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Chapter

When Hearing Loss Co-occurs with Dementia: Challenges and Opportunities in Diagnosis and Management

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Abstract

Both dementia and hearing loss are highly prevalent in older adults and often coexist, increasing the complexity of diagnosis and management of both conditions. As the population ages, an increasing number of people will experience both long-term conditions. The cause of the association is unclear, although there are several commonly proposed mechanisms. Within this chapter, we explore current challenges that exist in discriminating between symptoms and complications of hearing and cognitive difficulties, and how these factors can impact the identification and management of both conditions. Management options, including the role of audiology services and care, will be presented, and explored in context. As hearing loss has been identified as a potentially modifiable risk factor for dementia, contemporary research evidence will be highlighted, including the challenges associated with research study design and interpretation. We conclude by exploring opportunities in care, research, and knowledge exchange, offering new approaches to improve the quality of life of those living with both dementia and hearing loss and those who care for them. Throughout this chapter, we provide the perspectives of individuals who have personally dealt with these conditions, as well as the viewpoints of their caregivers. This helps us connect concepts and evidence with real-life experiences.

Keywords: dementia, hearing loss, multimorbidity, audiology, interprofessional care

1. Introduction

1.1 Overview of dementia

Dementia is a clinical syndrome caused by a range of diseases of the brain. It is characterised by cognitive impairments, most typically affecting memory, and functional limitations, such that a person starts to have difficulty managing their everyday life. The most common cause of dementia is Alzheimer's disease, which accounts for 60–70% of cases; other important causes are vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Dementia may also be associated with a variety of neurological disorders (e.g., Parkinson's disease) [1, 2].

Dementia is strongly associated with increasing age, and the prevalence rate of dementia rises exponentially from mid-life to above the age of 80. Nonetheless, dementia is not caused by ageing per se, as it requires some form of brain pathology before it occurs. As a result of the growing ageing global population, numbers of people with dementia are increasing and will continue to do so, especially in low- and middle-income countries. For example, the current estimated number of people with dementia in the United Kingdom (UK) is over 900,000, increasing to 1.6 million by 2050 [3], whereas globally these figures will rise from 50 million to 150 million in the same period [4].

Dementia most typically presents with memory problems, noticed either by the person themselves or by those around them, but other early symptoms may include word-finding difficulties or problems with day-to-day functioning (e.g., getting lost, inability to maintain activities, such as hobbies or attending to email). A person may become socially withdrawn or may experience changes in their mood (e.g., anxiety or depression). As dementia progresses, functional impairment may become more severe, so that help is required with personal care tasks. There may also be changes in perception and behaviour, such as hallucinations, agitation, aggression, or apathy [5]. Eventually, dementia may lead to death, often through pneumonia if the person's swallowing reflex is impaired. In the UK, most people with dementia continue to live at home, however some individuals who require additional support may transition into residential or nursing home care.

Dementia is usually diagnosed in specialist memory clinics, with a combination of clinical, cognitive, and radiological assessment (CT or MRI scans). More specialised investigations may be undertaken, e.g., other scans or tests for Alzheimer's biochemical markers in blood or cerebrospinal fluid. These are likely to become more widely used in future. There are no curative treatments for disorders like Alzheimer's disease, though recently anti-amyloid monoclonal antibodies (aducanumab and lecanemab) [6, 7] have been shown to be of some benefit. However, these treatments require hospital administration and intensive follow-up, so are unlikely to be in general use, without massive increases in resources. Otherwise, treatment and care is supportive, including cholinesterase inhibitors (e.g. donepezil), treatment of other symptoms like depression, and provision of supportive social care, including activities and carer support.

Where cognitive decline is present but not sufficient to impact everyday life, this is referred to as 'mild cognitive impairment (MCI)', which can be a precursor to dementia, but does not always lead to dementia. The focus of this chapter is dementia, though some of the literature cited and recommendations provided may also apply to MCI.

1.2 Overview of hearing loss, cognitive impairment, and dementia

Hearing loss increases in both prevalence and severity with age. However, it is not necessarily an inevitable accompaniment of ageing, with many lifestyle factors contributing to its' development [8]. There is a greater prevalence of cognitive impairment, such as dementia and cognitive decline, in people with hearing loss, compared to those without hearing loss [9, 10], with one study finding the majority of people attending a memory clinic for concerns related to dementia were experiencing hearing loss [11].

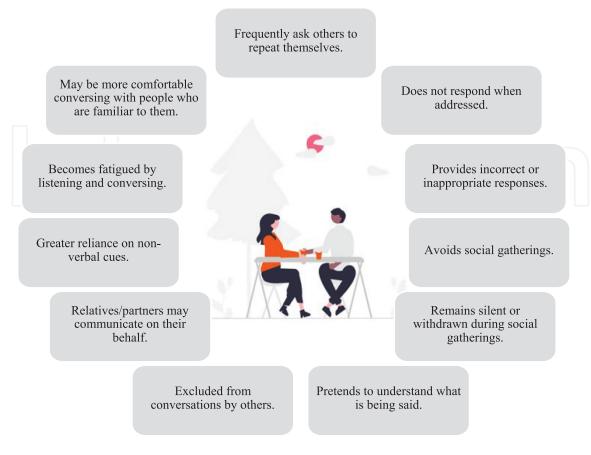


Figure 1.

Social interaction difficulties common to hearing loss and dementia.

