## Experiences of hearing aid use among patients with mild cognitive impairment and Alzheimer's disease dementia: A qualitative study

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### Abstract

**Objectives:** Hearing aid usage supports communication and independence; however, many do not use their hearing aids. This study explored the experiences of hearing aid use in adults with mild cognitive impairment or Alzheimer's disease.

**Methods:** Participants completed semi-structured interviews which were analysed using thematic analysis. Ten people (six males, age range 75–86 years old) with mild cognitive impairment or Alzheimer's disease who had been fitted with hearing aids were recruited to the study.

**Results:** We identified four major themes: (1) memory and other cognitive barriers to using hearing aids, (2) practical aspects of hearing aids, (3) benefits of hearing aids, and (4) ambivalence towards hearing aids.

**Conclusions:** Participants perceived a significant impact of cognitive impairment on the experience of using hearing aids. This population may benefit from targeted strategies to support use of hearing aids. The findings from this study can inform future research to optimise use of hearing aids in this population.

### **Keywords**

Aging, hearing aids, cognitive impairment, qualitative

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## Introduction

### Dementia

Dementia is a syndrome of declining cognitive abilities, most commonly memory loss, with multiple underlying aetiologies,<sup>1</sup> the most common of which is Alzheimer's disease (AD). There are an estimated 850,000 people living with dementia in the United Kingdom,<sup>2</sup> at a total cost to the UK of £26 billion per year.<sup>2</sup> Mild cognitive impairment (MCI) is a clinical label that refers to the stage between normal ageing and dementia where people have objective cognitive deterioration which does not impact on their functioning.<sup>3</sup> People with MCI have an increased risk of developing dementia compared to the cognitively healthy older population.<sup>3</sup> Both dementia and MCI primarily affect people over the age of 65.<sup>2</sup>

## Hearing loss

Hearing loss is also a common problem among older adults, with up to 48% of men and 39% of women aged 65 and over

reporting hearing difficulties and only 31% of adults aged 65 and over having good hearing or only minimal hearing loss on pure tone screening.<sup>4</sup> Of this, only 18% are reported to have hearing aids<sup>4</sup> and of the 2 million people in the United Kingdom who have hearing aids only 1.4 million use them regularly.<sup>5</sup> Over half of 85-year-olds who used their hearing aids reported it made their quality of life either 'quite a lot' or 'very much' better.<sup>6</sup> Other studies have similarly found the use of hearing aids improves quality life compared to those with hearing loss who do not use hearing aids.<sup>7–9</sup>

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## Dementia and hearing loss

Approximately 1 in 4 adults aged 65 years and older in developed countries have cognitive impairment that can be identified clinically (dementia prevalence 5.3%-8.6%; MCI prevalence 16%-20%).<sup>10,11</sup> Many people attending audiological clinics for age-related hearing loss will therefore have varying degrees of cognitive impairment, often undiagnosed. Hearing loss is more common in people with dementia than expected by chance as it is a risk factor for dementia development.<sup>12</sup> Sixty percent of patients aged over 50 seen in a tertiary care memory clinic with cognitive impairment had at least mildly impaired hearing in their better hearing ear.<sup>13</sup> Despite this high prevalence, and the association between hearing aid use and cognition, the role of cognitive impairment as a potential determinant of hearing aid use remains understudied.<sup>14,15</sup> Undiagnosed cognitive impairment and the difficulties associated with impaired cognition are likely to be largely unrecognised factors in the high rates of poor adherence with hearing aids in the older population.16,17

Hearing loss has been associated with poorer cognition and incident dementia in a number of studies. In a cross-sectional analysis of a cohort of cognitively healthy older adults (the Baltimore Longitudinal Study of Aging (18), hearing loss was associated with lower scores on the Mini-Mental State Examination (MMSE) and on tests of memory and executive function relative to normal hearing. A reduction of 25 dB in hearing abilities was equivalent to an age difference of 6.8 years on cognitive testing.<sup>18</sup> Hearing loss has also been associated in a dose-response fashion to incident dementia and with faster time to onset of dementia diagnosis.<sup>19–22</sup>

## Cognition and hearing aids

Hearing aid use has been associated with better cognitive performance independent of effects hearing aids may have on confounders such as social isolation or depression.<sup>23</sup> In the English Longitudinal Study of Aging, a cross-sectional association exists between reduced cognition and hearing loss in people who do not use hearing aids, while the association is not apparent in hearing aid users.<sup>24,25</sup> However, as there is limited longitudinal research regarding cognitive benefits of hearing aids, the evidence for this remains inconclusive.<sup>23,26–28</sup> The use of hearing aids has been associated with improved quality of life and reductions in social isolation and depression in older adults,<sup>29</sup> experiences which people with dementia are at elevated risk for experiencing.<sup>30,31</sup>

