able to converse with each other easily?</p> <p>What are the barriers and facilitators to meaningful conversation for residents?</p> <p>Do you feel they have access to a full range of sound and conversation?</p>
<p>OBSERVATION FOLLOW-UP QUESTIONS:</p> <ol style="list-style-type: none"> 1. What are your thoughts on what has just occurred? 2. How does that make you feel? 3. What would you have liked to have happened? 4. Tell me more about... 	<p>To gain depth and insight into observed communication experiences between residents, and the residents and care staff.</p>	<p>How often do you see residents interacting with one another?</p> <p>What sorts of things do they speak about?</p> <p>How connected do you feel residents are with other residents and care staff within this home?</p>

5. Is there anything else you would like to add?		
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Table 21: Interview schedule for relative participants

Questions for relative participants	Rationale for asking the question	Prompts
Can you tell me a bit about yourself?	To gain a sense of context about the individual, and their relative within the home	<p>Were you involved in the decision for your relative to reside here?</p> <p>How are you related to the resident?</p> <p>How long have they lived here?</p> <p>How often do you visit?</p>
How well do you think your relative has settled within the home?	To understand the relative's point of view on the resident's living experience	<p>Does your relative have their own social network within the home?</p> <p>Who does this consist of and what sorts of interactions do they have?</p> <p>Are they happy here in your opinion? Please explain.</p>
What are your views on the communication experiences your relative has with other residents and with care staff?	To gain insight into their understanding and experiences of their relative interacting with others	<p>Have you witnessed your relative interacting with other residents, and with care staff?</p> <p>What is the depth of their interactions?</p> <p>Is this environment suitable for quality communications and interactions?</p>
What are your thoughts on the listening environment of the home?	To understand the relative's views on the listening environment of the home	<p>How easily are you able to converse with your relative when you visit them at the home?</p> <p>What would make it easier for them to hear better and participate in meaningful conversation?</p>

		Do you feel they have access to a full range of sound and conversation?
Do you have any thoughts on how your relative and other residents living with hearing loss and dementia could engage more socially?	To understand their views on how social isolation can be tackled within the home	Are you aware of the current activities and strategies put in place to help residents to socially engage? Is there a better way this could be done?

Table 22: Description of resident participants

Participant Pseudonym (care home A or B)	Age-band and Gender	Description*	Interview Details	Level of Participation
Wendy (A)	90–95, F	Smiled several times. Early-stage dementia, mild hearing loss.	Interviews took place in the dining room before lunch.	Observation and Interview
Lana (A)	80–85, F	Quiet, sang quietly to herself, observed everyone. Moderate-stage dementia, moderate hearing loss.	Interviews took place in the dining room before lunch.	Observation and Interview
Emily (A)	85–90, F	Often sat on the edge of the chair, muttered to herself a lot. Moderate-stage dementia, mild hearing loss.	Interviews took place in the dining room before lunch.	Observation and Interview
Gia (A)	80–85, F	Often walked around on Zimmer frame talking to staff and other residents. Moderate-stage dementia, moderate hearing loss.	Interviews took place in library area before and after lunch.	Observation and Interview
Vina (A)	75–80, F	Quiet, smiled and waved at others several times. Early-stage dementia, moderate hearing loss.	Interviews took place in library area before and after lunch.	Observation and Interview
Cilla (A)	70–75, F	Laughed several times. Moderate-stage dementia, moderate hearing loss.	Interviews took place in dining room after lunch.	Observation and Interview
Kelly (A)	75–80, F	Always sat with her coat on and handbag on shoulder. Moderate-stage dementia, mild hearing loss.	Interviews took place in library area before and after lunch.	Observation and Interview
Leon (A)	75–80, M	Quiet, spent most of his day sitting in the entrance area of the home looking outside. Moderate-stage dementia, moderate hearing loss.	Interviews took place in entrance area after lunch.	Observation and Interview
Penny (B)	75–80, F	Smiled several times and sat next to Chloe or Susan. Early-stage dementia, moderate hearing loss.	Interviews took place in quiet lounge after lunch.	Observation and Interview
James (B)	80–85, M	Quiet, liked to sit by himself in dining room or upstairs lounge. Moderate-stage dementia, severe hearing loss.	N/A	Observation
Chloe (B)	70–75, F	Husband also resides in care home. Showed an interest in staff members. Early-stage dementia, mild hearing loss.	Interviews took place in dining room before lunch.	Observation and Interview
Sienna (B)	70–75, F	Only came down to communal areas for mealtimes and activities. Early-stage dementia, mild hearing loss.	Interviews took place in dining room before lunch.	Observation and Interview

Jenny (B)	75–80, F	Quiet, recently had a fall. Early-stage dementia, moderate hearing loss.	Interviews took place in ground floor lounge after lunch.	Observation and Interview
Miranda (B)	75–80, F	Laughed and spoke several times. Wore two hearing aids. Early-stage dementia, severe hearing loss.	Interviews took place in quiet lounge after lunch.	Observation and Interview
Desmond (B)	75–80, M	Talked several times, described the home as his place of work. Moderate-stage dementia, mild hearing loss.	Interviews took place in dining room before lunch.	Observation and Interview
Susan (B)	70–75, F	Quiet, smiled several times. Early-stage dementia, moderate hearing loss.	Interviews took places in quiet lounge before lunch.	Observation and Interview

*Hearing loss descriptions are based on my clinical observations and experience of how well a person can hear and communicate.

Table 23: Description of staff participants

Participant Pseudonym	Age-band and Gender	Description	Interview Details	Level of Participation
Jane (A)	40–45, F	Care Assistant. Talked often to residents and other members of staff.	Interviews took place in dining room before lunch.	Observation and Interview
Lucy (A)	30–35, F	Apprentice. Spent a lot of time with Lottie, been working at home for 6 months.	Interviews took place in dining room before lunch.	Observation and Interview
Sarah (A)	30–35, F	Team Leader. Quiet, spent a lot of time sorting medications.	Interviews took place in dining room before lunch.	Observation and Interview
Delia (A)	40–45, F	Housekeeper. Reported to spend a lot of time in resident flats having one-to-one interactions.	Interviews took place in dining room before lunch.	Observation and Interview
Lottie (A)	45–50, F	Care Assistant. Appeared to know all the residents very well. Worked for 10+ years in home.	Interviews took place in dining room before lunch.	Observation and Interview
Ria (A)	45–50, F	Care Assistant. Quiet, spent a lot of time with Jane.	Interviews took place in dining room before lunch.	Observation and Interview
Helen (B)	25–30, F	Team Leader. Observed to be active. Spent a lot of time doing medications.	Interviews took place in staff room during lunch.	Observation and Interview
Mike (B)	45–50, M	Handyman. Always observed in communal areas of home. Appeared to know all residents very well.	Interviews took place in dining room before lunch.	Observation and Interview
Alana (B)	40–45, F	Care Home Manager. Spent time in her office upstairs and joined in with activities/tidying.	Interview took place in office before lunch.	Observation and Interview

Tasia (B)	25–30, F	Team Leader. Observed to be active and interacting with residents in communal areas.	Interview took place in quiet lounge area during lunch.	Observation and Interview
Kim (B)	40–45, F	Housekeeper. Spent majority of time in resident flats and observed interacting with residents in communal areas.	Interviews took place in dining room before lunch.	Observation and Interview

Table 24: Description of relative participants

Participant Pseudonym	Age-band and Gender	Description	Interview Details	Level of Participation
Martin (A)	60–65, M	Wendy's far-distant relative. Visits once a fortnight.	Interview took place in entrance area during lunch.	Observation and Interview
Sylvia (A)	60–65, F	Wendy's far-distant relative. Visits once a fortnight.	Interview took place in entrance area during lunch.	Observation and Interview
Greg (A)	30–35, M	Visits Mother once a fortnight. Attended with his daughter.	Interview took place in dining room after lunch.	Interview
Robert (A)	60–65, M	Cilla's brother. Visits once a fortnight.	Interview took place in dining room after lunch.	Observation and Interview
Catrina (B)	85–90, F	Visits husband every day. Spends majority of time doing physical care for husband.	Interview took place in Catrina's husband's room during lunch.	Observation and Interview
Yulanda (B)	35–40, F	Penny's daughter. Visits 3–4 times a week.	Interview took place in quiet lounge area during lunch.	Observation and Interview

7.2.6 Data analysis

Grounded theory informed the data analysis of the field notes and interview audio recordings (Strauss and Corbin, 1997). I transcribed the interviews. I also completed an iterative process of data collection and analysis as part of a theoretical sampling framework (Charmaz, 2006). The aim of this analysis was to create a model to explain a multidimensional dynamic theory of how different factors affect human behaviour within residential care settings. Forty interview transcripts were analysed in addition to detailed field notes that were produced throughout the ethnographic observations. Six core concepts/mechanisms have been identified seeking to explain the communication behaviours within these residential care settings and how this contributes to social isolation among residents living with hearing loss and dementia.

Coding was done line by line to maximise the number of initial descriptive categories that later became analytic themes (Strauss and Corbin, 1998). The coding process was divided into three stages: open coding, axial coding, and selective coding. The former required data

examination, comparison, conceptualization, and categorization. This procedure was followed for both individual data frameworks (all resident, care staff, and relative interview and observation data) and collective data frameworks. This method allowed data to be analysed for individuals, participant groups, and between groups. Axial coding entailed reassembling data into groups based on the identified relationships, patterns, and themes. Selective coding produced a description of the central phenomenon and the underlying mechanisms (Corbin and Strauss, 2014).

Data analysis was completed using QSR NVivo version 11 software. Upon completion of selective coding, data analysis ceased when repetitions in mechanisms across both research sites became apparent. Through multiple verbal discussions, key concepts supporting the central phenomenon of social isolation mechanisms were labelled by me and checked by my research supervisor to assist development of the final model.

7.3 Findings

7.3.1 Results of environmental audit

The results of the environmental audit conducted in both homes is shown in table 25. The differences between the two care homes indicate that care home B is better equipped for promoting communication and encouraging conversation. The location of the main communal lounge was a significant factor in enabling residents to communicate without excessive background noise, compared with care home A. In care home A the communal lounge was located next to the dining area with the door always open. This meant that meal and dining preparations could be heard from the communal lounge, in addition to the other noise sources (television, radio, and Alexa device).

There were no sound resources identified in either home. For example, no telecoil loop system, no central speaker system, and no flashing or vibrating safety equipment to support hearing impaired people in emergencies. Both homes were part of the same business group so this could have been exclusive to this company, or a universal issue in care homes. The furniture choice in both homes was ideal for preventing or reducing echo within the communal areas. Care home B had an appropriate layout of furniture, conducive to encouraging conversation and interaction between residents. However, the smaller size of the communal area, compared to care home A, meant that relatives and friends visiting residents had little privacy. There were other communal areas and a library that offered alternative areas for privacy, however.

The dining area of care home A was very much like the communal area. In other words, high ceilings hard floors, and very little sound absorption. The dining area of care home B was

smaller and quieter, which may have promoted more conversation between residents during mealtimes. However, there was a tendency for more communicative and mobile residents to eat their meals before those who were frailer and generally sleepy. This may therefore not be a fair comparison of mealtimes between the two homes.

Table 25: Results of environmental audit at care homes A and B.

	Care Home A	Care Home B
Main Communal Lounge – General Overview	Challenging listening environment. Television and radio often switched on simultaneously (and loudly) in different corners of the open plan space. High ceilings and carpeted floors. Located next to dining hall with door always open. Windows looking out to garden area.	Smaller than care home A. Carpeted floors and located at the end of a corridor. Television is the only sound source within this space. Located down the corridor from dining hall, windows looking out to front carpark.
Sound Resources	No sound resources identified such as telecoil for hearing aid input.	No sound resources identified such as telecoil for hearing aid input.
Furniture	Soft furnishings that prevented echo. Armchairs were placed in clusters of three or four.	Armchairs placed around the edge of the room facing inwards towards television.
Dining Room – General Overview	Hard floors and high ceilings, with limited acoustic absorption around the room. Sound of food preparation, crockery and cutlery from the kitchen was heard prominently.	Natural light, low ceilings and lino floors. Very little sound heard from the kitchen when sitting on the dining tables.

7.3.2 The listening environment and processes of the home

All resident participants had some degree of hearing impairment, but only one of the 16 included residents who wore hearing aids. The other resident participants had not sought any hearing help. When communication opportunities occurred for these residents, it was clear that their inability to hear what staff or other residents said led to withdrawal. This type of behaviour embodied social withdrawal and isolation. It included residents falling asleep in their armchairs, staring into space, or adopting a shrivelled sitting position.

The hearing loss was exacerbated by the noisy conditions within communal areas of the home. High ceilings and hard floors provided poor acoustics. Staff compensated by speaking in a raised voice or directly into a resident’s ear to resolve hearing difficulties.

Most residents described undergoing a loss of function. There was a strong sense of what had been lost:

Wendy (resident): “You can’t do what you did before. It’s a very helpless situation. You do what you can but now you have to wait for others. Nobody can ever do what you do. They can try but it will never be as good as what you can do for yourself.”

The dependence that residents had on staff for their physical and medicinal needs contributed to the contextual factors responsible for social isolation. Staff perceived “care” as meeting a resident’s bodily needs rather than valuing communication, empathy, and interaction. This attitude was displayed through their dependence on following the routines of the home, from which they tried not to deviate. For some residents, this routine was comforting because it provided structure to their day. One resident noted, “I don’t even have to look at the clock, it must be morning coffee by the way she’s rushing around.” There appeared to be a connection to the processes that occur within the home, rather than residents having a connection to one another. In this chain, there had been a recent strategic decision to remove all dedicated activity coordinators from homes requiring carers to incorporate activities into their daily workload.