Although a key symptom, and perhaps the most recognisable one of dementia, is memory loss, some symptoms of dementia may also be indicative of hearing loss. For example, in dementia, difficulty following conversations and needing others to repeat information is common; understanding speech may be impaired over and above any difficulties in understanding written words [12]. Similarly, key features of gradual hearing loss include difficulty following conversation in noisy environments and asking people to repeat what they said [13]. Difficulties with social interaction are common across both dementia and hearing loss (See **Figure 1**) [14–16]. In people with dementia, family members and carers may misinterpret these difficulties, attributing them solely to dementia rather than a potentially correctable hearing problem [17, 18]. Therefore, people living with hearing loss and people living with dementia may experience similar challenges, making it difficult to tell which is the cause, especially in those who live with both conditions.

Both hearing loss and dementia are associated with increased risks of the same negative outcomes or symptoms and have shared risk factors [16]. For example, they are both associated with increased frailty [19, 20]; falls [21, 22]; depression [23, 24]; social withdrawal [25, 26]; and a reduction in quality of life [27, 28]. Dementia and hearing loss can both lead to third party disability, in which the individuals' relatives or carers are also negatively affected, for example, through having to take time to support the individual, repeat things, and experience difficulties dealing with their loved ones' denial, resulting in greater burden, and reduced socialising and quality of life [29, 30]. Hearing loss may also exacerbate the behavioural and psychological symptoms associated with dementia [12], such as depression, agitation, confusion,

and withdrawal. There is a risk of missing the impact of hearing loss on these factors, which may be erroneously attributed entirely to cognitive impairment [31, 32].

1.3 What mechanisms link hearing loss and dementia?

It is important to ask *how* hearing conditions contribute to cognitive impairment and dementia, not only to allow better understanding of the mechanisms at work but also to consider what therapeutic means may be useful. It is also important to consider the intimate linkage between the ear at the periphery and the central auditory processing activities of the brain. As ear and brain are linked by complex auditory pathways, they should be regarded as a whole system and not as separate entities [33]. It is noteworthy that the medial temporal lobe is a crucial meeting place for central auditory processes but also an area of the brain vulnerable to neurodegenerative processes such as Alzheimer's disease [34].

There are several hypotheses linking hearing and cognitive impairment. The first of these is that impaired hearing leads to increased cognitive demand, which is the degree of brain activity required to process cognitive tasks, such as following other people's voices [35]. In short, if you cannot hear, your brain has to work harder all the time. The effort to hear diverts processing power from other areas of activity, such as memory [36]. Eventually, this leads to a permanent depletion of cognitive reserves, though the hypothesis is perhaps vague on what the brain mechanisms underlying this may be.

The second hypothesis is that cognitive impairment results from sensory deprivation. A person with hearing loss may fail to detect auditory stimuli or else receive them in degraded form (if you cannot hear, you miss much information in your environment). This idea emphasises the impoverished auditory input rather than the increased auditory effort in the first hypothesis. It is suggested that this leads to permanent changes in brain structure and function in the auditory cortex and related brain areas, such as the hippocampus [34].

The third hypothesis suggests that there may be common cause of neurodegeneration in brain and auditory pathways. This may be the result of an underlying pathological process, for example vascular or Alzheimer's disease [37], that can affect brain areas involved in cognition and auditory processing as well as peripheral structures such as the cochlea.

The fourth hypothesis emphasises the importance of central auditory function. Central auditory dysfunction, or central auditory processing disorder, is the result of changes in the auditory processing network, which in turn lead to impaired auditory perception and speech communication [38]. It may affect around 15% of older people with acquitted hearing loss [39] and affected individuals show markedly poor perception of speech-in-noise relative to their performance on pure tone audiometry. Central auditory dysfunction may result from brain pathology, such as amyloid and tau, typical of Alzheimer's disease. People with Alzheimer's disease show evidence of central auditory dysfunction, and this may be present for several years before diagnosis [40].

The fifth hypothesis relates to social isolation and withdrawal (which can result from either hearing loss or cognitive changes but is exacerbated by the two occurring together). Social isolation is in itself a risk factor for dementia [4], which may result from the effects of decreased cognition activity and/or the effects of physical problems associated with isolation, such as heart disease and depression.

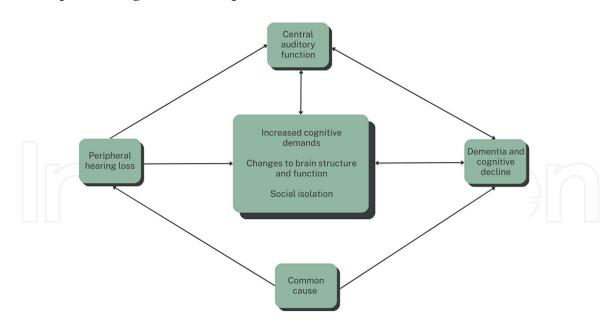


Figure 2.

Proposed framework: How hearing loss relates to dementia and cognitive decline. Adapted from [41]. This diagram offers a potential framework for understanding the connections between peripheral hearing loss and dementia/cognitive decline. The central box shows hypothesised causal pathways. A common cause (e.g., systemic vascular disease or genetic factors) may also lead to both peripheral hearing loss and dementia/cognitive decline. In addition, central auditory function may feature as a result of direct and indirect effects from the causal pathways and could serve as a marker of dementia/cognitive decline. One or more of the pathways shown may explain the association between peripheral hearing loss and dementia/cognitive decline.

It is of course conceivable that more than one mechanism may operate, or different individuals will be affected in diverse ways. These hypotheses are relevant to how hearing interventions might work. For example, it might be expected that hearing loss intervention (hearing aids or cochlear implants) would be effective against cognitive load or social withdrawal, but not against central auditory dysfunction (**Figure 2**).