### Experiences of hearing aid use

Previous research on the adoption and maintenance of hearing aids has shown the important role of the individuals' beliefs and expectations about hearing loss and hearing rehabilitation. The individual's perceived hearing handicap, that is, the extent to which hearing limits their daily life, has been shown to be a more reliable predictor of hearing aids use than the degree of hearing loss as measured through audiometry.14 Comfort and perceived benefit of hearing aids have previously been rated as the most important factor among users of hearing aids.<sup>32</sup> Those who do not consistently use hearing aids may also be more concerned about public reactions than regular users of hearing aids.<sup>32</sup> Costs, lack of perceived need, negative experience of others and difficulty of use are all previously identified barriers to hearing aid use among cognitively healthy older adults.33 However, the role of cognition, and specifically cognitive impairment, in hearing aid adoption and use remains understudied. Cognitive impairment is likely to result in additional practical and motivational challenges to hearing aid use. To date, two studies have shown that poor baseline cognition at the time of hearing aid fitting is associated with subsequent abandonment of hearing aids.<sup>34,35</sup> To our knowledge, the perspectives and experiences of hearing aid users with cognitive impairment have not been studied before. The aim of the present study was thus to interview people with MCI or mild dementia and hearing loss who had been fitted with hearing aids, to understand the experience of, and attitudes to, hearing aid use in this population.

## Methods

## Study design

This study was qualitative in design and utilised in-depth semi-structured interviews to explore participants' experiences of and attitudes towards hearing aid use. The design was selected to allow a detailed exploration of the experiences and attitudes of people with MCI and mild AD with hearing loss using hearing aids. We chose to limit the study to those with mild AD rather than any dementia as the majority of studies to date have been limited to this sub-type of dementia. We recruited participants from four memory clinics within one mental health trust where diagnostic pathways were standardised across clinics. We classified participants as mild on the basis of their sMMSE score as described below. The study was approved by London Riverside NHS Research Ethics (REC Reference 15/LO/2036) . The study took place from January 2016 until July 2016.

#### Interviewer characteristics

All participants were interviewed by the first author. The interviewer had a degree in Psychology and 6 years' experience working with people with a diagnosis of dementia, mainly in a research setting, and had previous experience of interviewing people with dementia and mental health conditions for qualitative research studies. The interviewer had met one of the participants in a previous research study. The interviewer completed the study in part-fulfilment for a master's degree in Mental Health Science Research.

### Recruitment

Participants were recruited from community memory clinics based in three inner London boroughs. Participants were recruited either from a research database or referred by clinicians and initially approached about the study either by phone or face-to-face. Participants were eligible if they were aged 50 or over, had a clinical diagnosis of MCI or mild AD, had hearing loss and had been provided with hearing aids and had a standardised sMMSE (standardised MMSE) score of 21 or above on the day of interview. Hearing loss was defined as any mention in primary care notes of confirmed hearing loss. Hearing aid use was defined either as mention in primary care notes of use or self-report by participant. The sMMSE is a test of cognitive function with possible scores ranging from 0 to 30 with higher scores meaning better cognition.<sup>36</sup> A score of 21 or over means that any cognitive impairment is mild. To ensure hearing impairment was not severe enough to impede sMMSE completion, all participants had successfully undergone cognitive testing previously as part of their clinical care. Participants were excluded if they did not speak fluent English or lacked capacity to consent to the study. Capacity to consent was assessed through a participants ability to understand and weigh up information provided about the study, reach a decision and then communicate that decision to the researcher. Participants were purposively sampled and recruitment was targeted to obtain a maximum variation sample with a broad range of participants and opinions. Recruitment continued until theoretical data saturation was reached, that is, with no new themes developing in further interviews. As such there was no formal sample size calculation for this study, rather it was decided during iterative data analysis at the point of data saturation.

## The interview

Participants were interviewed either in the research facility or in their own home, depending on the participant's preference. Family members were present in the room for three of the interviews but did not contribute to these and small interruptions if they occurred were not included in any data analysis. Following written informed consent, we collected demographic and diagnosis details from each participant. Participants completed the sMMSE to confirm eligibility for the study. The first author interviewed all participants using a semi-structured interview schedule to guide the conversation. The interview guide was developed from the literature in collaboration with local patient and public involvement group members The semi-structured interview guide included questions about the participants' experiences of hearing loss, how participants used hearing aids, what helped and what hindered participants from using their hearing aids. Interviews were audio-recorded and transcribed verbatim. Interview length ranged from 20 to 35 min. No field notes were made during interviews to ensure there was a natural flow of conversation for participants.