Fieldnote extract from care home B illustrating a reduction of creativity and increased workload in care staff:

“12 residents are sitting in ground floor lounge; one carer rushes in with pots of crayons and randomly places them on the tables scattered around the room. She mutters to herself “Right, if I can get them colouring, I’ll be able to finish my folders, now where did I put that paper?”

The cultural values between staff and residents contributed to a power imbalance. For example, staff members often played music loudly from the 60s or 70s, with an assumption that all residents would enjoy this. Apart from two residents smiling, the majority would remain seated in their chairs, expressionless. One resident turned to me and said, “What is all this nonsense, you would not have me listening to that?” The removal of choice and the inability of staff to recognise and understand what residents would prefer to listen to further enhances the power imbalance.

The severity of one resident’s dementia influenced the amount of communication they had with staff members. Inevitably, disordered language becomes more prominent in advanced stages of dementia. In addition, having a hearing impairment makes it difficult for a person to hear another when they speak to them, meaning the former is not afforded the same opportunities as someone else. This dynamic was frequently observed in the type of communication and interaction that occurred between staff and residents. Specifically, for those with disordered language, any communication from staff was largely task-focused and centred around the practicalities of personal care and mealtimes. There was no evidence of staff making positive nonverbal communication attempts, which may be because of a lack of effort or willingness on their part or simply a lack of confidence in effective engagement. This was evidenced in one interview with the wife of a resident who had advanced dementia.

Catrina (relative): “I don’t think he’s too happy here...He’s been in this room for 7 years. Can’t do anything about it. Doesn’t talk much, doesn’t say much. I don’t like watching him here.”

The relative participants within the research varied greatly from Katrina, who visited every day and was considered a member of the home by care staff, to others who visited fortnightly for short periods in an obligatory manner. Nevertheless, all the visitor interactions I observed during the research seemed to put resident participants in joyful spirits. Thus, demonstrating the importance of one-to-one focussed conversation and interaction.

7.3.3 Social interaction

Social engagement consisted of care staff sitting with residents during mealtimes and engaging in conversation. There were also examples of intermittent structured activities where there was an opportunity for interaction between staff and residents. Staff were clear about the residents they most enjoyed speaking to. In every case their language was not disordered, and they made active communications and positive utterances towards staff. Therefore, staff valued these residents and made an active effort to speak and interact with them.

I was actively identifying individuals who could offer a unique perspective on the research question by focussing on contrasts in the dataset and seeking out individuals who could potentially provide an alternative viewpoint or lived experience. This necessitated the identification of residents with varying care requirements or staff demands, as this may result in varying levels of social isolation. Again, I sought out individuals who could provide alternative perspectives on how and why social isolation is maintained. This meant that I sought interviews with individuals who could provide a rich perspective. For instance, in care home A, I approached a staff member who worked as a housekeeper because she was the only staff member who accessed residents’ rooms for extended periods of time, which meant extended one-to-one social interactions and meaningful conversations with those residents.

7.3.4 The effects of daily tasks

The pressures of workload on carers directly impacted the time available for them to communicate with residents. When residents required more time to communicate because of hearing and cognitive difficulties, staff appeared to feel conflicted between relishing the communication opportunity and the pressure of their daily tasks.

The tasks placed on carers were visible to residents. Residents describe staff rushing past to perform tasks and completing paperwork in sitting rooms, even in the presence of residents. The visibility of the business resulted in an expectation from residents that staff were too busy to communicate. In one interview a resident was asked the following:

Me: “Who do you spend time with here?”

Desmond (resident): “Myself (laughs) It is just too difficult to get hold of people. They’ve got other things to do.”

One staff member commented in an interview:

“Look there’s three staff members in the room I can see they’ve done the folder and now they’re free to spend time with the residents. What more can we do?”

The values held by this staff member imply that spending time with residents can only follow administrative tasks such as “doing the folder”.

7.3.5 The effects of social isolation

Hopelessness was identified as a key consequence of social isolation for residents. One resident commented, “my day consists of sitting in a chair, so what have I got to look forward to?” This sentiment — combined with my observations of many residents sitting silently in the communal lounge or staring into space for hours without communicating with anyone else — suggests a sense of hopelessness and lack of worth or meaningful relationships. When this is combined with the power imbalance, there is a clear lack of connection to anyone apart from relatives who may only visit once a fortnight. One staff member told me that the residents are constantly speaking to one another — “We can’t get them to stop sometimes.” This was not observed during the ethnographic visits. Alternatively, the “buzz” of conversation in the communal areas is often from staff members speaking amongst themselves. These views held by staff members preserve the barriers to good communication and meaningful interaction, particularly for those residents with disordered language who express their feelings and behaviours in nonconforming ways. When this is combined with a failure to adapt the acoustic environment for residents, regardless of degree or presence of hearing impairment, social isolation ensues.

Together, data analysis led to the identification of social isolation, underpinned by communication barriers. Despite the differences in location and socioeconomic status of the two homes, very few differences arose in the types of communication behaviours observed. Social isolation was fuelled by staff time constraints and by priority of physical tasks. Therefore, communication and meaningful conversation were not prioritised. This was internalised by residents who, in turn, did not value communication with other residents, as evidenced in this interview:

Me: “Do you have friends here in this home?”

Leon (resident): “No...what’s the point? You come here and suddenly you’re waiting to die.”

7.3.6 Development of model

The summary diagram provides an explanation of how and why social isolation occurs within the two residential care settings. The environmental audit and observations provided data on context and action/interaction strategies used by care staff. The informal discussions and interviews contributed to the context in greater depth, enabling the contextualisation of the data.

The components of the grounded theory model are outlined below, and figures 11-15 provide a diagrammatic summary. The components include internal and external barriers to communication, which lead to reduced opportunities for meaningful conversation, leading to the central phenomenon of social isolation.

7.3.6.1 Internal barriers to communication

Reduced mobility was identified as an internal barrier to communication because most participants used walking aids to help them mobilise around the home. When they were on their feet, their pace was slow, and they often required assistance from a staff member to help them get from one place to another. Their motivation for moving around was reduced because of the additional support required. This created a barrier for communication and interaction with other residents who were sitting on the other side of the communal lounge or dining area.

As explained in section 7.3.2, hearing loss was another internal barrier to communication. With only one participant using hearing aids, but all having some degree of hearing loss, the knowledge and awareness of hearing and communication management from staff was limited. Their response to those with hearing loss was met with gestures such as raising their voices and talking into the residents’ ears. Staff reported that the links with local Audiology services were virtually non-existent. Unlike optometry and podiatry who visited the homes regularly to screen residents, no such service existed for hearing health check-ups.

Disordered language appeared to be the biggest internal barrier to communication. The amount of disordered language a resident had was correlated with the severity of their dementia, and subsequently the amount of social isolation they experienced. This was striking because it appeared that the level of hearing impairment a person had was not a crucial factor, but rather the severity of dementia as this was what the cause of the disordered language. This was evidenced by observations of one participant (Miranda) with moderate-severe levels of hearing impairment and early-stage dementia having interactive and humorous conversations

with staff members. This occurred across the room from another participant Desmond who had mild hearing impairment but severe dementia and disordered language. There was very little interaction between care staff and Desmond observed, apart from basic questions related to his physical care.

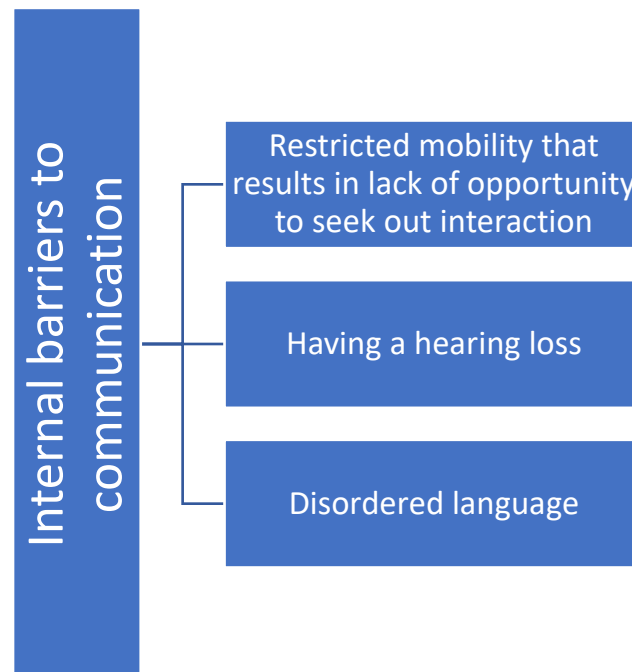


Figure 11: Internal barriers to communication

7.3.6.2 External barriers to communication

System dependence was identified as an external barrier to communication. There are very clear routines and schedules within the homes that staff do not like to deviate from. Another resident became anxious when I asked if I could interview her in the dining room before lunch. She said, “Oh I do hope that’s okay I wouldn’t want to disturb anyone or interfere I know it’s dinner soon.” Therefore, residents begin to connect to the processes that occur within the home, rather than residents having a connection to one another.

Staff are very much task-driven during their shifts and, therefore, consider activities or conversations with residents to be bonus tasks, only to be completed if everything else has gone smoothly and on time. There is a very strong dependence on the system and processes, removing autonomy and creativity within the role. In this particular chain, there has been a recent strategic decision to remove all dedicated activity coordinators from homes so that carers can incorporate activities into their daily workload. However, there is a clear conflict in the provision of autonomy and responsibility for carers to execute tailored activities whilst insisting they follow all processes and systems rigidly.

Cultural values and norms are another external barrier to communication. The very notion of residents being seated in their armchairs for most of the day whilst staff members rush past them or sit with large folders of paperwork to complete next to them, demonstrates a significant power imbalance and staff superiority. For some residents, this imbalance leads to a longing to have a social connection with staff (almost like a teacher's pet scenario). For those with early stages of dementia or big personalities, this arrangement seems to work well because those residents tend to be noticed by staff, and brief passing conversations occur. However, for those with disordered language and unaddressed hearing impairment, the task-driven behaviours of staff create a considerable disconnect between themselves and the residents. So only basic instructions and words are said, and ironically staff spend longer sitting next to these residents in silence to complete their paperwork. A striking observation from my time in both homes is that staff do not tread lightly in a residents' home; rather, the residents adapt to the workplace of the staff.

The cultural norms exacerbated the conflicting noise sources in the communal areas of the home. For example, the avoidance of silence in the communal lounges was considered the norm, to make the environment feel lived in and joyful. However, when relatives visited, the excessive noise sources prevented successful conversation from occurring.

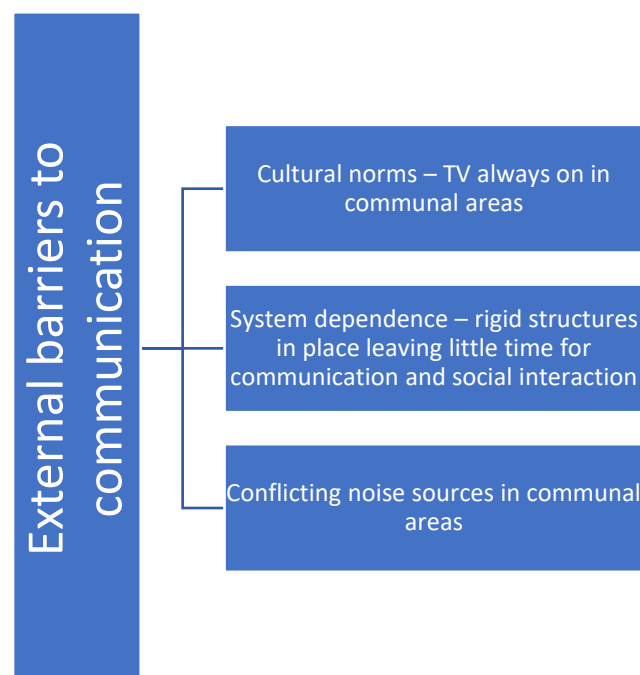


Figure 12: External barriers to communication

7.3.6.3 Reduced opportunities for meaningful conversation

Staff values and preferences were sometimes reported as residents' values and preferences. Staff mentioned that they would like there to be a cinema room within the home or regular movie afternoons because they feel this would be engaging and enjoyable for residents. However, this would contribute further to the extended period of "sitting and watching" that most residents experience all day, every day. Thus, providing further opportunity for a lack of communication and connection. More likely, staff would consider a movie afternoon to be something they would enjoy doing in their leisure time, and having residents occupied for a prolonged period allows them to complete their paperwork and other tasks with reduced pressure and commitment to be positive and upbeat. This contributed to reduced opportunities for meaningful conversation.