2. Diagnosis

2.1 Identification of dementia and hearing loss

2.1.1 Timely diagnosis of dementia and hearing loss

Timely diagnosis of dementia and of hearing loss is important, as this enables access to information and support at the right time so that the affected individual can access suitable treatments as early as possible [42, 43]. This is particularly important as some treatments may be more effective at earlier stages, for example, nonpharmacological therapies such as cognitive stimulation therapy for dementia [44]. Hearing loss in mid-life is associated with increased risk of dementia, accounting for ~8% of all cases [4]. Whilst people with unaddressed hearing loss are at greater risk of dementia (estimated at 2x, 3x and 5x the risk for those with untreated mild, moderate, and severe hearing loss respectively) [45], those who use hearing devices may not be. Providing hearing aids or cochlear implants as early as possible could potentially help delay or reduce dementia risk [46] and might even lead to improved cognitive performance in the short-term [47]. Additionally, diagnosis enables both the individual and their family and friends to gain an explanation and understanding of what is happening, resulting in emotional and social benefits, which could result in cost savings for individuals and governments [48, 49].

Without routine screening for dementia and hearing loss in the populations at risk, timely diagnosis relies on individuals identifying symptoms and then accessing healthcare services for support. However, evidence shows that people delay seeking diagnosis or support for both dementia and hearing loss. One longitudinal study found that there was an average delay of almost nine years between an individual becoming eligible for a hearing aid (as confirmed via audiometric testing) and adopting hearing aids [50]. Delays in help-seeking are also present in people with dementia, with one in four people in the UK waiting over two years since symptoms were first experienced to seek a diagnosis from a healthcare professional [51]. This finding is consistent across Europe, where there is, on average, a gap of over a two-years between symptoms first being noticed and receiving a formal diagnosis, with almost half of carers wishing this diagnosis had been made sooner [52]. Help-seeking inequalities exist across people with dementia and hearing loss. For example, people from minority ethnic backgrounds are at greater risk of delay in seeking diagnosis for cognitive impairment [53] and treatment for hearing loss [50].

2.1.2 Seeking diagnosis

Potential reasons why individuals delay seeking a diagnosis of hearing loss and dementia struggle are multifaceted. As age-related hearing loss occurs gradually, individuals may not initially realise that it is affecting them. People with dementia may lack insight into their own cognitive difficulties. In both cases, diagnosis may rely others to point out the problem, and require the individual to have the willingness and ability to respond to this concern [54, 55]. Furthermore, both hearing loss and dementia continue to carry stigma, which may affect help-seeking [49, 56]. For people seeking help for memory problems, there may be concerns about how a diagnosis might change their relationships and cause others to worry or treat them differently [56]. Perceptions about inaccessibility or unaffordability of services (particularly in countries without free healthcare) can significantly contribute to delayed helpseeking [57]. Having a rarer type of dementia is associated with an increased delay in help-seeking. A lack of awareness and misconceptions, such as a belief that symptoms are a normal part of ageing and that there is nothing to be done, are commonly cited reasons for not seeking help sooner [51, 52, 57]. Reasons for delayed help-seeking for hearing loss may overlap with that for dementia, such as beliefs around the limited benefits of intervention, though evidence is conflicting and sparse, with less research investigating reasons for delaying help-seeking itself, as the majority of studies focus on the uptake of hearing aids [58].

"What you've got here really is a... double whammy in that there's so much negativity around... hearing loss in general that it's... seen still as a kind of a weakness. People don't think twice about wearing glasses now, but they would think twice about wearing hearing aids... You almost [need to get] over that... negativity about hearing loss before you can even deal with... the cognitive... loss as well, so I can see why people will just kind of run away screaming from... the idea of either of them."

59-year-old woman with hearing loss and tinnitus (Broome et al., [59], page 8)

Fear of stigma, alternative beliefs about aetiology, lack of trust in health care systems due to discrimination and injustices, and lack of culturally appropriate care may also contribute to disproportionate reluctance to seek help in people from minority ethnic backgrounds [60, 61]. Similarly, previous research has shown that LGBTQ+ carers may avoid seeking help due to concerns about discrimination [62]. Less is known about reasons for delayed help-seeking for hearing loss in underserved groups, though one study of paediatric services similarly identified stigma and additionally identified a disparity in expectations of treatment based on experiences from their home country as barriers to help-seeking [63].

2.1.3 Public awareness of dementia and hearing loss

Both dementia and hearing loss can be 'hidden' conditions, meaning that they are not always recognised, understood, or accommodated for by communities and groups that are unaware of their presence. Given the reliance on individuals seeking help for symptoms of dementia and hearing loss, it is important to educate and raise awareness of these conditions and educate members of the public so that they are empowered to seek help [49]. For example, dispelling myths about dementia may include education around memory loss not being the only symptom, and both symptoms of dementia and hearing loss not being a normal part of ageing, but something that people can and should seek support for. Education about dementia and hearing loss should also include information about where to seek help, ensuring the recommended services are accessible. However, it may be important to additionally educate members of the public and clinicians about the link between dementia and hearing loss, how the two may mask one another, and how preventing or managing hearing loss may help reduce dementia.

"I never, ever... thought that hearing loss would be associated with a cognitive impairment... People should be made more aware of that rather than wait until it's too late and by the time you actually get a... diagnosis, you may well be in the stages where you're not aware enough to actually do anything about it."

