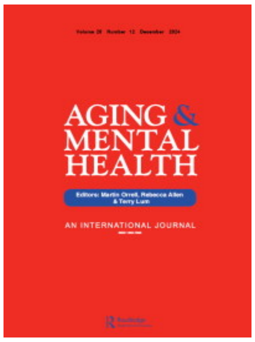

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Dementia and the Deaf community: prevalence, assessment and management in people with hearing loss since childhood

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ABSTRACT

Objectives: Deaf people face complex challenges in accessing healthcare, particularly for age-related conditions, yet the Deaf community is largely overlooked in dementia research. This study explores healthcare issues in relation to dementia for older Deaf individuals, and perspectives of stakeholders regarding dementia and the Deaf community.

Method: Combined approach of (1) narrative literature review using five online databases and grey literature and (2) semi-structured interviews with eight participants with lived experience or knowledge of the Deaf community and/or dementia. Interview data were analysed thematically and integrated with literature review findings.

Results: People in the Deaf community exhibit higher rates of dementia risk factors (eg obesity, hypertension, diabetes, and depression). Under-diagnosis and under-treatment are more common, likely attributed to language barriers and insufficient Deaf awareness among healthcare staff. Research on the relationship between profound hearing loss and dementia, and the prevalence of dementia among Deaf people, is scarce. Practical changes are needed to tailor dementia assessments and services for Deaf people.

Conclusion: Deaf awareness training, health-care information in sign language, and accessible dementia services are crucial for improving healthcare access and outcomes for Deaf people. Co-production with the Deaf community is required in future research and healthcare service improvement initiatives.

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Deaf; Deaf community; older people; dementia; health inequalities

Introduction

People with congenital or childhood-onset hearing loss, and who communicate primarily through sign language, often identify as being Deaf and as members of the Deaf community. Members of this community have their own unique rich culture and history, preferring not to view their Deafness as a disability (British Deaf Association, 2015). Many Deaf people identify themselves as a linguistic minority, rather than a collective group of individuals with hearing loss (Ferguson-Coleman, 2016). This paper pays attention to issues for Deaf people, often signified with capital 'D', rather than the larger majority with acquired hearing loss or deafness, often signified by lower case 'd'. The Deaf community often exists in small groups, with almost a fifth of BSL users residing in London. This is followed by significant populations in the South East (13%) and the North West (12%). The geographical diversity of the Deaf community can significantly affect the availability and consistency of service provision (Traverse, 2019).

Most research about challenges faced by the Deaf community focuses on developmental and education issues, and less attention has been paid to issues around ageing (Leigh et al., 2023). Deaf adults in the UK tend to have poorer socio-economic status than the general population and face unique challenges with health and access to healthcare (Emond et al., 2015). Deaf adults have higher rates of obesity, hypertension, depression, and raised cholesterol levels, all of which are risk factors for dementia, compared to the general population (SignHealth, 2014).

Dementia is a cognitive decline that interferes with a person's daily functioning (Gale et al., 2018), with impairment of such functions as memory, executive function, language, visual-perceptual skills, and social conduct (Emmady et al., 2023). Hearing loss from mid-life is the largest potentially modifiable risk factor for dementia (Livingston et al., 2020). Despite scientific interest in the link between age-related hearing loss and dementia, there is little research into Deaf sign language users and dementia (Reed et al., 2022). There are no accurate figures for the number of Deaf people living with dementia (DWD), though an estimate of DWD in the UK over age 65 is between 450 to 850 (Young et al., 2016). There is thus a research gap both in relation to the health of Deaf older people and DWD in particular.

This study provides an overview of key health issues experienced by Deaf people, focusing on the older population and those living with dementia. It contains data from two sources, combining a literature review with qualitative interview data, to address the following questions:

- What are the key health issues experienced by older Deaf people?
- What barriers do older Deaf people face when accessing healthcare?

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- What dementia assessment methods and services are currently available for Deaf people?
- What are the experiences of Deaf people living with dementia, their caregivers/relatives, and healthcare professionals in this field?

Methods

Literature review

The chosen approach was an extended literature review to enable a thorough, flexible exploration of published literature. An initial search was performed on MEDLINE *via* OVID, NUsearch, PubMed, Web of Science and Google Scholar with the key words 'dementia''deafness' and 'aged'. Both Medical Subject Headings (MeSH) and keyword searches were employed. Further search terms such as 'congenital hearing loss', 'mental health' and 'cognitive decline' were then examined to broaden the search. Additionally, references from key papers were evaluated to identify any other relevant literature, and grey literature was searched for relevant reports and policy statements. Current statistics and information from national charities and professional bodies supporting the Deaf community were included, eg RNID. Articles from websites with unclear authorship or information older than 15 years were excluded.