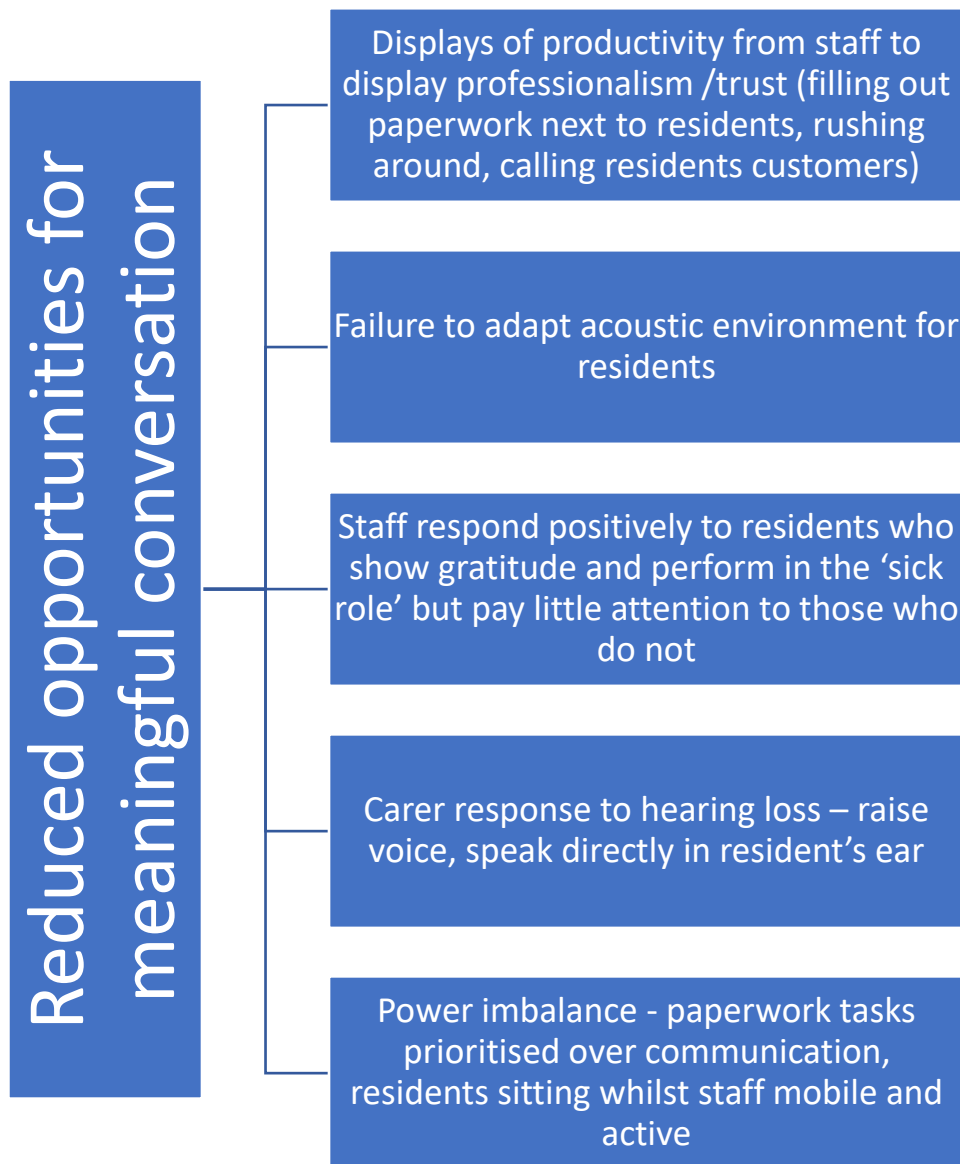


Figure 13: Reduced opportunities for meaningful conversation

7.3.6.4 Social isolation as a central phenomenon

One resident laughed and said sarcastically that she could not believe she paid to live here when all she does is sit all day. Another told me that their day consists of sitting in a chair so what do they have to look forward to. These responses — combined with the observations of many residents sitting silently in the communal lounge or staring into space for hours without communicating with anyone else — suggest a sense of hopelessness among the residents. This feeling then leads to a downward spiral of emotions where perhaps they do not feel worthy of friendships or meaningful relationships. When this is combined with power imbalance, residents face a clear lack of connection to anyone apart from relatives who may visit once a week or fortnight.

All the components mentioned have in some way contributed to the maintenance of social isolation in residential care settings. Fortunately, these factors can be improved to avoid social isolation from occurring and continuing.

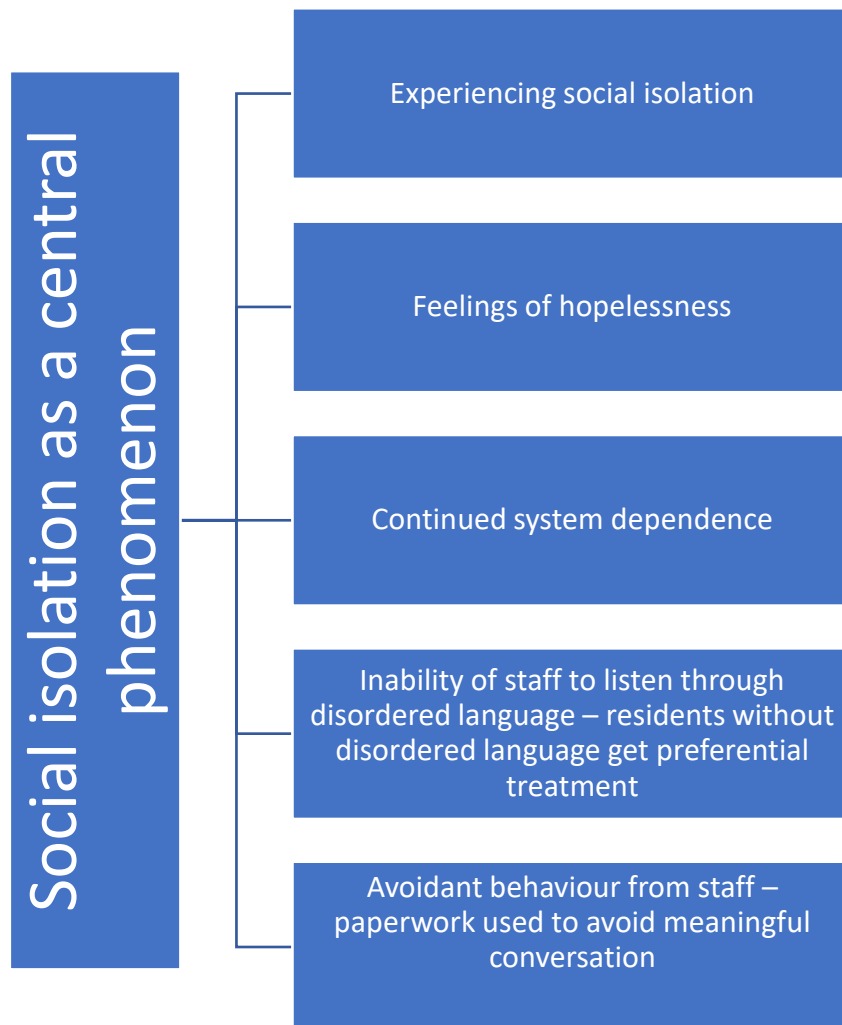


Figure 14: Social isolation as a central phenomenon

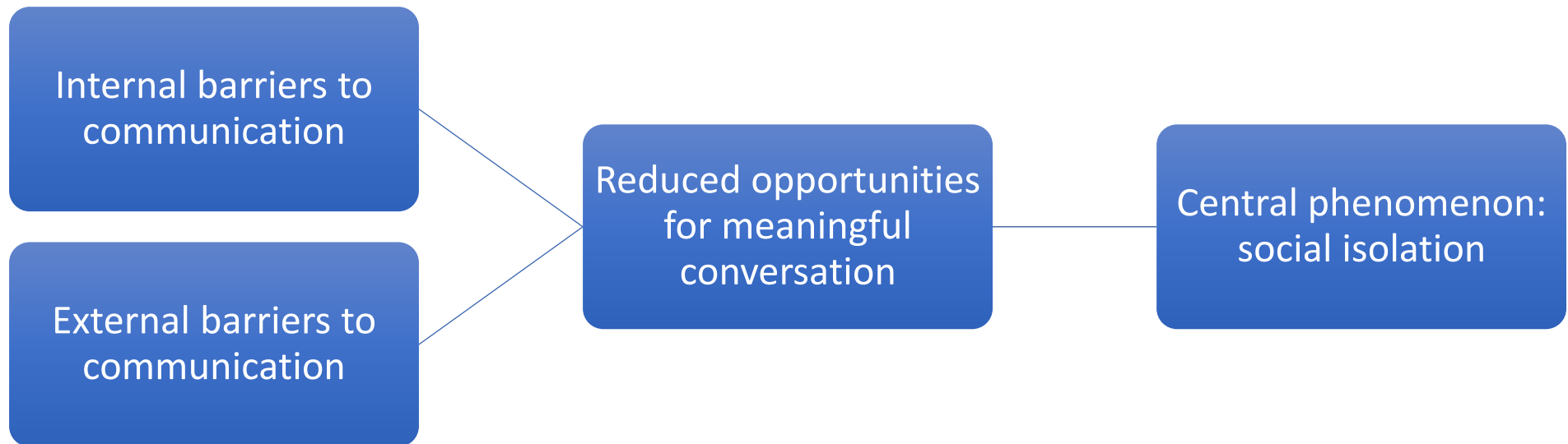


Figure 15: Summary grounded theory model to explain the factors involved in the phenomenon of social isolation

7.4 Discussion

7.4.1 Introduction

The multi-methods approach used in this study has provided a unique, rich, and meaningful interpretation to the lived experience of care home residents, supported by views from staff and relatives. I have conducted the empirical, ethnographic work with respect for the participants and the interviews and observations have yielded valuable data that have enabled the aims to be met. In particular, the realist-informed framework has enabled us to contextualise the mechanisms of social isolation identified. This study offers novel insight into how and why social isolation occurs in residential care settings, going beyond previous studies that have focussed on communication alone (Pryce and Goberman-Hill, 2011; Sprangers et al., 2015).

The grounded theory model was developed iteratively from the data. It demonstrates internal and external barriers to communication that contribute to the reduced opportunities for meaningful conversation. All the components that make up the internal and external barriers are either avoidable, or manageable. Success in overcoming these would require care staff to prioritise the communication needs of residents, which may prove challenging with their heavy workloads.

7.4.2 Key findings

The relative insignificance of having a hearing impairment and living with dementia in the presence of social isolation is striking. This has been evidenced by the popularity amongst staff of one resident participant with profound hearing loss and early-stage dementia compared to other residents with lesser degrees of hearing impairment but advanced stages of dementia, not afforded the same communication opportunities. Whilst the initial planning and engagement phase and environmental audit highlighted obvious environmental factors contributing to communication barriers, even with these overcome, a systemic change in the type of communication directed toward residents is required.

The critical mechanism appeared to be the level of expressive and receptive language a person had. This has been demonstrated as the deciding factor in whether a care home resident experiences social isolation or not, evidenced by the social engagement that did occur during the study. Thus, social isolation is not a product of resident communication function but results from how communication is valued within the setting. Specifically, residents lack choice in their communication options, since they have little control over the acoustic environment and their degree of language impairment, dictating how meaningful conversation may be with other residents and staff. These findings are similar to those of residential care research

carried out 10 years ago (Pryce and Goberman-Hill, 2011), highlighting the continued issues with “care” provision, even though person-centred care and decision-making now appear within NICE (2018) guidance on best practices. Bureaucracy has changed practice, requiring care staff to fill out vast amounts of paperwork for each resident; unsurprisingly, this process reduced opportunities for meaningful social engagement with residents.

Some staff stated that their job satisfaction and worth are mainly based on the positive feedback they receive from residents, such as a smile or a wave. However, it is not clear whether this means residents are happy or simply conforming to social etiquette because of the clear power imbalance within the environment. Furthermore, for those residents who have advanced stages of dementia and disordered language, the nonverbal cues they provide are very important aspects of their communication and are easily misinterpreted or ignored. Thus, if they do not provide the positive feedback that staff desire, they can be labelled as challenging or introverted. Staff can then favour other residents who do not have disordered language and are generally happier or more comfortable within the residential environment.

7.4.3 Approaches to care

This work has highlighted the difficulties that care staff face in reading nonconforming behaviour or listening through disordered language. Examples of nonconforming behaviour included a resident not being polite or cheerful or not displaying obvious gestures of gratitude for the care they were receiving. When these difficulties are combined with the biomedical model of hearing and the rigid structure of care systems, social isolation persists. Thus, a shift in care is required. The current state of care demonstrates dualistic thinking, which is to say, categorising a person as either healthy or visibly diseased and prioritising medical treatment (Antonovsky, 1996). The preferred state of care refers to one’s ability to see the entire person rather than solely the disease. This would require staff to listen through disordered language and to engage in meaningful conversation, where both verbal and nonverbal cues from residents are acknowledged. For example, when residents discuss past events in their lives (which may be unclear), staff members could sit and listen through the disordered language and engage in meaningful conversation rather than dismissing their words or responding with ‘elder speak’. In other words, both verbal and nonverbal cues from residents are taken into consideration. This is an important factor in reducing isolation in these environments.

What’s more, staff members retained a distance between themselves and the residents. This may have been to separate their workplace identities from their social identities. They referred to residents as “customers”, which maintained the distance. There appeared to be separate social groups within the homes: staff members were one group who had a connection to one another, i.e., laughing and joking with one another, and the residents as another group. The

latter were disparate individuals who did not have a connection to one another. There was no emphasis on social activity or the potential of being in a social group, so the status quo was maintained.