72-year-old man with tinnitus (Broome et al., [59], page 6)

2.1.4 Challenges in diagnosis

In addition to being a barrier for the identification of dementia and/or hearing loss by individuals or their carers, common or overlapping symptoms can also impede the help-seeking process. For example, when individuals do decide to seek help for their symptoms, receiving a diagnosis for hearing loss and/or dementia may be more difficult when the two conditions co-occur.

Most primary care providers (such as family doctors) assess patients for cognitive impairment if the patient or family report symptoms. If the assessment indicates a problem, they will refer the patient to see a specialist. However, sometimes family doctors report choosing not to assess patients for cognitive problems due to concerns about the impact of a diagnosis on the patient, or concerns about limited treatment options [48]. Furthermore, as many as one in five people who express concerns about hearing loss to their primary care provider do not receive a referral for further assessment [64]. Sometimes, providers might have insufficient knowledge about hearing loss, which can lead to them to normalise or minimise its importance and impact, particularly when hearing loss is 'mild,' or to assume that it cannot be effectively treated [54, 64].

"My hearing [loss] results in a lot of information in conversations being incomplete and or inaccurate as I rebuild and guess at missing words. So poor memory can be seen as the issue where my memory is ok but the original information, I heard is inaccurate. Someone not recognizing this could make incorrect assumptions resulting in a poor and misleading diagnosis."

67-year-old man with hearing loss (Broome et al., [59], page 8.)

Even when referral to secondary care for further assessment is achieved, making a diagnosis of both hearing loss and dementia is further complicated by the overlap in symptoms. Hearing loss may be misdiagnosed as cognitive impairment or dementia [16, 31], and conversely cognitive impairment may first be diagnosed or dismissed as hearing loss.

Cognitive testing (both simple screening tests and more comprehensive cognitive assessments) for dementia typically relies on normal hearing, using verbal instructions and tasks. There is a growing body of literature that highlights how cognition may be underestimated if sensory impairments are not considered [65, 66]. Evidence suggests that people with hearing loss tend to perform worse than individuals with normal hearing on cognitive tests which are verbally administered [67]. Individuals with unidentified hearing loss (and even those with known hearing loss where adjustments are not made) may mis-hear key information and must work cognitive assessments, and possibly being mis-diagnosed with cognitive impairment [16, 36].

Attempts have been made to adapt cognitive tests to account for sensory impairment. For example, adaptions to the Mini Mental State Examination (MMSE, a popular screening tool for cognitive impairment) include administering screening questions on written flashcards [68] or excluding three verbally administered items [69]. Data from studies evaluating these adaptations suggest that they may be acceptable for people with hearing loss, though no improvement in performance occurred. Research has also been conducted to evaluate modifications to another popular screening tool, the Montreal Cognitive Assessment (MoCA). A visual version of the MoCA, developed by Dupuis et al., [65] which removed auditory items from the standard MOCA, demonstrated a higher pass rate in comparison to the standard MoCA. Finally, Dawes et al., [70] developed a validated, sensitive, and reliable version of the MoCA-H to identify dementia in adults with hearing loss. However, whilst scoring adjustments are advised for those with lower education (12 years or less), it is not clear how it performs in those with poor literacy or dyslexia, and it is not suitable for those with dual sensory loss [70]. There remains a need for standardised diagnostic tests which are reliable and valid in these populations to detect and monitor cognitive function.

The diagnosis of hearing loss in adults with MCI/dementia can represent a significant challenge for audiology services, though some recommendations have been developed (see **Box 1**). First, audiologists are advised to consider that patients may have dementia even if it is not mentioned in their referral letter, particularly because many do not receive an 'official' diagnosis of dementia [71]. People living with dementia have varied needs, and an individualised approach to audiological assessment is

recommended [71, 72]. This could entail testing in a familiar environment, such as the patient's residence, and involving carers/family in the assessment [71–73]. Whilst some people living with dementia can complete standard behavioural assessments (e.g., pure-tone audiometry, speech audiometry), others will require adaptations, such as reducing or increasing test duration, providing breaks, accepting responses other than button presses (e.g., verbal responses), and repeating the instructions throughout [71, 73]. The use of objective tests, including otoacoustic emissions or auditory evoked potentials (AEPs), is recommended in cases where behavioural tests are not possible [71]. The use of objective assessments is not without challenges; capacity to consent may be difficult to establish and the accuracy of cortical evoked potentials can be affected by level of alertness requiring observation by someone who knows the patient well and electrophysiological tests must be considered within the context of information from the patient and any other available test data [74]. If behavioural and objective testing are not possible, audiologists could review previous audiometric results, where available, and carry out a functional assessment with the patient and/or their relative carer to determine their communication abilities and needs and their potential to benefit from an audiological intervention [71].

2.2 A role for audiologists in screening cognition?

Understanding the extent of both hearing and cognitive factors is essential in developing an appropriate treatment plan [75]. Cognitive screening, through formal testing and hearing professionals asking relevant questions around cognitive status has been recommended a useful tool in adult audiology clinics to aid in the detection of cognitive impairment, longer-term care planning and the programming of hearing aid devices [73]. This could help ensure more timely diagnosis of dementia, and also help highlight and reduce any issues with undetected cognitive impairment interfering with hearing assessment and treatment. However, consideration should also be given to the practical implementation of cognitive screening, including whether this would be acceptable to and feasible for both patients and audiologists. The need for training and appropriate questioning or use of screening tools is particularly important in this context as the provision of cognitive assessment (including history taking) currently sits outside of the scope of practice for audiology professionals.