After preliminary searching, inclusion and exclusion criteria were established (Table 1) to maintain the focus and refine results. Duplicates were removed, and titles and abstracts screened for relevance. Full texts were read to identify studies meeting the inclusion criteria. Next, major points were tabulated on Microsoft Excel. As papers including statistical data, eg population estimates on the Deaf community, were scarce, there were no limitations on the methodologies of included papers. All forms of research were considered, contingent upon them meeting the inclusion criteria. In view of the exploratory nature of the review, a formal assessment of paper quality was not conducted. Non-English language papers were excluded for lack of translation resources. All searches were conducted by the first author, with information specialist support. The inclusion/exclusion criteria were developed by all three authors, and decisions about inclusion or exclusion of articles were made by joint discussions.

Interviews

Data from in-depth qualitative interviews were also obtained to augment the literature, as it was anticipated at the outset that there may be limited published research on health issues in older Deaf people. This enabled us to incorporate experiences and perspectives of stakeholders, including members of the Deaf community, their relatives, and healthcare professionals, into the study. Semi-structured interviews were conducted online ($n = 4$) and in-person ($n = 2$). Three participants were interviewed together and the other five individually. Most interviews were conducted online for participant convenience. The interview questions were formulated in the light of the literature review and the interview schedule (see supplementary file 1) was developed jointly by all authors. The study received ethical approval from the University of Nottingham Faculty of Medicine and Health Science Research Ethics Committee (FMHS 438-0122).

Table 1. Inclusion and exclusion criteria for literature review.

Inclusion	Exclusion
Focus on members of the Deaf community including: • Congenital and childhood onset Deafness • Sign language users • Identification with the Deaf community	Focus on people not identifying as part of the Deaf community including: • Age-related hearing loss • Non-users of sign language
Focus on members of the Deaf community aged 50 and older	Focus on members of the Deaf community younger than 50 years
Research conducted within 15 years	Research older than 15 years
English language	Non-English language

Participants

Purposeful sampling was employed, involving the specific choice of individuals with expertise or experience with the Deaf community and/or dementia. Participants consisted of two groups, experts by experience (EbE), and experts by profession (EbP). EbE were recruited from the NIHR Nottingham Biomedical Research Centre Hearing Theme Participant Database, and *via* social media posts. EbP were recruited through the professional network of the research team, social media posts, and conference leaflets. Participants were aged 18 years or over, and willing to give informed consent. EbP had experience working with people with hearing loss, particularly profound hearing loss, and/or dementia. EbE had lived experience of dementia and/or the Deaf community, including being a family caregiver, and/or were a member of the Deaf community. Participant selection ceased once a diverse range of individuals had been chosen, and comprehensive relevant data had been collected. There were eight participants, three women and five men, with mean age of 58 (range 35–79) years (Table 2). Participants P3, P4, and P5 were interviewed together while the others were interviewed individually.

Procedure

All participants gave informed, written consent and completed a demographics questionnaire. Professional BSL interpreters attended interviews when required. On average, each interview

Table 2. Summary of participants interviewed.

Identification code	Status	Details
P1 (EbE)	Carer and BSL user	Member of the Deaf community who cares for her husband who is Deaf with dementia
P2 (EbE)	Former carer and BSL user	Member of the Deaf community, who cared for her mother who was Deaf and had dementia
P3 (EbP)	Social work professional	Works with members of the Deaf community, particularly those who have mental illnesses and learning disabilities
P4 (EbP)	Social work professional	Works with members of the Deaf community
P5 (EbE and EbP)	Social work professional and BSL user	Works directly with the Deaf community, and those who are Deaf-blind, to help promote their independence
P6 (EbP)	Audiologist	Works with older adults with hearing loss and cognitive issues
P7 (EbP)	Audiologist	Has experience with complex cases, including people with dementia
P8 (EbP)	Consultant nurse	Works with members of the Deaf community who have suspected or diagnosed cognitive decline/dementia

lasted 45 min. Both in-person and online interviews were audio-recorded, while online interviews were also video-recorded. Each interview was transcribed verbatim, and comprehensive field and reflexive notes were taken throughout. Participants received a voucher or small payment.

Also, a panel of Patient and Public Involvement (PPI) representatives, individuals living with dementia and/or hearing loss and their relatives or caregivers, was actively involved in study design and conduct. They assisted in designing study materials, offering feedback on the recruitment strategy and study procedures to ensure their appropriateness.

Analysis

Extensive literature reading helped to identify key areas of interest and formulate interview questions. Thematic analysis (Clarke & Braun, 2017) was conducted on the interview transcripts, as follows. Initially, for familiarisation, transcripts were read in depth, listening back to the recordings, and reviewing field notes. Next, codes relevant to research objectives were derived from the data, including barriers to healthcare, available services, and assessment methods. This facilitated the generation of themes, derived by grouping related codes together. Literature review findings were then incorporated, with themes continuously refined where necessary. The resulting themes form the structure of this review. Peer debriefing followed, involving research team discussions about the identified themes to challenge or confirm their relevance. The first author undertook the primary analysis, with themes discussed critically at each stage by all three authors. This process, coupled with consistently referring to the original interview dataset, helped to refine the themes for writing up.

Results

The search identified 1384 titles (Figure 1) from search databases and 24 titles from websites and citation searching. 26 key studies were included in the review.

The results section presents findings from both the literature review and qualitative interviews collectively. The results show four main themes with subthemes related to each one (Table 3).