When person-centred care and social engagement occurred between staff and residents, it was evident that residents appreciated those interactions, which led to improved resident conversations. This is a key factor in reducing isolation within these settings. Staff are trained to prioritise a resident's physical needs over their communicative needs. This training results in a lack of social engagement between staff and residents, such that the latter are either overlooked or subject to time constraints. Therefore, those who are most challenging to communicate with are given neither the time nor the opportunity to be "heard" because of the effort required to read and understand their nonverbal cues and verbal utterances (Ward et al, 2008).

The humanised elements of care include dedicated attention to communication through meaningful and sincere actions (Todres et al., 2009). These are not a priority for staff, because their training is focussed on routine and bodily tasks. This issue is systemic within residential care, based on financial structure, high staff turnover, and overlooking communication as a valuable activity (Bradshaw, 2022). Those with reasonably good language and communication skills engaged in some level of meaningful and humorous conversation with staff, avoiding a vulnerable state of social isolation.

7.4.4 Care staff conditions

Kemper et al. (2008) explored how managerial practices could be changed to improve care providers' experiences. When interviews with residential care employees were conducted, the authors found that 76% of the respondents had recommendations for improving their jobs and providing increased satisfaction. Under half of the care staff mentioned improved remuneration as their top proposal for increased satisfaction and value. The second suggestion offered by care workers was better working relationships. Listening, admiration, and respect were mentioned as qualities that enhanced working relationships, mainly in the context of interactions between care workers and their managers. The results of Chou and Robert (2008), who discovered a positive link between instrumental and emotional supervisory support and a negative correlation between job satisfaction and role overload, support these characteristics. When discussing work relationships and workplace support, respondents' wording was significantly more individualised than when discussing other recommendations, according to Kemper et al. (2008). They hypothesised that the reason was the elevated stress levels brought on by the care workers' strained interpersonal interactions.

The attention of working conditions of health and social care sector employees, particularly care workers, has increased over the past decade (and more recently post-covid) (Ravalier et al., 2019). Details include the number of care workers on "zero hours" contracts, the low pay in the industry, the high turnover of employees, and employee exhaustion because of having to make up for staff shortages (Guardian, 2020). The annual personnel turnover rate in England's social care industry is 27.8% (Skills for Care 2022). About 30% of the 170,000 care workers in the residential care home sector (care homes without nursing) left their positions in 2016–17, making this number even higher (Skills for Care 2022). However, nothing is known about what is behind this high turnover rate. The working circumstances of residential care personnel are known, but little research has been conducted to determine whether these conditions contribute to the high turnover rate. For instance, realising the emotional and psychological aspects of care work (Gillespie et al., 2013); its physical and "dirty" nature (Stacey 2005; Twigg et al., 2011); and how, under these circumstances, care workers may be inspired by and find dignity in their work (Folbre and Nelson 2000). The understanding, definition, and conceptualisation of care and care work and their ramifications for how we value care and care work have been reported in the literature (Baines 2006; Dodson and Zinavage 2007).

7.4.5 Care staff training

Numerous studies have shown a link between care professionals' training and the calibre of the care they deliver (Miller et al., 2010; Gospel and Lewis, 2011; Kemp et al., 2013). In 1998, at a time of social care reform, there was a report published on the link between carer training and caregiving quality (SCIfE, 1998). There was attention to the fact that, in the UK, 80% of social care professionals lacked formal training or qualifications. A quarter of a century later, there are minimum qualification requirements and apprenticeship opportunities for care workers, but communication and person-centred care is still not a mandatory part of training in most facilities (Smythe et al., 2017). In the two homes that took part in the research, all staff were required to have the minimum level of vocational qualifications. However, there was no formal requirement to pursue further continued professional development during their roles, apart from the mandatory training that occurs annually such as manual handling and first aid. This appears to be aligned with the research literature and general position of residential care settings. Caregiving for persons with dementia can be emotionally and physically taxing. Therefore, it's crucial that staff members feel competent enough to carry out their duties (Pitfield et al., 2011). Training staff members may improve coping mechanisms and lessen work-related stress, ensuring they have the abilities necessary to sustain consistent resident care (Coogole et al., 2006).

Providing care staff with an understanding of humanisation and its essential components (Todres et al., 2009) could trigger better communication and greater engagement with residents with disordered language. However, doing so would require adjustments in their perception of time and efficiency to ensure all necessary tasks are still completed. This would be challenging in the two care homes that took part because the portrayal of being busy and rushing around, alongside prioritising paperwork, appears to be led from management rather than the choice of care staff “on the ground”. Lifeworld-led care could help guide care delivery to make it more humanised (Pryce and Shaw, 2019). This would indicate that to understand the importance of the environment on people's sense of wellbeing, care staff need to acquire an in-depth understanding of people over time in their “home-world” (Shaw et al., 2016). Lifeworld-led care (Galvin & Todres, 2013) builds on the idea of embodied knowledge by arguing that to be able to care for others, it is necessary to integrate three key areas of holistic understanding. These are “knowing” (having a wider understanding), “being” (enacting certain qualities), and doing what is good or morally right for another person (Walseth and Schei, 2011). In order to successfully demonstrate the domains of the lifeworld within residential care, staff members would need to develop the skills to provide open communication and “empathic imagination” (Galvin & Todres, 2013). There were high quality moments of interaction and communication observed between care staff and residents, where the three key areas of holistic understanding were demonstrated. However, this was the exception rather than the norm based on my limited observations and field work. Holistic understanding actively involves the person receiving care and the care provider to imagine prospective outcomes and the specifics of the person's lifeworld (Shaw et al., 2018b). It could be argued that in the absence of pursuing lifeworld-led care, residents are not wholly treated as human beings, but simplified to “tasks” for people to attend to during their shifts (Baars and Dohmen, 2013).

7.4.6 Data saturation

More settings wouldn't necessarily have improved my understanding of the phenomenon because the care facilities I chose supplied high-quality data. I had seen and heard enough, though, to be able to explain the results and judge their application to a larger world in the framework of a time-limited study that intended to create preliminary understandings. This is not to imply that a more thorough investigation and additional information would not be beneficial, particularly in light of socioeconomic disparities (Morse et al., 2002).

In qualitative research, saturation is viewed as being a little contentious. While its practical explanation is hazy, some may use it as a sign of excellence (Guest et al., 2006). Despite its roots in grounded theory (Glaser and Strauss, 2017), a researcher may utilise this method to determine when to stop collecting data for a more general qualitative study, such as when no

new concepts develop, stories and incidents reflect well-known themes, and trends recur (Fetterman, 2010; Silverman, 2011; Corbin and Strauss, 2014). This was expressed by asking, "What else will I or can I learn here?".

I had attained saturation with each care facility as soon as I was able to predict what would occur during an observation. When there were no "new" types of situations, problems, or incidents, I realised I had spent enough time studying inhabitants. The stories and relationships I had observed began to repeat themselves as I observed and conversed with staff members and residents. Since it would have taken longer to find patterns if I hadn't been actively evaluating the data in the field, an iterative approach to data collection and analysis was important to recognise saturation. This is not meant to suggest that saturation is easy to define or locate. In fact, many claim that achieving this goal is impossible (Patton, 2002). The want to conduct one more observation or interview was incessant, as was the fear that if I left the environment, something new would occur. In fact, one could argue that saturation is a myth from an interpretive and constructionist perspective because everyone applies their own interpretation to the situation and creates a new reality.

7.4.7 Summary

This work has shed an important light on the communication realities within residential care settings. Older adults residing in care homes have many conditions to manage, whilst adapting to a new environment, people, systems, and processes. The priorities of care home staff need to be amended to include regular and meaningful communication with residents, regardless of their language skills, hearing ability, or dementia severity.

7.5 Reflections

I have extensive experience working with older people in a clinical capacity within hospital and community settings. Patients have told me stories about the impact their hearing loss has had on their quality of life, especially when there were situations where the environment or other persons could have easily adapted to help the person with hearing impairment. Therefore, I am sensitive to ensuring people with hearing loss feel included and have the appropriate sound resources to be comfortable within an environment. I value the importance of communication in all settings, and this shaped my interpretation of the data. Observing communication not being valued was challenging for me and may have biased my readings of the situations that I came across during data collection. For example, I was dismayed when I initially experienced the communal area of care home A where there happened to be a television, radio, and music speaker all on loudly at the same time. This was clearly uncomfortable for the residents, and I felt disturbed by it. When I reflected on this incident with

my supervisor, it was helpful to talk in depth about why I felt disturbed and how my expectations were perhaps higher than they should have been because I was entering a health and social care facility. In my opinion, it should have been obvious how to accommodate for older people with hearing loss, but this is in fact not obvious or always possible within residential care settings.

I ensured to reflect with my primary supervisor after each extended observation period and was therefore mindful of how the data was interpreted and shaped. This limited authorial bias in the data analysis presented. I was also mindful of my presence within the homes influencing staff behaviour, particularly following initial interviews and observations. The reflections helped me to appreciate the hard work and caring nature of the care staff, who were largely overworked and seemingly undervalued.

The ethnography phase of the PhD was mentally draining for me. I was overwhelmed with emotion during each visit. On one hand, I was pleased to see the residents and filled with warmth at the few who recognised me and seemed pleased that I had arrived. I was also saddened at some of the observations of social disconnect, disengagement, and withdrawal. My clinical background had a significant impact on my feelings and reactions whilst in the home, and my personal attitude towards residential care and the fear of developing dementia. This stems from societal and cultural beliefs.

As much as possible I tried to remain open-minded and objective in my observations, but also appreciate the need to include part of me in this analysis to embrace the epistemology of the work and reflect on my findings. Whilst there is great advantage to my knowledge of hearing and communication needs for older adults, this may have influenced my judgements on the amount of care and attention being provided in this area. As a result, I was very critical of the lack of knowledge concerning hearing tactics, access to Audiology services, and general listening environments. For example, the communal areas of care home A were extremely overwhelming from an acoustic viewpoint. Such a setting most certainly was the norm and not considered to be an issue by staff members or even relatives. I was so interested to understand what the residents felt about the acoustic environment and whether they felt this has had an impact on their quality of life.

Of course, symptoms of hearing loss largely overlap with symptoms of dementia when considering communication, and this cannot and should not be ignored during the ethnography. My knowledge of hearing was balanced out with my novice approach to dementia. Having said that, the understanding I have gained of dementia throughout this PhD work provides me with confidence that I comprehend the needs of people living with hearing

loss and dementia, who may have an exacerbated vulnerability to social isolation that is either a consequence of the two, or a mediating factor between the two.

It's also important to discuss the impact of Covid-19 during the course of my PhD research. As stated earlier, the planning and engagement work that took place in four care homes did not translate into data collection at those four homes because of the national lockdown restrictions in March 2020. I had everything organised in place for the ethnographic work to be conducted consecutively at the four homes, but this ceased after the first two homes because of the pandemic. I was distraught at the thought of only being able to collect "half" of my expected data but soon realised the significance of Covid-19, particularly for the care home residents. I sent emails to the care home managers to wish them well during the challenging period ahead, feeling helpless that I could not be of any assistance during the crisis. I received a reply months later, when they were most likely able to catch a breath, and was thanked for my well wishes. During the first lockdown period, I often thought about the care home residents and staff with whom I had become acquainted. It was a sad feeling, synonymous with the mood of the nation. I particularly felt saddened by the number of deaths of care home residents and the severe restrictions placed on visits, knowing the vulnerabilities to social isolation that existed.

I am pleased to have stayed in touch with the care home managers as I hope to return in the near future to disseminate the research to care staff and residents. I also hope to conduct future intervention development work at the homes, to apply the grounded theory model and identified mechanisms into practice.

I strongly feel that the ethnographic work has done justice in capturing the voice and lived experience of care home residents. The learning curve of these methods combined with the emotional toll has further shaped my worldviews and prepared me for future qualitative research in this area. I felt honoured to be in the presence of the care home residents and staff, who gave me their time and stories. Some of my observations made me feel extremely negative about care homes and want to avoid them when I reached my senior years. Now looking back, I realise how much potential there is for (and may currently exist) true friendships, connections, and a "home away from home".

CHAPTER 8

DISCUSSION

8.1 PhD research questions

- 1. What is the current evidence to support the hearing-cognition association?**
- 2. Does hearing loss cause later cognitive impairment and/or dementia diagnosis in adults?**
- 3. Is social isolation a mediating factor in the relationship between hearing loss and later cognitive impairment/dementia diagnosis?**
- 4. Is there population level evidence to support an association between hearing threshold and later cognitive score, and hearing threshold and later social isolation presence in older adults?**
- 5. How is communication affected in older adults living with hearing loss and dementia in residential care settings?**
- 6. How is social isolation created and maintained in older adults living with hearing loss and dementia within residential care settings?**

8.1.2 Purpose of work

The purpose of this programme of work was to explore the role of social isolation in older adults living with hearing loss and dementia. Several research questions were formed to contribute to this exploration using a pluralist approach. At a population level, I wanted to investigate whether social isolation has been identified as a mediator in the association between hearing and cognition. My investigation into mediation and the causal pathway led to a novel epidemiological analysis of hearing threshold data and cognitive score, alongside hearing threshold and social isolation score, using the same dataset from the Hertfordshire Ageing Study.

In parallel, I was interested in how the experience of not hearing contributes functionally to social isolation. I, therefore, developed a detailed set of qualitative methods to analyse how communication and lived experience were created and maintained. Specifically, how communication between staff members and residents, as well as between residents, themselves contributed to the realisation of group belonging and social connectedness.