## Supplementary data collection

In addition to the interview, we also recorded sex, ethnicity, age, sMMSE score on day of interview, confirmation of hearing loss in medical notes and confirmation of hearing aids provided to participant. We did not gather additional information about degree of hearing loss or quantitative information about frequency or duration of hearing aid use.

### Data analysis

The initial analysis was performed by the first author and began with familiarisation with the transcripts through several iterations of reading and re-reading of the information. Transcripts were added to NVivo7 software to aid coding of the data. A thematic analysis approach to data analysis was followed.<sup>37</sup> An inductive approach was used to code the data and combine text into categories with subthemes. The codes and themes were refined in an iterative process. Discussions were held between authors S.G., S.G.C. and J.B. about emerging themes and appropriate labels to group experiences to similar areas. Following this the final coding scheme was agreed upon. All quotations have been anonymised, providing non-specific demographic information.

## Results

Sixteen people were identified from participant memory clinics as potentially suitable for the study; two did not respond to the study invitation and four were ineligible after assessment against inclusion criteria (either did not have a confirmed memory diagnosis or had hearing loss but had not yet been recommended to use hearing aids). Ten participants were included in the final sample: six men and four women, age range 75-86 years, and 50% identifying as White British, others identifying as White Irish, Black, Asian and Punjabi. Eight had a diagnosis of AD, two had a diagnosis of MCI and sMMSE score ranged from 21 to 28. All had hearing loss in their medical notes and all had been provided with hearing aids. Participants were encouraged to wear their hearing aids for both the sMMSE and the interview, and 9 of the 10 participants agreed to do so for the duration of the study visit. Wearing hearing aids during the study visit was not listed as a perquisite for study participation, and as such the participant was able to continue in the study assessments. The interviewer was satisfied that this participant was able to hear the questions, although we acknowledge that cognitive performance for this participant had the potential to be affected by a barrier in hearing. As the participant scored above the required 21/30 points to enter the study, suggesting their cognitive impairment was mild, the researchers do not feel this impedes on the below reported results. Table 1 shows the four main themes emerging from the thematic analysis with additional supportive quotations.

## Theme one: 'it's the memory loss'; memory and cognitive barriers to using hearing aids

Participants discussed how their memory and thinking difficulties led to misplacing or losing their hearing aids:

*Tve* ... lost them ... once ... *I've* lost them twice I think' (P6-M-AD); 'Well ... the only bad thing is, if for some reason I misplace them or anything happens [they] gets[sic] lost completely' (P8-M-MCI). Remembering to use the hearing aid regularly was also a common issue: 'Sometimes if I left in a hurry, and didn't put them on, as soon as something [sic], I go out and I can't hear anything I'll know straight away' (P8-M-MCI); 'if you're not used to them you just forget about [them]' (P10-M-AD).

Participants described strategies they employed to minimise the risk of losing their hearing aids. Many identified having a regular place to keep the hearing aids when they were not wearing them, which also helped to incorporate them into their daily routine: 'I have them right by the bed, when I've had my shower I come straight in the bedroom . . . and I can't forget them' (P3F-AD). The need for perseverance and habit was also reported: 'whether it's helping me or not I wear them religiously because what else can you do' (P3F-AD).

Many participants relied on family or friends to remind them to put their hearing aids in '[I wear them] . . . when my daughter nags me to put them in' (P5F-AD). These reminders could be motivated by the need to communicate better with significant others: 'if my children come to talk to me and I seem to be ignoring them, mum where are you hearing aids, you know' (P3F-AD), or to avoid inconveniencing relatives:

Quite often what happens is we get up and we put the news on, and then I can't hear it . . . if I'm there first I put it up louder so I can hear and . . . my husband comes in . . . put your ears in he says . . . so of course he is the one who's quite often instigating because he can't stand the noise. (P9F-MCI)

Participants also mentioned that social prompts such as expectations that they would use the hearing aids from significant others and professionals prescribing the hearing aids could be a determinant for use: 'well as I found out my hearing was going and I wasn't aware . . . because, ah, my children say you would not have been given them unless you needed them' (P3F-AD).