"Since I was carer for my mother who had Alzheimer's, I would be only too pleased to be assessed because the earlier the treatment the better if any is needed." 72-year-old woman with hearing loss

(Broome et al., [59], page 6.)

"Only if the audiologist had been suitably trained in dealing with a very sensitive topic."

75-year-old woman with hearing loss (Broome et al., [59], page 8.)

Recent qualitative research has suggested that patients perceive cognitive screening to be acceptable within adult audiology services [59]. However, the successful delivery of cognitive screening in adult audiology services relies upon audiologists being sufficiently trained and feeling comfortable enough to deliver and discuss such tests with a patient. Yet, a survey of hearing professionals in the United Kingdom on managing sensory and cognitive impairment in older adults highlighted limited awareness of cognitive screening tests and a lack of adequate training [76]. This clearly impacts practice as, in another UK survey, although 90% of audiologists reported a willingness to conduct cognitive assessments but only 4% did so, due to lack of training, time and resources [77]. Furthermore, as discussed previously, despite attempts to make screening tools suitable for people with hearing loss, there is still a lack of valid and reliable tests that can reduce the impact of hearing loss on cognitive screening which can be implemented in hearing clinics [78]. Ultimately, cognitive screening tests only demonstrate a snapshot view into an individual's cognitive ability at the time of administration. Thus, the results may be unreliable, particularly in populations who live with sensory impairment. There are other attributes which may impact testing scores such as level of education, age of patient and mood which should be taken into account.

There remains a clear need for recommendations around direct referral pathways, (mentioned briefly by Littlejohn et al., [73]), particularly criteria for onward referral of patients from audiology to memory care services. Implementing cognitive screening within adult audiology services is one step towards addressing the challenge of an ageing population living with comorbid disorders. However, this application requires careful consideration into the management and training within clinical settings, and may be better addressed through building links between audiology and memory services. Guidance on facilitating early detection and access to memory services is essential to support audiology professionals and patients with suspected MCI/ dementia.

2.3 A role for memory services in screening hearing?

Currently NICE [79] guidance recommends a referral to a memory clinic for suspected dementia, after an investigation of reversible causes of cognitive decline, including delirium, depression, and sensory impairment. It is unclear if hearing loss is investigated in all referrals to memory clinics, and in view of the evidence that adults with hearing loss often (i) do not acknowledge hearing loss and (ii) do not disclose hearing difficulties to their primary care provider [64], it is highly likely that many are not referred for audiological assessment. Once the patient is referred to a memory clinic, it is unlikely that they will receive a hearing assessment, as evidenced in a survey of professionals working in the UK National Health Service (NHS) memory services, in which only 4% reported performing hearing assessments within the clinic [77]. To address this gap, some NHS audiology services in England and Wales are piloting hearing assessments as a part of the memory clinic pathway. Initial findings indicate that service users who receive an audiological assessment as part of this pathway consider it a valuable part of their cognitive assessment, but also suggest that they may need additional information provision and follow-up appointments to maximise uptake and use of hearing aids [80].

3. Management of hearing loss

3.1 Improving care for people living with coexisting dementia and hearing loss

There has been much recent attention on understanding the link between hearing loss and dementia risk [4, 16]. A growing ageing population means that the prevalence of people living with chronic conditions is increasing, leading to an imbalance

between conditions and care [81]. While prevention (or risk-reduction) efforts are crucial, they alone are insufficient to address the pressing needs of individuals currently living with co-existing dementia and hearing loss and who urgently require appropriate and ongoing support. There is no standard system of care for people living with these long-term co-occurring conditions, and the co-existence of these conditions presents unique challenges in terms of management in health and social care settings [16, 72, 82]. To enhance the care and support rendered to individuals currently living with both dementia and hearing loss and their caregivers, as well as those who will go on to live with these conditions in the future, it is imperative that we draw from and build on existing research knowledge. This will enable us to better understand the complex interplay between dementia and hearing loss, identify effective interventions, and develop and implement comprehensive care frameworks.

3.2 Health and care services for adults with hearing loss and dementia

3.2.1 Audiology services for adults with dementia

Despite an awareness of associations between dementia and hearing loss, and the potential for hearing interventions to reduce the risk of dementia and improve outcomes in patients living with both conditions, there is limited peer-reviewed evidence around effective audiological practice for people living with, or at risk of, dementia. Furthermore, although a range of interventions for people living with dementia have been developed, many of them are auditory in nature and little is known about their effectiveness specifically in people who also live with hearing loss, despite the high prevalence of this co-morbidity. This is especially important to establish for the numerous dementia interventions that rely on hearing, such as music therapy, dance therapy, drama therapy/storytelling, reminiscence therapy, counselling, and peer support groups [83].

Work has commenced on the development of practice recommendations and models of care for co-existing dementia and hearing loss (See **Box 1**) [71–73]. Littlejohn and colleagues [73] developed International Practice Recommendations for the Recognition and Management of Hearing and Vision Impairment in People with Dementia using consensus methods with key stakeholders (including professionals and lay experts). They outlined recommendations according to six domains: awareness and knowledge, recognition and detection, evaluation, management, support, and services and policies. Those recommendations specific to the management of hearing loss in adults with MCI/dementia included advance provision of information about the appointment, adjusting appointment lengths and allowing for breaks, offering domiciliary appointments where appropriate, and including caregivers/family members in the appointment, such as by providing them with written instructions on hearing aid care and troubleshooting [73].