Whilst this thesis is not a traditional mixed methods piece of research, the pluralist approach utilises different ontologies, epistemologies, and methods, appropriate to each research question (May et al., 2017). The quantitative (systematic review, meta-analysis, and epidemiology analysis) and qualitative elements (ethnography using grounded theory) of the research were analysed separately and helped to inform interpretation of the other.

This work was an original and novel contribution to the field because of the multiple perspectives used to understand the patterns and mechanisms of hearing loss, dementia, and social isolation in older adults. The findings from the three empirical pieces of research each contribute significantly to the literature. The systematic review highlighted the heterogeneity of cognitive measures used in hearing-cognition longitudinal studies and the selection bias that influences results. It also highlighted that social isolation has not been measured enough in longitudinal studies and is therefore not considered a mediating factor. The meta-analysis supported the notion of a hearing-dementia association, but causality is yet to be established.

The multiple linear regression demonstrated that even when a sensitive measure of social isolation is used in a cohort study, there are many factors that influence the observed result that leads to acceptance or rejection of the null hypothesis. For example, the type of participants used (affluent, community-dwelling older adults), or the age of participants when the measures were taken. There are still massive gaps in epidemiological data because the social isolation measures are not as reliable as they should be (Mansfield et al., 2023). Unfortunately, a mediation analysis could not be completed because of the timing of when variables were measured. This supports the lack of longitudinal research using mediation in the systematic review because either the variable was not measured at all, or it was not measured at the right timepoint (Rijnhart et al., 2021). It was highly valuable to do the separate multiple linear regression analyses on hearing threshold and later cognitive score and then hearing threshold and later social isolation score because it was crucial foundation work for future mediation analysis if appropriate. Two of the three relationships (hearing threshold, cognitive score, social isolation score) were examined and demonstrated that the type of population or participants used in the analysis is a big indicator as to what the results will be. This is in comparison to the other longitudinal cohort datasets, and the participants involved in the qualitative work, since healthy participants living in the community are very different to frail individuals living in residential care settings.

The use of multiple methods has provided a rich interpretation of communication in two residential care settings for residents living with hearing loss and dementia. This has highlighted the need for social and environmental changes to be implemented to help reduce social isolation in care home residents (Boamah et al., 2021).

A pluralist approach was deemed most approach to answer my research questions because each component has produced a unique contribution to knowledge and helped to inform the other. The systematic review informed the multiple linear regression analyses by highlighting the lack of studies that considered social isolation within the hearing-cognition pathway. This led to novel analyses of two out of three pathways for mediation i.e., hearing threshold and

later social isolation, and hearing threshold and later cognitive score. The multiple linear regression analyses provided some insight into the characteristics of community-dwelling adults within the population of interest, and more importantly how varied the sample was compared to those included in the systematic review and meta-analysis. In addition, the systematic review informed the empirical ethnography study by providing a broader context and background knowledge on the topic area of hearing loss and dementia. The findings of the systematic review were used to identify key variables or factors that were important to the population/ culture being studied in the ethnography. Specifically, the cultural beliefs and practices related to health and illness among older adults living with hearing loss and dementia.

The MOS Social Support Survey used within the multiple linear regression analyses provided a framework of the possible elements of social isolation, which informed the type of language to be used in the ethnography. The ethnography study highlighted that the measures used in epidemiology studies are not sensitive enough to capture social connectedness and social isolation. It also highlighted that people living in residential care are hugely different to the community dwelling adults that were used in the systematic review. What's more, the ethnography helped to contextualise and explain the findings of the systematic review, and provide a more complete understanding of the hearing, social isolation, dementia phenomenon. Although the entire MOS social support survey was not used in the epidemiology dataset, the components can help with questionnaire development that would derive from the ethnography findings about how to capture the lived experience of social isolation. This was not a mixed methods PhD. This was a PhD investigating a hugely complex phenomenon, requiring multiple research questions that were answered with the most appropriate methods. Each component helped to inform the other and provide a unique contribution to the geriatric field.

A pluralist approach can offer a more comprehensive understanding of hearing loss, dementia, and social isolation by considering different perspectives and approaches. This approach can address the diverse needs of research stakeholders, including caregivers, family members, and individuals with hearing loss and dementia. Additionally, it can identify gaps in existing research and suggest new directions for further study. By considering a range of perspectives and approaches, a pluralist approach can increase the relevance of hearing loss and dementia research for policymakers, healthcare professionals, and the public. This thesis utilised a pluralist approach to address its research questions, with each research element informing the other.

8.2 What lessons have been learned from this work?

When I consider the initial research questions outlined in the thesis, I realise how much has been learnt about this multifaceted and fascinating topic. Simply put, social isolation in older adults is a very complex process. When this is explored with conditions such as hearing loss and dementia i.e., comorbidities that significantly affect a person's ability to communicate, the process becomes even more complex.

I have described the mechanisms that contribute to communication breakdown and maintain social isolation in older adults living with hearing loss and dementia. This work, combined with the population level understanding of the topic, form the initial steps in intervention development. The use of pluralism in this research has been a key strength because understanding the nuances of hearing loss, dementia, and social isolation is too broad to be covered by a single research question, and indeed a single research approach. A pluralist approach is crucial to understand complex lived experience from multiple perspectives. The different perspectives complement understanding of each other.

The evidence on a population level about hearing loss, dementia, and social isolation has been ill-defined, demonstrating a limited understanding of social isolation. The novelty of this work was based on exploring the ill-defined definitions of social isolation in a community environment to identify how and why the problems were occurring. The result is epidemiology studies better defining social isolation measures by inductively understanding what underpins them. By their very nature, epidemiology studies will never go into the complexities and intricacies of variables, especially a phenomenon like social isolation. That is why pluralist methods are so powerful. The combination of ontologies allows for inductive data analysis to build theory and understanding, which can then be used deductively to test hypotheses.

Most significantly, the humanisation of care should be employed within residential care settings. A toolkit developed for humanising healthcare incorporates many strategies and adaptations that care staff could implement to enrich the lives of older adults living in residential care (Galvin et al., 2020). This involves actions such as avoiding the use of "elder speak" towards residents and maintaining a sense of interest towards older adults living with hearing loss and dementia. Moreover, being consciously aware of the realities of the residents. For example, frailty is a complicated condition with diverse constituent elements, and one that most residents within my study were described as. It must therefore be effectively overcome via the provision of preventative initiatives that support older individuals in maintaining their social connections and experiencing wellbeing despite physical limitations (Shaw et al., 2018a).

The four stages of psychological safety (Clark, 2020) also tie into the humanisation of healthcare framework (Todres et al., 2009). An older adult who feels safe to challenge the status quo, is encouraged to voice their opinions and concerns, and take charge of aspects of their care, will contribute greatly to the dignity and respect involved in humanising care. Together with the person-centred care approach (Kitwood, 1998), an older adult living in residential care has the potential to be filled with dignity and grace whilst living with severe dementia, hearing loss, and disordered language.

8.3 Challenges of pluralism

Bringing this research together into a coherent narrative and understanding how the individual components fit together was challenging. There was always a conflict about this PhD not being a mixed methods piece of research, but a mixture of methods being used to answer research questions under an umbrella topic. I not only had to grapple with the concept of pluralism, but also with terms such as multi methods, ontology, epistemology, grounded theory, and subject specific jargon. The learning curve was steeper than I ever imagined.

Although disagreements exist regarding the comparability of conclusions drawn from various theoretical frameworks and the practical application of different analytic techniques (Clarke et al., 2015), pluralism was a vital approach for my research because of the complexities of understanding the interactions between social isolation, hearing loss, cognitive impairment, and dementia in older adults.

I specifically found challenges in using different populations for the different elements of research. They were appropriate populations to answer the research questions, but the differences in their demography and environments made the interpretation challenging. This was especially true when trying to understand how each element informed the other. For example, the cohort studies included within the systematic review and meta-analysis largely involved affluent community-dwelling older adults. Similarly, the profile of the participants in the Hertfordshire Ageing Study were generally healthy and lived in the community, whilst the unhealthy participants did not reach the second time point, so could not be included in the analysis. This participant demographic contrasted widely to the care home residents who had multiple comorbidities, and obvious frailty. It was therefore difficult to consider the two types of population under the one topic area. Nevertheless, the systematic review and multiple regression analyses revealed big gaps in the way social isolation is measured and labelled in epidemiology datasets. What's more, the social support questionnaire used in the Hertfordshire Ageing Study did provide initial guidance on how social isolation could be defined and viewed. This complemented the iterative nature of using the qualitative data to interpret my observations and interview transcripts and develop the grounded theory model

from within the data. I am proud to have learnt the valuable research skills related to evidence synthesis, data modelling, and theory development.

8.4 Planning and engagement work reflections

The planning and engagement phase provided a unique insight into involving persons living with dementia in research. This was my first opportunity to do so, and it was a huge learning curve, but extremely rewarding. People living with dementia have so much to offer in terms of their life experience, stories, and general company. It was a pleasure working with the residents, but not always easy knowing where to take the conversation or how to proceed with discussing the research. The impact of Covid-19 made this even harder, but fortunately the time I did spend for the planning part of the research was highly worthwhile.

Despite the huge gains in PPI which ensure that policy, service development, and research meet the needs of the people for whom it is being designed, many barriers remain. The researchers are responsible for some of the barriers, but the individual may be too (Fudge et al., 2008). Some professionals and researchers may avoid PPI or make tokenistic efforts to involve people. The reasons for this avoidance include limited time and resources, along with the competing pressures of multiple workloads (Cluley et al., 2022). Some barriers are much less tangible and are associated with the beliefs of the researchers. For example, the work may be too complicated for the service users to understand. Service users may lack an understanding of what and how PPI works and may therefore arrive with their own agendas for being involved (Mockford et al., 2011).

Just as people with communication difficulties (e.g., hearing loss and dementia) are often excluded from research, they are also often excluded from PPI activities (Miah et al., 2020; Dawes et al., 2022). Training and support may be logical methods to reduce some of these barriers, both for researchers and for service users. Where service users did not receive adequate training and support, they felt unable to contribute (Brett et al., 2012). There is an even greater risk of this occurring when service users have communication difficulties. This may be because of ethical and practical challenges, such as including people living with dementia who may have fluctuating mental capacity. The Public Involvement Impact Assessment Framework Guidance (Collins et al., 2018) emphasises that groups should be involved but that careful consideration should be given on how best to do this.

Barriers to participation in PPI are not dissimilar to barriers in day-to-day conversation difficulties for people with communication difficulties. The barriers may be combinedly held by both the listener, and the person with communication difficulties. Therefore, highlighting that these barriers to involvement are a problem for the researchers themselves. They can and

must change their behaviour to address the issues. Moreover, people with communication difficulties are not a homogenous group. They vary widely, presenting with different severities of communication difficulties and different areas of communication strength. As such, one adaptation to communication will not suit the needs of all service users involved. As anyone does, people with communication difficulties have different styles of communication. They have personal preferences beyond their communication difficulties and areas of strength. People with communication difficulties often present with additional needs, beyond being able to understand the materials they are presented with. For example, for those living with hearing loss and cognitive impairment concurrently, it can be difficult to attend to a group conversation. Listening to others for prolonged periods is tiring because of the mental strain or the effort of listening. Cognitive skills such as attention, inhibition, and topic maintenance may be compromised as part of an individual's overarching impairment. Within topic maintenance, these concurrent difficulties can impact, for instance, the balance of conversational turn-taking and other group dynamics.

In addition to challenges to involvement resulting from communication difficulties, people may experience other social and cultural barriers. For example, people from underserved communities such as minority ethnic backgrounds and lower socioeconomic backgrounds may experience communication difficulties. Researchers must acknowledge the nuances of a person's identity and how these nuances may impact their communication, participation, and general involvement in PPI activities and research.

There are various ways to reduce barriers to participation for people with communication difficulties. For example, remembering that turn taking within the encounter will take place at a slower pace than would perhaps occur with somebody without communication difficulties. Promoting self-advocacy and self-determination will help service users to meaningfully contribute and empower them in the process. This promotion of self-advocacy requires an element of trust from the researchers and avoidance of researcher bias. Feedback from conversation partners is essential for people with seldom heard voices, some of whom will have had communication impairments all their lives, whilst others would have become impaired later in life through unaddressed hearing loss or cognitive impairment.

8.5 How the grounded theory has built on previous research

Section 2.7.1 discussed the difficulties in communication within residential care facilities, including hearing impairment, environmental factors, and limited social interaction opportunities. Effective communication between care personnel and residents is crucial for high-quality care, and communication skills training for care workers is one way to address

these issues. The training should include a comprehensive set of communication skills taught within a cogent theoretical framework, along with behavioural management tactics. While effective communication techniques and adaptations from care staff have a positive influence on residents, there is still a need to understand the factors that contribute to sustained communication adaptations and the long-term benefits for residents.

Understanding the procedures, settings, and behaviours of the personnel and residents at care facilities would increase the possibility of successful communication outcomes.