## Theme two: practicalities of hearing aid use

Putting the hearing aids on could be a problem and participants spoke of the time it took to insert and adjust the hearing aid: *I fiddle around thinking is it this way*... *is it that way*  ... then suddenly hear things' (P1F-AD); particularly for those wearing glasses: 'I've got glasses ... I take off quite often ... um the hearing aid comes out with it ... and I've got to put it back' (P9F-MCI). Some participants dealt with difficulties of fitting the hearing aid by having the help of someone else to fit it: 'I mean to be honest I don't put the hearing aid in ... so I know I can blame her if they're not in' (P1F-AD). However, once fitted, participants did not report problems with the comfort of the hearing aids: 'I wouldn't know I've got them on' (P1F-AD); 'I can't say they're uncomfortable' (P2-M-AD).

Excessive loudness of noise when using the hearing aids was reported a barrier to using them:

I mean if I was out and had it in all the time, like on buses and whatever, it'd drive me mad . . . Well all the noise you know . . . with the traffic . . . so basically I, when I'm out I don't out a hearing aid in. (P7-M-AD)

Others would still wear hearing aids when outside but may need to adjust the volume to make the noise more bearable: 'occasionally if I'm in a situation where it's very loud I'll turn this down a bit' (P2-M-AD).

# Theme three: 'they're a help': how the hearing aids help

Generally, most participants identified improved communication with relatives and friends deriving from hearing aid use: 'with the hearing aid . . . I can just have reasonable conversation . . . it's part of me, without hearing aids I am just lost completely' (P8-M-MCI). Many people discussed what they felt they missed out on due to poor hearing when they did not use their hearing aids: 'to spend [time] with my family, my husband, my friends . . . talk among yourselves . . . no good trying to talk to me 'cus I can't hear what you're saying' (P1F-AD). Some participants spoke of increased confidence – 'it's the confidence it gives me' (P3F-AD) – or of hearing aids and increased audibility as protective – 'with a hearing aid you think well I'm hearing so . . . I'm protected by my hearing' (P3F-AD).

However, participants would often use the hearing aids selectively, for some activities but not others. For example, some would use them at home but would not leave the house wearing them; '*if I go out in the shops to buy something, basically I can hear* . . . *if I go somewhere where I don't know I probably put it in'* (*P7-M-AD*). Some participants would use hearing aids only at times when they felt they really needed to: 'sometime[s] I can't be bothered to take them out . . . *if I'm struggling then I will put them in'* (*P9-F-MCI*).

## Theme four: ambivalence and stigma

Some participants remained ambivalent about whether their hearing loss was significant enough to need hearing aids. This perceived lack of need could lead to reduced usage:

Overall themes	Sub-themes	Additional supportive quotations
Theme One: 'lt's the memory loss'; Memory and cognitive	Misplacing or losing hearing aids and remembering to use them	'I misplace them' (PI F-AD); 'And it might be just my memory that I just, if I'm in a hurry and I don't put them in, then I'll say oh I haven't got them and I can't go back' (P3 F-AD)
barriers experienced when using hearing aids	Strategies to optimise use	'I put them on the bedside table' (P3 F-AD); 'I have them right by the bed, when I've had my shower I come straight in the bedroom and I can't forget them' (P3 F-AD): "When I get up in the
0		morning, have a bath dress up and put my hearing aid on' (P8-M-MCI); 'it's just become part of the everyday routine bit like deaning your teeth like'(P2-M-AD).
	Using friends and family as reminders for use	'I have a wife who reminds me to put them in'(P6-M-AD);
	Social reinforcement	ît's hard work for him [son] you know he's, he's a sort of person to say have you got your hearing aid in?' (PI F-AD)
Theme Two: Practical aspects of hearing aid use	Fitting and adjusting the hearing aids	'I have difficulty putting them in it's the positioning of the, um, I put them in and then put them down.'. (P6-M-AD); 'well it's a blooming thing to stick in your ear' (P2-M-AD); 'First of all I don't know how to put it in' (P4-M-AD).
	Coping with excessive noise	When they [the grandchildren] start screaming I keep them out' (P7-M-AD); 'if I ended up in some very noisy situation I might just take it out' (P2-M-AD); 'they're a blooming nuisance if I go to the theatre or the cinema and then you find it really is loud is too loud' (P9F-MCI); But sometimes if there's background noise going on then it's a problem the consequences have been I used to go to some meetings before, now I stopped them because I'm not getting anything' (P8-M-MCI).
Theme Three: 'They're a help': perceived benefits of hearing aids	Improved communication and confidence	"I'm grateful to them you know if people ask me about them I say you know, I hope they're helping me' (P3F-AD); 'so it was a help alright, they're a help' (P10-M-AD); 'I think in a big group when there's crosstalk then you lose something because you don't know which one you're supposed to be listening to' (P5F-AD);
	Activity specific benefits	'some days it's alright and other day's it's not' (P7-M-AD); 'I don't put them in when I go outI never wear them, and I don't take them to church with me' (P5 F-AD)
Theme Four: Ambivalence and stigma	Questioning severity of hearing loss	'don't know how effective they are but I use them' (P3 F-AD); 'you have to have what you get really' (P7-M-AD)
	Visibility and appearance	'they seem to be quite unobtrusive because nobody seems to make any remarks, or they're very polite' (P3F-AD); 'I don't think I don't wear them because I think people can see them because that doesn't bother me'(P5F-AD); 'I suppose people have other things that you can see and you accept it' {P5F-AD};