Dawes and colleagues applied Brooker and Latham's VIPS model of personcentered dementia care to hearing healthcare for people living with co-existing dementia and hearing loss. The key components of the VIPS model are (i) *valuing* people with dementia and those who care for them (e.g., ensuring audiology services are accessible to all, provide dementia training to staff) (ii) seeing the *individuality* of people living with dementia (e.g., develop an understanding of the individual to build trust and rapport, use preferred communication methods,), (iii) viewing the world from the *perspective* of the person (e.g., understand they may find hearing assessments intimidating or confusing, observe their non-verbal Prior to appointments

- Ensure the individual can be seen by an appropriately trained clinician.
- Consider appointments early in the day.
- Make contact after referral and ask about needs (communication/informational needs/format of information/accessibility/environment).
- Provide details about when and where the appointment will take place.
- Provide details about who the appointment will be with and what will happen.
- A recommendation that the individual is accompanied by a partner/spouse, family member or friend can be useful for both the individual and the clinician.
- Consider if there are any outcomes you can send in advance of the appointment for extended consideration (e.g., history taking).

During appointments

- Address the patient directly and assume capacity to consent, unless it has been confirmed otherwise.
- Consider whether a home visit is preferable and feasible.
- Keep the partner/spouse, family/friend visible.
- · Keep instructions short and clear, check for understanding.
- Be prepared to vary the length of the appointment as necessary. Allow for breaks.
- Adapt testing response modes and hearing aid fitting. This may be easier with two clinicians present to support with the detection of response.
- Gather most important information first.
- Consider slowing the pace of stimuli presentation, collecting fewer thresholds and/or automated tests of hearing thresholds.
- Consider using pulsed tones rather than pure tones to assist with alertness and orientation.
- Where standard behavioural hearing assessment is unsuccessful, consider functional or objective tests.
- Involve the partner/spouse, family/friend where necessary to support effective hearing diagnosis and treatment options.
- Do not rule out hearing aid technology or features for people with dementia Consider on an individual basis. However, hearing aids might not be suitable for all.
- Provide written instructions on hearing aid care and troubleshooting that can be shared with others.

Aftercare

- · Consider whether a home visit is preferable and feasible.
- Offer regular follow-up hearing assessments as part of a long-term care plan.
- Provide scheduled rather than opt-in follow-ups, with service/maintenance of any hearing devices where possible.
- Be flexible in approach and care over time to deal with any changes in cognitive and hearing status.
- Provide flexibility in how you deal with e.g., missed appointments and lost hearing devices.

For detailed person-centered recommendations for providing hearing healthcare to people with dementia, please see Dawes et al., [71] and Littlejohn et al., [73].

Box 1. Suggested adjustments to audiology and hearing services to benefit people with cognitive decline and dementia:

cues), and (iv) ensuring the person's *social* environment supports relationships and interactions that promote well-being (e.g., ensure they can invite a relative/carer to attend appointments, involve them in conversations even when communication is difficult) [71, 84].

The discussion of hearing services has largely been limited to evidence from high-income countries, particularly the USA and European nations, but dementia remains under-recognised, under-disclosed and undertreated in low- and middleincome countries [85], who also bear over 51% of the estimated \$981 billion costs of hearing loss [86]. Addressing dementia and hearing loss jointly may require different approaches to those adopted in high income countries, and research is urgently needed to identify tailored solutions in low- and middle-income contexts.

3.2.2 Residential care for adults with hearing loss and dementia

The majority of residents in long-term care homes (LTCHs) live with hearing loss [87]. Many of these residents experience communication breakdowns with staff and fellow residents, often stemming from environmental issues (e.g., background noise, poor lighting), over which residents may have little control [88, 89]. Consequently, residents with hearing loss frequently struggle to participate in social activities and group conversations, which can lead them to become isolated through exclusion or withdrawal. These difficulties are exacerbated in residents with co-existing hearing loss and dementia [88, 90]. This is a critical concern given that most LTCH residents who live with dementia likely also live with hearing loss, particularly hearing loss that is undetected, untreated, or under-treated [91–93]. Of those who do own hearing aids, usage is often low, and the devices commonly become broken or lost [94, 95]. The impacts of hearing loss on residents living with dementia can include increased agitation and behavioural disturbances, accelerated cognitive decline, depression, greater carer burden, and reduced quality of life [16, 95, 96].

Numerous barriers impede the provision of hearing healthcare to residents in LTCHs, especially those living with dementia [88, 89]. First, residents and staff may consider hearing loss to be a normal aspect of ageing and thus do not seek to address it [89]. Staff may also mistake hearing difficulties for cognitive difficulties [17, 97]. Furthermore, hearing loss is not prioritised in many LTCHs, and its prevalence is under-estimated [89, 98]. Additionally, LTCHs tend to have poor links with audiology services and to have few on-site hearing healthcare facilities or resources (e.g., assistive listening devices, hearing-friendly rooms) [76, 88, 89]. Moreover, LTCHs rarely undertake routine hearing checks or appoint hearing healthcare champions [96, 99]. Several studies highlighted the lack of LTCH staff training in hearing device management, communication tactics, and hearing loss awareness, identification, and assessment [89, 96, 97, 99]. Finally, the provision of hearing healthcare to residents living with dementia is especially challenging and time consuming. For instance, they may not tolerate hearing aids, forget to wear them, struggle to use them, or may not understand why they should wear them [89, 96, 99].