Grounded theory has been used in the dementia field to explore a range of topics, such as the experience of living with dementia, the perspectives of caregivers and healthcare professionals, and the development of interventions for individuals with dementia. The studies by Pryce and Goberman-Hill (2011, 2013) emphasise the impact of social and environmental elements on effective communication among people with hearing loss. My findings concurred with those of Pryce and Goberman-Hill (2011, 2013), and enhanced the understanding of lived experience within care home settings by modelling the creation and sustenance of social isolation amongst residents living with both hearing loss and dementia. Moreover, the study by Wittich et al. (2018) revealed that staff training on sensory impairment is inadequate. The study found that there was a high prevalence of hearing loss among nursing home residents and that staff training related to sensory impairment was insufficient. The study also found that the use of hearing aids did not necessarily improve communication activity or reduce hearing handicap, which suggests that additional interventions may be necessary to improve the overall communication experience of residents with hearing loss in nursing homes. This supports what I found in the ethnographic work and supports my recommendations for care staff to receive communication training from Hearing Therapy professionals who are expert in receptive and expressive communication strategies for individuals experiencing communication difficulties.

According to Nygaard et al.'s (2020) research, residents in care homes wish to have significant relationships with people around them as it helps them to feel better and less homesick. Additionally, it is essential to provide a private space within the care home where residents and their spouses can meet and maintain meaningful connections, as highlighted in Førsund and Ytrehus's (2018) study. My work builds on this by providing the contextual factors and mechanisms that would hinder a resident from feeling comfortable within their surroundings and environment, and more importantly, connected to those around them. The provision of a private space for residents to converse with other residents or with their relatives would not only contribute to an enhanced "home-like" feeling, but also practically make sense in terms of an appropriate acoustic environment where there is minimal

background noise and distractions.

Overall, grounded theory has been used in the dementia and communication field to provide rich, in-depth insights into the experiences of individuals with dementia and related comorbidities, caregivers, and healthcare professionals, and to inform the development of interventions that are responsive to their needs (Brossard, 2019). The study by Crosbie et al. (2019) provided valuable insights into improving communication for people with hearing loss and dementia in nursing homes. The researchers used a realist synthesis approach, which is an innovative method for systematically identifying context-specific factors that can influence the effectiveness of interventions. My work has gone a step further in identifying not only the care staff training that would be beneficial for resident communication, but also the behaviours that could be reduced to improve the overall lived experience of residents.

8.6 Limitations

The planning and engagement phase involved potential participants' views on methods. It was not possible to involve those persons in the data analysis and theory emergence due to funding limitations (Pizzo et al., 2015) and the national lockdowns of Covid-19 in 2020. Moreover, the exclusion of participants who did not have the capacity to consent limits the applicability of the findings. Future research exploring the lived experience of individuals without the capacity to consent would be worthwhile.

Research observations during the ethnographic work were limited to communal areas, so it is not known how communication may be handled in smaller spaces, such as the residents' own rooms. Interestingly, staff participants who were housekeepers of the care homes spoke of the detailed conversations they have with residents during the 30–60 minutes they are cleaning their private spaces. Further research exploring communication patterns in these private spaces would be necessary to better understand the social isolation phenomenon within these environments. Since dementia and hearing loss are almost ubiquitous in care homes, separating out their effects on any other variable (such as social isolation) will always be challenging, but worthy of exploration.

8.7 Recommendations

The systematic review and meta-analysis have highlighted the need for better reporting and better study design in longitudinal studies to ensure risk of bias is minimised. It also highlighted the need for participant groups to be considered more appropriately to reduce selection bias and increase the validity of findings. Furthermore, the type of measures needs to be more

sensitive to the actual conditions being measured. For example, hearing thresholds should be measured using pure tone audiometry (screening method or otherwise), rather than alternative methods that are less reliable. There also needs to be a more streamlined battery of cognitive tests for testing the hearing-cognition causal pathway, as the current variance between tests is very high, making comparisons difficult.

The epidemiology analysis has demonstrated the importance of having variables measured at appropriate timepoints for specialist analyses like mediation to be completed. This will be very welcomed in supporting causal inference and testing hypotheses based on directed acyclic graphs. Of course, most importantly it has highlighted the need for more studies to include sensitive and specific measures of social isolation. This was the best of the data that was available, but cohort dataset variables need to improve.

Surprisingly little study has been done to determine the best methods or viable management strategies to improve hearing-related communication in people living with dementia residing in nursing homes. To solve this issue, a five-component programme theory was created with a realism perspective in mind (Crosbie et al., 2019). For a resident's hearing-related communication to be effective and useful, the authors identified five essential components. These strategies included training for dementia and hearing loss, knowing the person and awareness, supporting, and observing residents' requirements for hearing-related communication, and noise control in the care facility setting. These factors supported the need for care personnel to interact meaningfully with residents and were in line with my ethnographic research findings. The idea of "permission," which denotes how staff can feel empowered to pursue fulfilling interactions with residents and make it a natural part of their work, served as the connecting thread across all these components (Crosbie et al., 2019).

The ethnographic research has identified the potential for social and environmental recommendations implemented within the homes to help improve communication and reduce social isolation. For example, reducing power imbalance could involve staff dining with residents during their mealtimes. This would encourage conversation and allow residents to view staff members as companions who share their home rather than purely caregivers. Furthermore, specialist training from a Hearing Therapist could provide care staff with valuable skills in enabling meaningful conversation and listening through disordered language. Greater awareness of acoustic factors contributing to reduced communication opportunities must also be considered. These recommendations align with previous research (Pryce and Goberman-Hill, 2013) that suggested interventions for enhanced communication opportunities, but our work focuses mainly on overcoming social isolation. Of course, interventions are dependent on fiscal and government systems. As a practical example, a carpet cannot be cleaned as

easily as a hard floor. This is a Care Quality Commission (CQC) infection control requirement for care homes (CQC, 2022), and therefore leaves little room for variation. Unfortunately, hard floors inhibit conversation and increase unwanted noise from loud footsteps and moving furniture. Therefore, there would be value in educating residential and nursing home governing bodies since the quality of life for residents should encompass their remit of “quality”. There are potentially significant efficiencies in creating a culture conducive to meaningful communication, not only in terms of residents’ quality of life but also in physical structures and design of homes, and reductions in work-related stress and staff turnover.

Employee attitudes towards hearing care and their training levels are crucial. Staff members frequently lack expertise in maintaining hearing aids (Cohen-Mansfield and Taylor, 2004; Solheim et al., 2016). As a result, they may avoid hearing care for residents or rely on family members or visitors to do it. Poor communication between care staff and outside professionals, a lack of staff involvement because, for example, policies do not place enough importance on the significance of hearing impairment, a lack of adequate knowledge and training, and a low priority is given to managing hearing loss especially in comparison to other demands may also hinder the management of tinnitus and hearing loss in care home settings (Wittich et al., 2018).

The concept of care home volunteers should also be explored. Volunteering within health and social care is distinctly different from paid care workers volunteering their time beyond their usual shifts to provide further care (Saunders et al., 2019). Whilst the latter may be considered the norm nowadays because of the political landscape within health and social care and continued decline of workforce (Charlesworth and Baines., 2015), this will not be discussed within the remit of these recommendations. Volunteers could provide uninterrupted, and invaluable social support to residents (Cameron et al., 2022). The purpose of the volunteers would be to engage in meaningful conversation with residents to promote social interaction. The conversations could either be held one-to-one or in small groups, preferably in quieter areas of the homes. The regular presence of volunteers within a residential care setting could be comforting and familiar to residents, especially for those who do not receive regular (or any) visitors.

A recent study reported the role of volunteers as “something extra” to what is provided by paid care workers (Johnson et al., 2022). This is most probably a view held by many in relation to the role of volunteers, but what’s striking is how the “something extra” is defined and described by care home stakeholders, in relation to boundaries between volunteers and care workers. The common occurring theme was “emotion work”. This of course is difficult to conceptualise and quantify. The authors found that the emotional work of building relationships and having

meaningful conversations with residents, was considered outside of paid care work. These findings are further supported by the work of Campbell et al. (2020) in their evaluation of person-centred care in people living with dementia. That's not to say paid care workers do not perform these activities, it's that these activities are largely undervalued, and may be easier to perform by volunteers given the time and energy required (Johnson et al., 2022). Therefore, the setup of volunteering would need to be carefully considered.

Finally, residential care links with audiology services need to be vastly improved. This could begin with regular visits from Audiologists to do hearing screening tests on willing residents, repair and maintenance work for hearing aids and other assistive listening devices and provide recommendations to the care home management on improving the acoustic environment. Further work would involve training care home staff on effective communication strategies, and basic repairs for hearing aids. Whilst the latter is already taking place (AoHL, 2018b), it is of little value if the access to Audiology services is so restricted to begin with. It may be surprising that hearing aids as an intervention have not been at the forefront of the recommendations. This is because they are largely unsuitable in care home environments, as I have witnessed from the planning and engagement work, and ethnographic observations. The unsuitability is not only because of the noisy communal environments, making unwanted noises louder. It is also because of the difficulties that a person living with dementia may experience in processing complex sound signals through a hearing aid. There is certainly a place for hearing aids within care homes, but the context and person need to be adequately suited.

These recommendations are reinforced as a priority area for health and social care research as per the most recent version of the Department of Health and Social Care's Area of Interest document (2023). This document explicitly states the need for research outputs to improve access to health services and ensure that the social care system can deliver the best outcomes for people. This, in part, can be achieved by investing in the social care workforce training.

8.8 Conclusion

The original and novel contribution of my three empirical pieces of research have enriched the literature and understanding of the role of social isolation in older adults living with hearing loss and dementia. This work has comprehensively deciphered the mechanisms contributing to and maintaining social isolation in residential care settings. Future research will focus on the groundwork to develop an intervention package to help reduce social isolation in residential care settings. This will involve stakeholder participation for co-design

and co-operative inquiry. Therefore, creating a positive contribution to policy on how to encourage social connectedness and engagement for residents with communication loss.

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APPENDICES

Appendix 1 – Evidence of academic scholarship during PhD

Publications

Book chapter – in print. Pryce, H. and Dhanda, N. Older People and Hearing in Older People and Nursing Redfern 5th edition 2023 - ISBN: 9780702082467.

Journal article currently under peer review with BMC Geriatrics – Dhanda N. and Pryce H. The role of social isolation in older adults living with hearing loss and dementia in residential care settings.

Systematic review/meta-analysis and epidemiological analyses to be submitted for publication imminently.

Media

Podcast guest – “The Methods Matter Podcast - from Dementia Researcher & the National Centre for Research Methods. Specialist topic on grounded theory: [Dementia Researcher: Methods Matter - Grounded Theory on Apple Podcasts](#)

Blog contributor – National Institute of Health Research Enabling Research in Care Homes (ENRICH) - Keeping in touch with your care home collaborators through Covid-19: [Keeping in touch with your care home collaborators through Covid-19 | ENRICH \(nhr.ac.uk\)](#)

Conference presentations

Hearing Therapy Conference (oral), Birmingham UK (September 2022)

Intensive Programme on Audiology across Borders Conference (oral), online international (January 2021)

British Academy of Audiology (poster), Liverpool UK (November 2019)

Interdisciplinary Conference (oral), Aston University, UK (March 2019)

British Society of Audiology (poster), Wolverhampton UK (June 2018)

Award

Aston University 3-minute thesis (3MT) competition, second place (2019)

Training

Introduction to Epidemiology at University of Bristol (February 2019)

Mixed Methods Course at University of Oxford (April 2017)

PhD-related roles

Member of DemiQual – Qualitative research in Dementia (UK research network group), since 2021

Cognition in Hearing Committee Member, British Society of Audiology (2021-22)

Equality, Diversity and Inclusion Committee Member. British Academy of Audiology (2021-22)

Graduate School Student Representative for College of Health and Life Sciences, Aston University (2019-20)

Appendix 2 – Risk of Bias Questions and Scoring for Systematic Review and Meta-analysis

Question Number	RTI Question
1	Study design
2	Inclusion/exclusion criteria in cohort study
3	Inclusion/ exclusion criteria of sub-study clearly stated?
4	Inclusion/ exclusion criteria measured using valid and reliable measures?
5	Level of detail in describing the exposure? Who did it/ test environment/ equipment used/ level of training
6	Are important outcomes pre-specified by researchers?
7	Did researchers isolate the impact from an unintended exposure that might bias results?
8	Were outcome assessors blinded to exposure status?
9	Are exposures assessed using valid and reliable measures?
10	Are outcomes assessed using valid and reliable measures?
11	Is length of time following exposure sufficient to support evaluation of primary outcome?
12	Did attrition from any group exceed 30%?
13	Are confounding variables assessed using valid and reliable measures?
14	Were important confounding variables taken into account during design and/or analysis?
15	In cases of high loss to follow-up, is the impact assessed through sensitivity analysis?
16	Are any important primary outcomes missing from results?
17	Are statistics used to assess primary outcome appropriate to the data?
18	Are results believable taking study limitations into consideration?
19	Is the source of funding identified?
20	Any additional notes/comments?

See table on next page for detailed bias assessment scoring.