'Just don't feel I need them so much . . . if I thought I really need the . . . If I thought I should . . . then perhaps I will' (P5F-AD); 'it could be good but I've not used it at all' (P4-M-AD).

Some people thought hearing aids could be helpful but might cause them undesirable effects, such as diminished concentration: 'I think if you get too used to them you, when you haven't got them in you, you lose that concentration of listening' (P5F-AD).

Attitudes about the visibility and appearance of the hearing aids varied greatly among participants. Attitudes ranged from not minding about appearance: 'I don't really care much... how they look' (P1F-AD), to concern that visible hearing aids reveal the wearer as impaired and might result in stigma: 'why people should [sic] see that I'm, I'm deaf' (P4-M-AD); 'only you wonder what is everybody looking at' (P10-M-AD); 'if you're blind people are very sympathetic if you're blind... but deaf people don't get the same support I think as blind people' (P1F-AD). Some participants sought less visible hearing aids or tried to conceal them: 'when I first started I thought oh if I had hair I'd hide them' (P3F-AD). On the other hand, participants spoke of their reassurance that other people were able to see the hearing aids and be aware of their difficulties: 'it's a warning to people it they notice . . . that if I ask again, what have they said, they don't think I'm stupid' (P3F-AD).

## Discussion

This is the first study to report on the experience of hearing aid use in people with MCI and mild AD. Participants in our study talked about perceived benefits, ambivalence, stigma and practical difficulties of using hearing aids. These themes reflect findings from previous research in older non-cognitively impaired adults.<sup>14,15</sup> Our participants, however, also spoke of additional challenges in using hearing aids brought about by their cognitive problems, as well as the strategies they have developed and support that has helped them overcome these difficulties. During thematic analysis, there were no obvious differences emerging in the themes arising from participants with MCI compared to those with AD, and as such the below discussions relate to the group of participants in totality.

### Comparison of findings to existing literature

The negative impact of cognitive impairment and memory loss on the experience of hearing aid use is an expected but not previously reported finding. In a population-based study of persons aged over 75 years, those who had hearing aids prescribed to them but had abandoned them had a median MMSE score of 23, consistent with possible cognitive impairment, and significantly worse than those participants who continued using their hearing aids, who had a median MMSE score of 27.<sup>35</sup>

Our participants experienced memory loss and cognitive impairment as clearly detrimental to hearing aid use, a finding not previously identified among older adults without cognitive impairment. Memory related difficulties included misplacing the hearing aid and forgetting to use them regularly. Participants described incorporating the use of hearing aids into their routine as one of the successful strategies for using them regularly. Forgetting to complete daily routine activities is described as one of the early symptoms of AD<sup>38</sup> and as such it is important to include the hearing aids in a routine that patients can easily learn and recall. Some participants raised difficulty with isolating background noise when using the hearing aids. This may be associated with challenges people with cognitive impairment can have with understanding speech39 or auditory scene analysis40 and warrants further work to minimise discomfort or confusion from hearing aid use for this population.

Our participants talked about how they overcame their memory-related difficulties, suggesting pathways to develop interventions to support hearing aids adherence in people with cognitive impairment. In agreement with previous literature, motivational factors were regularly mentioned, and in particular an awareness of the benefits of hearing aids in supporting communication, overcoming hearing disability in everyday life and promoting independence and communication.<sup>14</sup> Previous research on non-use of hearing aids has also highlighted the role of ambivalence and poor subjective benefit.<sup>41</sup> Along these lines, motivational interviewing as part of hearing aids use<sup>42</sup> which could be extended to this population with MCI and mild dementia.