A range of strategies for improving hearing healthcare in LTCH residents with dementia have been proposed. Staff training and behaviour change is recommended so that they can recognise hearing loss and understand its consequences, adopt tactics to enhance communication, and support the use and maintenance of hearing devices [76, 93, 97]. Environmental modification is also recommended, such as by reducing background noise, implementing quiet hours or quiet activities, and using sound-absorbing materials [88, 89, 93, 97]. In addition, shifting from task-focused to person-centred care,

(e.g., personalised communication plans), and involving family members in hearing healthcare (e.g., changing hearing aid batteries, history taking, shared decisions) are advised [89, 93, 94]. Furthermore, practice guidelines for managing hearing loss in residents with dementia should be developed and implemented [76, 89]. Finally, strong leadership and institutional support are vital to improving hearing healthcare, particularly building relationships with audiology services and family physicians, implementing policy change, providing sufficient resources, and ensuring staff have the autonomy and training needed to provide empathetic, person-centred care [76, 89, 93, 97].

4. Opportunities for diagnosis and management

Delivering care to people living with dementia and hearing loss is complex. A comprehensive approach to care should therefore be adopted, encompassing timely diagnosis, appropriate treatment, and ongoing support [71, 82]. Many opportunities exist to improve the evidence-based care of those living with both dementia and hearing loss, spanning clinical practice, research, the health and care workforce, and effective sharing of knowledge.

4.1 Opportunities for health care services

Due to the high co-occurrence of hearing loss and dementia, both conditions cannot be diagnosed and managed effectively without acknowledging the potential for comorbidity [100]. Yet, clear and appropriate referral pathways between memory and audiology services are not often in place, and no standard best practice guidelines across services exist to ensure consistent care [77, 101]. Finally, clinicians often feel they do not have the right skills and knowledge to provide appropriate provision [102, 103]. Recently developed guidance supports the identification and management of hearing difficulties in people living with dementia [71, 73, 104]. However, there remain many unanswered questions about the best way to provide diagnoses and care to people living with dementia and hearing loss, both within and outside of hearing services. Additional evidence is required to inform best practice, whilst considering how interprofessional support can be adopted and streamlined to ease the burden on health and care services [103].

Because of the progressive nature of both conditions, guidelines for the management of hearing loss health and social care settings should include tailored training, flexibility to deal with the changing needs of the population over time, clear pathways for onward referral where necessary, and practical guidance for the joining-up of general, audiological, memory and geriatric services, as appropriate [37, 71, 94, 99]. In addition, it is imperative that consideration is given to the inclusion of individuals and communities typically underserved within healthcare. These can be defined as groups of individuals with lower inclusion than would be expected from population estimates, those with high healthcare burden that is not matched by the volume of healthcare resource designed for the group, and/or groups with important differences in how they respond to or engage with healthcare interventions, compared with other groups [105]. For example, the British Deaf Association (Scotland) produced a toolkit for people who use British Sign Language (BSL) and who are living with dementia, their families, and professionals who are supporting them. The primary aim of the toolkit is to help ensure that BSL users and their families have equal access to information and services for dementia and experience fair treatment [106].

4.2 Opportunities for research

Given the suggested beneficial role for hearing devices in the reduction of risk for cognitive decline and dementia in adults with hearing loss via the UK Biobank cohort [Jiang et al] and meta-analysis of published studies [47], further high-quality randomised controlled trials that seek to answer the question of whether hearing loss intervention can delay, reduce, or prevent cognitive decline or dementia are of paramount importance for researchers and clinicians. In the United States, the Ageing and Cognitive Health Evaluation in Elders (ACHIEVE) study was a randomised controlled trial designed to determine whether treating hearing loss in older adults could reduce cognitive decline that can precede dementia, compared with a health education control. Initial results showed that the hearing intervention did not reduce 3-year cognitive decline in the primary analysis of the total cohort. However, a prespecified sensitivity analysis showed that the effect differed between two different study populations that comprised the cohort, and that hearing intervention might reduce cognitive change over 3 years in populations of older adults at *increased risk* for cognitive decline [107]. The study was extended to examine longer-term outcomes.

However, trials of this nature present a number of challenges for the research community. First, withholding any hearing loss intervention from individuals identified as eligible and likely to benefit from them (e.g., to create a clinical trial control group) can be unethical if not appropriately managed and addressed. Linked to this, those in the control group who decide to obtain hearing intervention during the study period may need to leave the study [107]. Third, individuals who may benefit most from the intervention (i.e., for ACHIEVE, those at greater risk of cognitive decline and dementia) may not be the same individuals who volunteer take part in health research through standard recruitment routes. Finally, although a key goal for research in the field is to understand how hearing loss relates to dementia risk and to find treatments to reduce that risk, there is a current pressing need for research that addresses the challenges faced by the vast number of people who already live with both long-term conditions.

Incorporating the perspectives of people living with hearing loss and dementia, their caregivers, and healthcare professionals, across the entire research process, from design and conduct to dissemination, is crucial to fostering comprehensive and impactful outcomes in the realm of hearing loss and dementia. These stakeholders bring invaluable insights based on real-world experiences, which can greatly enrich the relevance and applicability of research findings [108]. Research priority setting exercises involving key stakeholders are important for identifying where research would make the most difference [109]. By involving patients and their caregivers, researchers can ensure that the research questions and methodologies resonate with the challenges they face on a daily basis [110], reducing waste in research, and ultimately yielding interventions that are more practical and effective. Involving healthcare professionals provides unique clinical perspective that aid in the translation of findings into actionable recommendations, bridging the gap between research and practice, and ensuring that the outcomes are not only scientifically rigorous but also relevant to the needs of the individuals receiving care. Collaboration among researchers, patients, caregivers, and healthcare professionals enhances the credibility and validity of research outcomes whilst facilitating ownership and shared responsibility in addressing the complex interplay between hearing loss and dementia. Yet the focus of research needs to be widened from single disease models to the complex challenges associated with managing and treating individuals with multiple long-term health conditions [100].