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20	
Alattar 2020	P	2	1	1	1	2	2	0	2	2	2	0	1	2	2	2	2	2	2	2	NA
Anstey 2003	P	2	1	1	1	2	1	0	2	2	2	0	1	2	2	2	2	2	2	2	NA
Armstrong 2018	P	2	1	1	1	2	2	0	2	2	0	2	2	2	2	2	2	2	1	2	NA
Croll 2021	P	2	2	2	2	2	2	0	2	2	0	0	2	2	2	2	2	2	2	2	NA
Deal 2017	P	2	2	1	1	2	2	0	2	2	1	0	2	2	2	2	2	2	2	2	NA
Fischer 2016	P	2	2	2	1	2	2	0	2	2	2	2	2	2	2	1	2	2	2	2	NA

Gallacher 2012	P	1	1	2	2	2	1	0	0	2	2	0	2	2	2	2	2	1	2	Analysed change score – not appropriate
Ge 2020	P	2	2	2	1	2	1	0	0	2	1	2	2	2	2	1	2	2	2	NA
Hong 2016	P	2	0	1	1	0	2	0	2	0	2	0	2	2	0	0	2	1	2	NA
Lin 2011	P	2	2	2	1	2	2	0	2	2	2	0	2	2	0	2	2	2	2	NA
Lin 2013	P	2	2	2	1	2	1	0	2	2	1	2	2	2	2	2	2	2	2	NA
Lindenberg er 2009	P	1	0	0	0	2	2	0	2	2	2	0	2	1	0	2	1	1	2	NA
Okely 2019	P	2	1	2	2	2	2	0	2	2	0	2	2	2	2	2	2	1	2	NA

Uchida 2016	P	1	2	2	1	2	2	0	2	2	2	0	2	2	0	2	2	2	2	NA
Valentijn 2005	P	2	2	2	0	2	2	0	2	2	1	2	2	1	2	2	2	2	2	NA

Key: P = prospective, 0 = No, 1 = Partially, 2 = Yes, NA = not applicable

Appendix 3 – Environmental audit proforma used in ethnographic work at care homes A and B

	Current Situation	Changes Recommended
Is there a sound field and/or loop in the room?		
Are hearing maintenance kits and schedules easily available?		
Are there quiet rooms or areas for relaxing?		
Is there accessible information about the needs of individuals with hearing impairment?		
Is there an echo when a sound is made?		
Are there soft furnishings in the room?		
Are there acoustic ceiling or wall tiles?		
Are tables, shelving, storage covered to reduce noise?		
Are there carpets in the room or is flooring low echo?		
Are there curtains or blinds?		
Do doors fit well and have an acoustic seal?		
Is there double/triple or single glazing?		
Are ceilings high or low?		
Do all chairs and tables have rubber feet? Are they intact?		
What sounds are in the communal and dining rooms?		
What sounds are coming from outside the communal areas?		
What sounds are coming from outside the home?		

RESEARCH VOLUNTEERS WANTED

We are interested in the links between a person living with hearing loss and dementia, and being socially isolated.

If you choose to take part as a **resident** or **care staff member** then you will be observed doing your usual day-to-day activities, with some short interviews in between.

If you choose to take part as a **relative** then you will be interviewed once only, lasting up to one hour and may be observed whilst visiting your relative in the care home.



**For more information please contact Nisha Dhanda
on 0121 204 5001 or email n.dhanda1@aston.ac.uk**

Nisha is a researcher at Aston University.



Exploring the role of social isolation in people living with hearing loss and dementia, within residential care settings

Consent Form (Resident)

Name of Principal Investigator: Nisha Dhandra

Please initial boxes

1.	I confirm that I have read and understand the Participant Information Sheet (Version 1, 02/09/19) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	
3.	I agree to my personal data and data relating to me collected during the study being processed as described in the Participant Information Sheet.	
4.	I understand that if during the study I tell the research team something that causes them to have concerns in relation to my health and/or welfare they may need to breach my confidentiality.	

5.	I agree to observations being recorded on paper, to be used for later analysis.	
6.	I agree to my interview being audio recorded, to be used for later analysis.	
7.	I agree to be quoted directly if my name is not published and a made-up name (pseudonym) is used.	
8.	I agree to take part in this study.	

Name of participant

Date

Signature

Name of Person receiving
consent.

Date

Signature

Exploring the role of social isolation in people living with hearing loss and dementia, within residential care settings

Consent Form (Staff)

Name of Principal Investigator: Nisha Dhandra

Please initial boxes

1.	<p>I confirm that I have read and understand the Participant Information Sheet (Version 1, 02/09/19) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</p>	
2.	<p>I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.</p>	
3.	<p>I agree to my personal data and data relating to me collected during the study being processed as described in the Participant Information Sheet.</p>	
4.	<p>I understand that if during the study I tell the research team something that causes them to have concerns in relation to my health and/or welfare they may need to breach my confidentiality.</p>	

5.	I agree to observations being recorded on paper, to be used for later analysis.	
6.	I agree to my interview being audio recorded, to be used for later analysis.	
7.	I agree to be quoted directly if my name is not published and a made-up name (pseudonym) is used.	
8.	I agree to take part in this study.	

Name of participant

Date

Signature

Name of Person receiving
consent.

Date

Signature

Exploring the role of social isolation in people living with hearing loss and dementia, within residential care settings

Consent Form (Relatives)

Name of Principal Investigator: Nisha Dhandra

Please initial boxes

1.	<p>I confirm that I have read and understand the Participant Information Sheet (Version 1, 02/09/19) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</p>	
2.	<p>I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.</p>	
3.	<p>I agree to my personal data and data relating to me collected during the study being processed as described in the Participant Information Sheet.</p>	
4.	<p>I understand that if during the study I tell the research team something that causes them to have concerns in relation to my health and/or welfare they may need to breach my confidentiality.</p>	

5.	I agree to observations (if any) being recorded on paper, to be used for later analysis.	
6.	I agree to my interview being audio recorded, to be used for later analysis.	
7.	I agree to be quoted directly if my name is not published and a made-up name (pseudonym) is used.	
8.	I agree to take part in this study.	

Name of participant

Date

Signature

Name of Person receiving
consent.

Date

Signature

Exploring the role of social isolation in people living with hearing loss and dementia, within residential care settings

Participant Information Sheet

Invitation

We would like to invite you to take part in a research study.

Before you decide if you would like to participate, take time to read the following information carefully and, if you wish, discuss it with others such as your family, friends or colleagues.

Please ask a member of the research team, whose contact details can be found at the end of this information sheet, if there is anything that is not clear or if you would like more information before you make your decision.

What is the purpose of the study?

The reason for doing this study is to understand how and why people become socially isolated in care homes. It can be difficult to listen and concentrate in care homes when there are lots of different sounds and people around. This can be challenging for people living with hearing loss and dementia as their ability to communicate may not be as good as it used to. Research has shown that there are links between having hearing loss, dementia, and being socially isolated. It is therefore important to understand what the communication experiences of people who are living with hearing and dementia are in care homes, and whether social isolation exists.

Why have I been chosen?

We are interested in the experiences of residents who are living with hearing loss and dementia.

What will happen to me if I take part?

Firstly, you will meet with Nisha who will discuss the study in detail and give you the opportunity to ask any questions you may have. You do not need

to make a decision straight away. If you would prefer to discuss the study with friends and family before you make a decision then you will have the time to do so. Once a decision has been made to take part in the study, then you will be asked to sign a consent form.

Taking part in the study will involve you being observed at different times over a two-week period by the researcher. The observations will be between 7am-7pm, and will include your usual daily activities when you are with others in the home. For example, during meal times, group activities, and general lounging. During the observations you will also be asked to take part in short interviews in a quiet area of the home, where you will be asked questions about your day-to-day communication experiences.

Nisha will record observations on paper and interviews will be audio-recorded with a Dictaphone. All recorded data will be kept securely at the university, and to ensure that you cannot be identified, you will be given a made-up name.

Do I have to take part?

No. It is up to you to decide whether or not you wish to take part.

If you do decide to participate, you will be asked to sign and date a consent form. You would still be free to withdraw from the study at any time without giving a reason.

Will my taking part in this study be kept confidential?

Yes. A made-up name will be attached to all the data you provide to maintain confidentiality.

Your personal data (name and contact details) will only be used if the researchers need to contact you to arrange study visits or collect data by phone. Analysis of your data will be undertaken using coded data.

The data we collect will be stored in a secure document store (paper records) or electronically on a secure encrypted mobile device, password protected computer server or secure cloud storage device.

If Nisha sees or hears something that relates to your safety then she will tell the care home manager and follow the correct steps to report it. This may mean that information about you is no longer confidential.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from the study may help to increase the understanding of social isolation in hearing loss and dementia.

What are the possible risks and burdens of taking part?

The topics discussed during the interviews may be upsetting if you are recollecting unpleasant memories and feelings. If you find a topic upsetting then speak with Nisha, who will be able to support you.

What will happen to the results of the study?

The findings of the study will be summarised for you and other participants to read. They will also

be given to the care home managers, and published in an academic journal and/or presented at a scientific conference. There will be made-up names used for any direct quotations used in published materials so that you cannot be identified.

Who is funding the research?

This study is funded by Aston University, and will contribute to the award of a PhD.

Who is organising this study and acting as data controller for the study?

Aston University is organising this study and acting as data controller for the study. You can find out more about how we use your information in Appendix A.

Who has reviewed the study?

This study was given a favorable ethical opinion by the West Midlands – Coventry & Warwickshire Research Ethics Committee.

What if I have a concern about my participation

in the study?

If you have any concerns about your participation in this study, please speak to the research team and they will do their best to answer your questions.

If the research team are unable to address your concerns or you wish to make a complaint about how the study is being conducted you should contact the Aston University Director of Governance, Mr. John Walter, j.g.walter@aston.ac.uk, telephone 0121 204 4869.

Research Team

Mrs Nisha Dhanda (PhD Student)

0121 204 5001

n.dhanda1@aston.ac.uk

Dr Helen Pryce (Supervisor)

0121 204 4131

h.pryce-cazalet@aston.ac.uk

Thank you for taking time to read this information sheet. If you have any questions regarding the study please don't hesitate to ask one of the research team.



Aston University takes its obligations under data and privacy law seriously and complies with the General Data Protection Regulation (“GDPR”) and the Data Protection Act 2018 (“DPA”).

Aston University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study. Aston University will process your personal data in order to register you as a participant and to manage your participation in the study. It will process your personal data on the grounds that it is necessary for the performance of a task carried out in the public interest (GDPR Article 6(1)(e)). Aston University may process special categories of data about you which includes details about your health. Aston University will process this data on the grounds that it is necessary for statistical or research purposes (GDPR Article 9(2)(j)). . Aston University will keep identifiable information about you for 6 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information at www.aston.ac.uk/dataprotection or by contacting our Data Protection Officer at dp_officer@aston.ac.uk.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

Exploring the role of social isolation in people living with hearing loss and dementia, within residential care settings

Participant Information Sheet

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We would like to invite you to take part in a research study.

Before you decide if you would like to participate, take time to read the following information carefully and, if you wish, discuss it with others such as your family, friends or colleagues.

Please ask a member of the research team, whose contact details can be found at the end of this information sheet, if there is anything that is not clear or if you would like more information before you make your decision.

What is the purpose of the study?

The reason for doing this study is to understand how and why people become socially isolated in care homes. It can be difficult to listen and concentrate in care homes when there are lots of different sounds and people around. This can be challenging for people living with hearing loss and dementia as their ability to communicate may not be as good as it used to. Research has shown that there are links between having hearing loss, dementia, and being socially isolated. It is therefore important to understand what the communication experiences of people who are living with hearing and dementia are in care homes, and whether social isolation exists.

Why have I been chosen?

We are interested in the experiences and views of care home staff who interact with residents living with hearing loss and dementia. If you are a permanent member of staff within the home and are interested in taking part, then please speak to Nisha for more information.

What will happen to me if I take part?

Firstly, you will meet with Nisha who will discuss the study in detail and give you the opportunity to ask any questions you may have. You do not need to make a decision straight away. If you would prefer to discuss the study with friends and family before you make a decision then you will have the time to do so. Once a decision has been made to take part in the study, then you will be asked to sign a consent form.

Taking part in the study as a staff member will involve you being observed at different times over a two-week period by the researcher. The observations will be between 7am-7pm, and will include your usual daily activities when you are caring for residents within the home. For example, during meal times and group activities. During the observations you will also be asked to take part in short interviews in a quiet area of the home, where you will be asked questions about your day-to-day communication experiences. These will take place at convenient times for you, usually at the beginning or end of a shift.

Nisha will record observations on paper and interviews will be audio-recorded with a Dictaphone. All recorded data will be kept securely at the university, and to ensure that you cannot be identified, you will be given a made-up name.

Do I have to take part?

No. It is up to you to decide whether or not you wish to take part.

If you do decide to participate, you will be asked to sign and date a consent form. You would still be free to withdraw from the study at any time without giving a reason.

Will my taking part in this study be kept confidential?

Yes. A made-up name will be attached to all the data you provide to maintain confidentiality.

Your personal data (name and contact details) will only be used if the researchers need to contact you to arrange study visits or collect data by phone. Analysis of your data will be undertaken using coded data.

The data we collect will be stored in a secure document store (paper records) or electronically on a secure encrypted Dictaphone, password protected computer server or secure cloud storage device.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from the study may help to increase the understanding of social isolation in hearing loss and dementia.

What are the possible risks and burdens of taking part?

The topics discussed during the interviews may be upsetting if you are recollecting unpleasant memories and feelings about residents. If you find a topic upsetting then speak with Nisha, who will be able to support you.

If poor practice towards residents is seen or heard during observations or interviews, Nisha will inform the care home manager and follow the correct steps for reporting incidents.

What will happen to the results of the study?

The findings of the study will be summarised for you and other participants to read. They will also be given to the care home managers, and published in an academic journal and/or presented at a scientific conference. There will be made-up names used for any direct quotations used in published materials so that you cannot be identified.

Who is funding the research?

This study is funded by Aston University, and will contribute to the award of a PhD.