The role of supportive relatives was also highlighted by our participants. They mentioned receiving practical help such as providing reminders to use hearing aids, and used positive social reinforcement to increase motivation to use the hearing aids. In a study of recent users of hearing aids, participants reported that a positive supportive attitude from a significant other increased the likelihood of using their hearing aids for at least 1 h a day, compared to those without this source of support.<sup>34</sup> Interventions to support hearing aid use are being developed that include formal involvement of family members in audiological rehabilitation.<sup>43</sup> Again, this could usefully be extended to those with mild dementia and MCI.

Many of our participants highlighted the role of perseverance in hearing aid use, as well as integration of the aids in every routine. While episodic memory loss is frequently an early impairment in AD and other forms of dementia, implicit or procedural learning such as learning of habits and repeated motor acts are often relatively preserved.<sup>44</sup> Rehabilitation of activities of daily living through procedural learning and repetition have therefore been proposed in dementia,<sup>45</sup> and these approaches could be adapted to support hearing aid use in people with cognitive impairment. Perseverance may be particularly important in the first few weeks of use, a period often when a process of acclimatisation (or 'getting used to' the hearing aids) is taking place.<sup>23</sup>

Our participants also raised other elements of their experience that are commonly reported by hearing aid users without cognitive impairment. Practical aspects of hearing aid use, including operation, adjustment and comfort may be affected by poor manual dexterity and have been previously identified as potential obstacles to use.<sup>15</sup> Perceived concerns about appearance and the stigma associated with hearing aids can also impact the decisions to seek assessment and treatment for hearing loss.<sup>46</sup> In hearing aid users, stigma influences whether hearing aids are used or not, and in what context.<sup>47,48</sup> These concerns were no different among those with mild dementia and MCI.

### Strengths

This study offers novel insight into the views and experiences on hearing loss, and hearing aid use of those with cognitive difficulties associated with MCI or mild AD. This group is often underrepresented and marginalised in research, and their views on this issue have not previously been sought.

### Limitations

A limitation in our study is that due to the nature of their diagnoses, some participants' accurate recall of their experiences may have been limited by memory problems. In addition, we did not interview people without cognitive impairment to find out if they have similar difficulties forgetting and losing their hearing aids. Future work may consider including family members in the conversations to enrich the experiences shared. While all participants lived in London, they encompassed a variety of ethnicities and varying degrees of cognitive impairment. As such, we have been able to gather a range of opinions from a diverse range of people in terms of demography and cognitive impairment and continued until no new opinions were being expressed (theoretical saturation). Nevertheless, larger samples in future research would be useful to establish the generalisability of the findings from this study. As this was an exploratory study, we did not gather detailed information on duration or severity of hearing loss, frequency or duration of hearing aid use or details about the type of hearing aid the participant had. As such, we are not able to infer relationships between experiences and degree of hearing loss, or delineate differences in experiences between those first using hearing aids before and after diagnosis of dementia. A mixed-methods study combining this quantitative information with qualitative information may be suitable for future work.

## Suggestions for future work

Some of the experiences related by our participants with regard to use of hearing aids warrant further work with both patient groups and professionals to develop evidence-based strategies to promote successful use of hearing aids. Collaboration between the audiology and dementia research communities is necessary to allow optimal progression of work in this area. A recent pilot study investigated a low-burden intervention for hearing loss utilising communication techniques and over the counter amplification devices for people with hearing loss and dementia, and showed a caregiver reported benefit and reduction in depression and neuropsychiatric outcomes for patients with high baseline symptom burden.<sup>49</sup> A feasibility study is also underway utilising sensory support specialists to deliver communication-based interventions for those with visual and hearing deficits.<sup>50</sup> However, further investment in research in this area is warranted.

### Conclusion

Experiences of and attitudes towards the use of hearing aids among those with MCI and mild AD are complex. It is important for clinicians and researchers to understand these experiences to enable development of support strategies that optimise the use of hearing aids. Unique findings from the study emerged around memory- and cognitionrelated difficulties experienced by this population when trying to use their hearing aids. Other challenges emerged which have previously been cited in general hearing aid user literature around patient experience. Future work in this area is warranted to develop enriched information about these experiences from family members and to move towards developing evidence-based strategies to support use of hearing aids

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### **Declaration of conflicting interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### **Ethical approval**

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### **Informed consent**

Written informed consent was obtained from all subjects before any study procedures took place. All participants had the capacity to consent and therefore no consent was provided by legally authorised representatives.