Priority setting exercises have previously been completed for both hearing (mildmoderate hearing loss in adults) [111], and dementia [112, 113] as individual conditions, but until recently, these have not been considered in combination. In 2023, a James Lind Alliance Priority Setting Partnership in co-existing dementia and hearing conditions was launched in collaboration with key charities: RNID and Alzheimer's Research UK [114] It is the first such partnership to bring together two specific disease areas. It involves identifying and prioritising research questions about the prevention, diagnosis, and management of these co-existing conditions. The partnership emphasises the need to consider hearing conditions other than hearing loss that are potentially important for people with dementia (such as tinnitus and hyperacusis). It also promotes the representation of individuals and groups who may be typically underserved in research (e.g., LGBTQ+ communities, unpaid carers, individuals from ethnic minority groups, people with lived experience of hearing loss and dementia, including those with early onset dementia and members of the Deaf community). Emerging priority research questions can guide research funders and commissioners, investigators, campaigners, and policymakers, to achieve tangible impact.

4.3 Opportunities for developing the health and care workforce

Taking a holistic, patient-centred care approach to the management of individual living with multiple health conditions is a challenge not only for dementia and hearing loss. For individuals experiencing a range of multiple long-term conditions, evidence has shown that integrated approaches to healthcare are more effective than services that address conditions on an individual basis [115–117]. Yet, hearing healthcare is still in its' infancy when it comes to integration with other healthcare services, largely due to organisational and financial constraints [115].

In the interim, important steps can be made to nurture holistic practices in hearing care. For example, the incorporation of training into curriculums for primary care providers (e.g., family doctors) on hearing loss in isolation *and* alongside cognitive impairment and dementia would serve to increase detection and onward referral, to support early diagnosis. A good example is provided by the Royal College of General Practitioners via their Deafness and hearing loss toolkit [118]. Furthermore, greater awareness and consideration of hearing loss by family doctors about the importance and common comorbidities of hearing conditions can help ensure that treatment and referrals are harmonised [100].

With an increasing number of people living with dementia and hearing conditions, there is a need to consider how to build capacity and support the development of a skilled clinical academic research workforce [119, 120]. There should also be an emphasis on supporting the development and delivery of research within dementia and hearing services to enable the growth of research activities for patient benefit. Identifying strategies to support professionals in conducting and delivering research is crucial, enabling them to contribute to advancing knowledge and improving clinical practices in these domains. The challenge is with increasing caseloads due to an ageing population [121], how can clinicians be supported to engage in both research and upskilling practices.

4.4 Opportunities for the sharing of knowledge

Efforts are urgently required to raise public awareness of dementia, of hearing loss, and of the importance of addressing declines in hearing to promote overall brain health [122]. Rather than focusing on dementia risk reduction, emphasising

the positive aspects of preserving and enhancing hearing can motivate people to take proactive measures, not only to safeguard against potential cognitive decline but to embrace a fuller and more connected life experience. Just as physical exercise is championed for its positive impact on overall health, nurturing auditory health through hearing care can be highlighted as a strategy to support lifelong cognitive vitality.

In addition to public health endeavours, the sharing of research needs, efforts and findings with patients and the public is paramount for bridging the gap between the scientific community and society. When people have access to credible and evidence-based information, they are more likely to trust medical recommendations and follow best practices [123]. Enhanced public dissemination of research fosters transparency and greater awareness of emerging health treatments, enabling individuals, and their families to make informed decisions about their ongoing healthcare.

5. Conclusions

Within this chapter, we have explored the multifaceted challenges that exist in discriminating between symptoms and complications of hearing and cognitive difficulties and how these impact patient research and care. Insights from those with lived experience of hearing loss and dementia and their carers offer important perspectives on challenges faced, as well as what we might do to address them. A collaborative approach integrating across healthcare specialties and expertise is likely to offer significant advances for diagnoses and care.

We discuss the proposed mechanisms linking hearing loss and dementia and review emerging research evidence about the role hearing rehabilitation might play in reducing the risk and progression of cognitive decline and dementia. We also highlight the many challenges associated with research addressing these issues and take a forwards look to the evidence we can expect to see in years to come. Practical suggestions, backed by health and care professionals, provide guidance for clinical adaptations that can improve quality of life for patient and their experiences of care.

As we enter a new horizon in our understanding of comorbid conditions, this chapter identifies opportunities to overcome challenges faced by clinicians and researchers alike, to improve evidence-based care and support for people living with dementia and hearing loss and the people who care for them.

Acknowledgements

EB, CB, EH, SC and HH are supported by funding from the National Institute for Health and Care Research (NIHR) Biomedical Research Centre (BRC-1215-20003) and NIHR Clinical Research Network East Midlands (UF18 and TF53). HH, EB and EH are also supported by NIHR funding award PB-PG-2018-2111-016, and EB and EH by NIHR Three Schools Dementia Career Development Awards. The views expressed in this chapter are those of the author(s) and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care.

Conflict of interest

The authors declare no conflicts of interest.

Notes/thanks/other declarations

The authors wish to thank all of the participants and patient research partners who contributed to the research cited in this chapter. We also wish to thank Ms. Sandra Smith and Ms. Izabela Popis from the NIHR Nottingham Biomedical Research Centre for their assistance.



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