Who is organising this study and acting as data controller for the study?

Aston University is organising this study and acting as data controller for the study. You can find out more about how we use your information in Appendix A.

Who has reviewed the study?

This study was given a favorable ethical opinion by the West Midlands – Coventry & Warwickshire Research Ethics Committee.

What if I have a concern about my participation in the study?

If you have any concerns about your participation in this study, please speak to the research team and they will do their best to answer your questions.

If the research team are unable to address your concerns or you wish to make a complaint about how the study is being conducted you should contact the Aston University Director of Governance, Mr. John Walter, j.g.walter@aston.ac.uk or telephone 0121 204 4869.

Research Team

Mrs Nisha Dhanda (PhD Student)

0121 204 5001

n.dhanda1@aston.ac.uk

Dr Helen Pryce (Supervisor)

0121 204 4131

h.pryce-cazalet@aston.ac.uk

Thank you for taking time to read this information sheet. If you have any questions regarding the study please don't hesitate to ask one of the research team.

Aston University takes its obligations under data and privacy law seriously and complies with the General Data Protection Regulation (“GDPR”) and the Data Protection Act 2018 (“DPA”).

Aston University is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study. Aston University will process your personal data in order to register you as a participant and to manage your participation in the study. It will process your personal data on the grounds that it is necessary for the performance of a task carried out in the public interest (GDPR Article 6(1)(e)). Aston University may process special categories of data about you which includes details about your health. Aston University will process this data on the grounds that it is necessary for statistical or research purposes (GDPR Article 9(2)(j)). . Aston University will keep identifiable information about you for 6 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information at www.aston.ac.uk/dataprotection or by contacting our Data Protection Officer at dp_officer@aston.ac.uk.

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

Exploring the role of social isolation in people living with hearing loss and dementia, within residential care settings

Participant Information Sheet

Invitation

We would like to invite you to take part in a research study.

Before you decide if you would like to participate, take time to read the following information carefully and, if you wish, discuss it with others such as your family, friends or colleagues.

Please ask a member of the research team, whose contact details can be found at the end of this information sheet, if there is anything that is not clear or if you would like more information before you make your decision.

What is the purpose of the study?

The reason for doing this study is to understand how and why people become socially isolated in care homes. It can be difficult to listen and concentrate in care homes when there are lots of different sounds and people around. This can be challenging for people living with hearing loss and dementia as their ability to communicate may not be as good as it used to. Research has shown that there are links between having hearing loss, dementia, and being socially isolated. It is therefore important to understand what the communication experiences of people who are living with hearing and dementia are in care homes, and whether social isolation exists.

Why have I been chosen?

We are interested in the views and experiences of people who are related to residents of a care home who are living with hearing loss and dementia. If you have a friend or family member living at this care home, and you visit regularly then we would like you to take part. Please ask Nisha for more information.

What will happen to me if I take part?

Firstly, you will meet with Nisha who will discuss the study in detail and give you the opportunity to ask any questions you may have. You do not need

to make a decision straight away. If you would prefer to discuss the study with friends and family before you make a decision then you will have the time to do so. Once a decision has been made to take part in the study, then you will be asked to sign a consent form.

Taking part as a relative will involve one interview lasting up to an hour, in a private room. You may also be observed whilst you are visiting your relative.

Nisha will record observations on paper and interviews will be audio-recorded with a Dictaphone. All recorded data will be kept securely at the university, and to ensure that you cannot be identified, you will be given a made-up name.

Do I have to take part?

No. It is up to you to decide whether or not you wish to take part.

If you do decide to participate, you will be asked to sign and date a consent form. You would still be free to withdraw from the study at any time without giving a reason.

Will my taking part in this study be kept confidential?

Yes. A made-up name will be attached to all the data you provide to maintain confidentiality.

Your personal data (name and contact details) will only be used if the researchers need to contact you to arrange study visits or collect data by phone. Analysis of your data will be undertaken using coded data.

The data we collect will be stored in a secure document store (paper records) or electronically on a secure encrypted mobile device, password protected computer server or secure cloud storage device.

If Nisha sees or hears something that relates to a resident's safety then she will tell the care home manager and follow the correct steps to report it. This may mean that information about you or them is no longer confidential.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from the study may help to increase the understanding of social isolation in hearing loss and dementia.

What are the possible risks and burdens of taking part?

The topics discussed during the interviews may be upsetting if you are recollecting unpleasant memories and feelings about your relative. If you find a topic upsetting then speak with Nisha, who will be able to support you.

What will happen to the results of the study?

The findings of the study will be summarised for you and other participants to read. They will also be given to the care home managers, and published in an academic journal and/or presented at a scientific conference. There will be made-up names used for any direct quotations used in published materials so that you cannot be identified.

Who is funding the research?

This study is funded by Aston University, and will contribute to the award of a PhD.

Who is organising this study and acting as data controller for the study?

Aston University is organising this study and acting as data controller for the study. You can find out more about how we use your information in Appendix A.

Who has reviewed the study?

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What if I have a concern about my participation in the study?

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If the research team are unable to address your concerns or you wish to make a complaint about how the study is being conducted you should contact the Aston University Director of Governance, Mr. John Walter, j.g.walter@aston.ac.uk, telephone 0121 204 4869.

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West Midlands - Coventry & Warwickshire Research Ethics Committee

The Old Chapel
Royal Standard Place
Nottingham NG1 6FS

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

18 December 2019

Mrs Nisha Dhanda
Audiology Dept, Vision Sciences Building
Aston University
Birmingham
B4 7ET

Dear Mrs Dhanda

Study title: Exploring the role of social isolation in people living with hearing loss and dementia, within residential care settings
REC reference: 19/WM/0294
Protocol number: 288-2019-ND
IRAS project ID: 268453

Thank you for your letter of 17/12/2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion:

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

Notifying substantial amendments

Adding new sites and investigators

Notification of serious breaches of the protocol

Progress and safety reports

Notifying the end of the study, including early termination of the study

Final report

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Research Poster]	2	06 November 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Aston University Professional Indemnity]	1	01 August 2019
Interview schedules or topic guides for participants [Interview Schedule and Topic Guide]	1	18 July 2019
Letter from sponsor [Sponsor Letter]	1	30 August 2019
Other [Ethnography Proforma]	1	18 July 2019
Other [GCP Certificate]	1	05 March 2019
Other [Confirmation Email Anchor Holmpark]	1	18 July 2019
Other [Confirmation Email Tandy Court]	1	18 July 2019
Other [Confirmation Email Gracewell]	1	18 July 2019

Other [Confirmation Email Robert Harvey House]	1	18 July 2019
Other [Amanda Hall CV]	1	31 July 2019
Other [Nisha Dhanda CV]	1	18 July 2019
Other [Patient and Public Involvement Summary]	1	02 September 2019
Participant consent form [Consent Form for Relatives]	2	11 September 2019
Participant consent form [Consent Form for Residents]	2	11 September 2019
Participant consent form [Consent Form for Staff]	2	11 September 2019

Participant information sheet (PIS) [Residents]	3	17 December 2019
Participant information sheet (PIS) [Relatives]	3	17 December 2019
Participant information sheet (PIS) [Staff]	3	17 December 2019
REC Application Form [SC_Form_11092019]		11 September 2019
Referee's report or other scientific critique report [Qualifying Report]	1	26 April 2019
Research protocol or project proposal [Research Protocol]	2	11 September 2019
Research protocol or project proposal [Research Protocol]	3	06 November 2019
Summary CV for Chief Investigator (CI) [Helen Pryce CV]	1	17 May 2019
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Verbal Summary Sheet]	1	18 July 2019

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

19/WM/0294

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project. Yours sincerely

A handwritten signature in black ink, appearing to read "Dr. H. Brittain". The signature is written in a cursive style with a large, sweeping initial "H".

Dr Helen Brittain Chair

Email: NRESCommittee.WestMidlands-CoventryandWarwick@nhs.net

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Appendix 12 – Examples of email correspondence with participating care home

Anonymised email correspondence with care home managers

CARE HOME A

From: Dhanda, Nisha
Sent: 14 September 2018 15:38
To: XXX
Subject: Re: Aston University Research
Perfect see you Monday at 11am.
Regards,
Nisha

On 14 Sep 2018, at 15:22, XXX wrote:
Hello Nisha,

Monday 11am?

Kind regards,

XXX

From: Dhanda, Nisha [<mailto:n.dhanda1@aston.ac.uk>]
Sent: 14 September 2018 12:56
To: XXX
Subject: Re: Aston University Research

That would be great. I'm available all day Monday or Friday afternoon, if that's any good?
Regards,
Nisha

On 14 Sep 2018, at 12:53, XXX wrote:
Hello Nisha,

Thanks for your email. Perhaps we could arrange a meeting next week?

Kind regards,

XXX

From: Dhanda, Nisha [<mailto:n.dhanda1@aston.ac.uk>]
Sent: 14 September 2018 12:43
To: XXX
Subject: Re: Aston University Research

Hi XXX

The research I will be conducting will be sponsored by Aston University who abide by the appropriate regulations regarding data protection and privacy. Furthermore I will seek and obtain National Research Ethics Committee approvals of which the data falls under "legitimate use" for GDPR.

Having said that, research of this kind is relatively unaffected by GDPR as we always seek written informed consent from all participants and do not assume an 'opt-in' to data being retained. I have undergone training to obtain informed consent under the Mental Capacity Act, and have studied research ethics throughout my years as both a student and clinician.

Please do let me know if you have any further questions.

Regards,
Nisha

On 13 Sep 2018, at 13:17, XXX wrote:
Hello Nisha,

I am interested to hear how the project will meet DGPR and how you plan to obtain consent from our customers for the project to get the go-ahead.

Kind regards,

XXX

From: Dhanda, Nisha [<mailto:n.dhanda1@aston.ac.uk>]

Sent: 10 September 2018 14:07

To: XXX

Subject: Aston University Research

Dear XXX

Following our telephone conversation earlier, I am pleased to provide you with further details of myself and my research. I am a qualified Audiologist who is currently working within a teaching capacity at Aston University. In addition I am completing a PhD that will explore social isolation and loneliness amongst older adults who have hearing loss and dementia, living in residential care.

The first part of the project will involve me observing residents and carers within the care home setting in order to get a full understanding of the conditions in which the residents live and experience. I will then invite the residents, carers and their relatives to meet and discuss practical ways to reduce any loneliness, as well as helping to improve their communication. Once the strategies have been agreed, they will be trialled in the care home and monitored to see whether or not they are helpful.

I would be more than happy to meet you in person to discuss my research aims further, and answer any questions you may have.

I look forward to hearing from you.

Regards,
Nisha

CARE HOME B

From: XXX

Sent: 10 February 2020 16:24

To: Dhanda, Nisha <n.dhanda1@aston.ac.uk>

Subject: RE: Aston University Research

Hi Nisha,

I am good thanks. I hope you are well yourself.

Thanks for the information attached.

Kind regards,

XXX

From: Dhanda, Nisha <n.dhanda1@aston.ac.uk>
Sent: 10 February 2020 16:14
To: XXX
Subject: RE: Aston University Research

Hi XXX

Hope you're well. Really looking forward to starting on the 24th February. Please find attached the care home agreement that we both signed, which has now also been countersigned by our Pro-Vice Chancellor of Research.

Best,
Nisha

From: XXX
Sent: 05 December 2019 10:32
To: Dhanda, Nisha <n.dhanda1@aston.ac.uk>
Subject: RE: Aston University Research

Hi Nisha,

Yes that's fine, I will be busy in the afternoon so that would be perfect.

Kind regards,

XXX

From: Dhanda, Nisha <n.dhanda1@aston.ac.uk>
Sent: 05 December 2019 10:26
To: XXX
Subject: RE: Aston University Research

Hi Arianne

Many thanks for your reply. Shall we say 9am on 17th December?

Best,
Nisha

From: XXX
Sent: 05 December 2019 10:19
To: Dhanda, Nisha <n.dhanda1@aston.ac.uk>
Subject: RE: Aston University Research

Hi Nisha,

I hope you are well.

Yes been very busy organising a lot of stuff here.

I am available the 17th December at the moment.

Kind regards,

XXX

From: Dhanda, Nisha <n.dhanda1@aston.ac.uk>
Sent: 04 December 2019 10:44
To: XXX
Subject: RE: Aston University Research

Hi XXX

Hope you're well and getting into the festive spirit! Just wanted to let you know that I am within touching distance of getting all of my ethical approvals to begin data collection at the end of January 2020. Is it possible to come and meet with you in the next couple of weeks so that we can start putting some preliminary dates in the diary? I am available next Tuesday 10th December, Tuesday morning 17th December or Thursday morning 19th December.

Look forward to hearing from you.

Best,
Nisha

From: XXX
Sent: 15 July 2019 11:11
To: Dhanda, Nisha <n.dhanda1@aston.ac.uk>
Subject: RE: Aston University Research

Hi Nisha,

This is to confirm that I am happy for you to do your research here in Tandy Court.

If there's anything else I could do please let me know.

Kind regards,

XXX

From: Dhanda, Nisha [<mailto:n.dhanda1@aston.ac.uk>]
Sent: 15 July 2019 09:03
To: XXX
Subject: Aston University Research

Dear XXX

Can you please confirm that you are happy and willing to support the research I am proposing to conduct at XXX, subject to ethics approval?

This email will be used as part of my ethics application to show that I have research sites on board to support the work I am proposing.

Many thanks,

Nisha