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### References

- Gustafson L. What is dementia? Acta Neurol Scand 1996; S168: 22–24.
- 2. Prince M, Knapp M, Guerchet M, et al. *Dementia UK: overview*. 2nd ed. London: Alzheimer's Society, 2014.
- 3. Petersen RC. Mild cognitive impairment. *New Engl J Med* 2011; 364: 2227–2234.
- Scholes S and Mindell J. Healthy survey for England, chapter
  hearing, 2014. https://files.digital.nhs.uk/publicationimport/pub19xxx/pub19295/hse2014-ch4-hear.pdf
- 5. Action on Hearing Loss. *Facts and figures on hearing loss and tinnitus*. London: Action on Hearing Loss, 2011.
- Oberg M, Marcusson J, Nagga K, et al. Hearing difficulties, uptake, and outcomes of hearing aids in people 85 years of age. *Int J Audiol* 2012; 51(2): 108–115.
- Hyams AV, Hay-McCutheon M and Scogin F. Hearing and quality of life in older adults. *Journal of Clinical Psychology* 2018; 74(10): 1874–1883.
- Kitterick PT and Ferguson MA. Hearing aids and healthrelated quality of life in adults with hearing loss. *JAMA* 2018; 319(21): 2225–2226.
- Yamada Y, Svejdikova B and Kisvetrova H. Improvement of older-person-specific QOL after hearing aid fitting and its relation to social interaction. *J Commun Disord* 2017; 67: 14–21.
- Roberts R and Knopman DS. Classification and epidemiology of MCI. *Clin Geriatr Med* 2013; 29(4): 753–772.
- 11. Alzheimer's Society. *Dementia UK: update*. London: Alzheimer's Society, 2014.
- Livingston G, Sommerlad A, Orgeta V, et al. Dementia prevention, intervention and care. *Lancet* 2017; 390: 2673–2734.
- Nirmalasari O, Mamo SK, Nieman CL, et al. Age-related hearing loss in older adults with cognitive impairment. *Int Psychogeriatr* 2017; 29(1): 115–121.
- Knudsen LV, Oberg M, Nielsen C, et al. Factors influencing help seeking, hearing aid uptake, hearing aid use and satisfaction with hearing aids: a review of the literature. *Trends Amplif* 2010; 14(3): 127–154.
- 15. McCormack A and Fortnum H. Why do people fitted with hearing aids not wear them? *Int J Audiol* 2013; 52(5): 360–368.
- Aazh H, Prasher D, Nanchahal K, et al. Hearing-aid use and its determinants in the UK National Health Service: a cross-sectional study at the Royal Surrey County Hospital. *Int J Audiol* 2015; 54(3): 152–161.
- Hartley D, Rochtchina E, Newall P, et al. Use of hearing aids and assistive listening devices in an older Australian population. J Am Acad Audiol 2010; 21(10): 642–653.
- Lin FR, Ferrucci L, Metter J, et al. Hearing loss and cognition in the Baltimore Longitudinal Study of Aging. *Neuropsychology* 2011; 25(6): 763–770.
- Fritze T, Teipel S, Ovari A, et al. Hearing impairment affects dementia incidence. *PLoS ONE* 2016; 11(7): e0156876.

- 20. Golub JS, Luchsinger JA, Manly JJ, et al. Observed hearing loss and incident dementia in a multiethnic cohort. *J Am Geriatr Soc* 2017; 65(8): 1691–1697.
- Gurgel RK, Ward PD, Schwartz S, et al. Relationship of hearing loss and dementia: a prospective, population-based study. *Otol Neurotol* 2014; 35(5): 775–781.
- 22. Lin FR, Metter J, O'Brien RJ, et al. Hearing loss and incident dementia. *Arch Neurol* 2011; 68(2): 214–220.
- Dawes P, Emsley R, Cruickshanks KJ, et al. Hearing loss and cognition: the role of hearing aids, social isolation and depression. *PLoS ONE* 2015; 10(3): e0119616.
- Amieva H, Ouvrard C, Meillon C, et al. Death, depression, disability and dementia associated with self-reported hearing problems: a 25-year study. *J Gerontol A Biol Sci Med Sci* 2018; 73(10): 1383–1389.
- Ray J, Popli G and Fell G. Association of cognition and agerelated hearing impairment in the English Longitudinal Study of Ageing. *JAMA Otolaryngol Head Neck Surg* 2018; 144(10): 876–882.
- Amieva H, Ouvrard C, Giulioli C, et al. Self-reported hearing Loss, hearing aids, and cognitive decline in elderly adults: a 25-year study. *J Am Geriatr Soc* 2015; 63(10): 2099–2104.
- Deal JA, Betz J, Yaffe K, et al. Hearing impairment and inci dent dementia and cognitive decline in older adults: the health ABC study. *J Gerontol A Biol Sci Med Sci* 2017; 72(5): 703–709.
- Maharani A, Dawes P, Nazroo J, et al. Longitudinal relationship between hearing aid use and cognitive function in older Americans. *J Am Geriatr Soc* 2018; 66(6): 1130–1136.
- 29. Chisolm TH, Johnson CE, Danhauer JL, et al. A systematic review of health-related quality of life and hearing aids: final report of the American Academy of Audiology Task Force on the health-related quality of life benefits of amplification in adults. *J Am Acad Audiol* 2007; 18(2): 151–183.
- Iliffe S, Kharicha K, Harari D, et al. Health risk appraisal in older people 2: the implications for clinicians and commissioners of social isolation risk in older people. *Br J Gen Pract* 2007; 57(537): 277–282.
- Richard E, Reitz C, Honig LH, et al. Late-life depression, mild cognitive impairment, and dementia. *JAMA Neurol* 2013; 70(3): 374–382.
- Garstecki DC and Erler SF. Hearing loss, control, and demographic factors influencing hearing aid use among older adults. *J Speech Lang Hear Res* 1998; 41(3): 527–537.
- Gopinath B, Schneider J, Hartley D, et al. Incidence and predictors of hearing aid use and ownership among older adults with hearing loss. *Ann Epidemiol* 2011; 21(7): 497–506.
- Hickson L, Meyer C, Lovelock K, et al. Factors associated with success with hearing aids in older adults. *Int J Audiol* 2014; 53(Suppl. 1): S18–S27.
- Lupsakko TA, Kautiainen HJ and Sulkava R. The non-use of hearing aids in people aged 75 years and over in the city of Kuopio in Finland. *Eur Arch Otorhinolaryngol* 2005; 262(3): 165–169.
- Vertesi A, Lever JA, Molloy DW, et al. Standardized minimental state examination: use and interpretation. *Can Fam Physician* 2001; 47: 2018–2023.
- 37. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3(2): 77–101.

- Parsons-Suhl K, Johnson ME, McCann JJ, et al. Losing one's memory in early Alzheimer's disease. *Qual Health Res* 2008; 18(1): 31–42.
- 39. Akeroyd MA. Are individual differences in speech reception related to individual differences in cognitive ability? A survey of twenty experimental studies with normal and hearing-impaired adults. *Int J Audiol* 2008; 47(Suppl. 2): S53–S71.
- Goll JC, Kim LG, Ridgway GR, et al. Impairments of auditory scene analysis in Alzheimer's disease. *Brain* 2012; 135(Pt. 1): 190–200.
- Linssen AM, Joore MA, Minten RKH, et al. Qualitative interviews on the beliefs and feelings of adults towards their ownership, but non-use of hearing aids. *Int J Audiol* 2013; 52(10): 670–677.
- Ferguson M, Maidment D, Russell N, et al. Motivational engagement in first-time hearing aid users: a feasibility study. *Int J Audiol* 2016; 55(Suppl. 3): S23–S33.
- Scarinci N, Meyer C, Ekberg K, et al. Using a family-centered care approach in audiologic rehabilitation for adults with hearing impairment. *Perspect Aural Rehabil Instrum* 2013; 20(3): 83–90.

- Chauvel G, Maquestiaux F, Gemonet E, et al. Intact procedural knowledge in patients with Alzheimer's disease: evidence from golf putting. *J Mot Behav* 2018; 50(3): 268–274.
- Zanetti O, Zanieri G, Di Giovanni G, et al. Effectiveness of procedural memory stimulation in mild Alzheimer's disease patients: a controlled study. *Neuropsychol Rehabil* 2001; 11(3–4): 263–272.
- 46. Heffernan E, Coulson NS, Henshaw H, et al. Understanding the psychosocial experiences of adults with mild-moderate hearing loss: an application of Leventhal's self-regulatory model. *Int J Audiol* 2016; 55(Suppl. 3): S3–S12.
- Barker AB, Leighton P and Ferguson MA. Coping together with hearing loss: a qualitative meta-synthesis of the psychosocial experiences of people with hearing loss and their communication partners. *Int J Audiol* 2017; 56(5): 297–305.
- Wallhagen MI. The stigma of hearing loss. *Gerontologist* 2009; 50(1): 66–75.
- Mamo SK, Nirmalasari O, Nieman CL, et al. Hearing care intervention for persons with dementia: a pilot study. *Am J Geriatr Psychiatry* 2017; 25(1): 91–101.
- Regan J, Dawes P, Pye A, et al. Improving hearing and vision in dementia; protocol for a field trial of a new intervention. *BMJ Open* 2017; 7(11): e018744.