Health disparities in the Deaf community

Comorbidities

The overall health of the Deaf community is poorer than the general population, although Deaf people tend to have healthier lifestyles in terms of smoking and alcohol (Emond et al., 2015; SignHealth, 2014). Notably, obesity is commoner in the Deaf population, especially over 65 years old, and the incidence of hypertension is double that in the general population. Deaf people are at higher risk of under-diagnosis and under-treatment of serious health conditions, including hypertension, diabetes, hyperlipidaemia, and cardiovascular disease. This increases the risk of preventable heart attacks, strokes, and diabetic complications (eg kidney failure, blindness) (SignHealth, 2014). Additionally, mental health conditions are more prevalent among Deaf people, with 24% living with depression, compared to 12% observed in the general population. These factors collectively contribute to significant health needs, much of which could be avoided with timely interventions (Emond et al., 2015; SignHealth, 2014).

The heightened prevalence of these conditions could lead to increased risk of dementia among Deaf people, as hypertension, obesity, diabetes, and depression are potential modifiable risk factors for dementia (Livingston et al., 2020). Furthermore, the risk of dementia among people with acquired hearing loss increases in line with hearing loss severity (Lin et al., 2011), and Deaf people typically fall within the profound range for hearing loss. The risk of cognitive decline is further increased when moderate or greater hearing loss is accompanied by depressive symptoms (Powell et al., 2022). Furthermore, Deaf people may have increased risk of cognitive impairment due to organic causes of Deafness, eg prematurity, meningitis, maternal rubella, or prenatal cytomegalovirus, along with untreated circulatory disorders (Atkinson et al., 2015). Consistent with this,

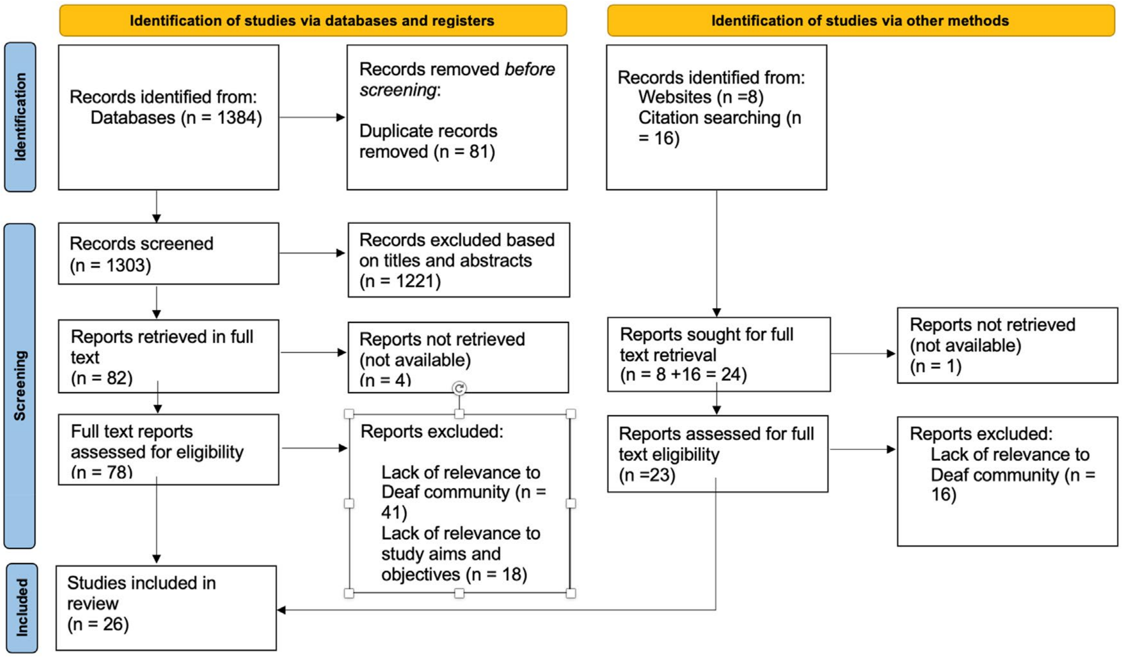

Figure 1. PRISMA flow chart showing the studies selected and screened.

Table 3. Themes and subthemes.

Main themes	Subthemes	Illustrative quotes
1. Health disparities in the Deaf community: contrasting with the general hearing population	Comorbid health conditions	'…Deaf people in their fifties who had undiagnosed learning disabilities'.
	Late diagnosis, misdiagnosis, underdiagnosis	'Someone had undiagnosed encephalitis for thirty years'.
2. Complex challenges in accessing healthcare	Access to healthcare and information services	'Deaf people have to assert their rights which some perceive as being aggressive'. 'Face to face information about dementia with an interpreter would help educate Deaf people'.
	Importance of Deaf awareness	'Deaf awareness training for staff would help them be more confident communicating with Deaf people'.
	Communication with healthcare staff	'…not enough interpreters so information about health benefits is missed by the Deaf community'.
3. Specialist dementia services for Deaf people	Appropriate assessment for Deaf people	'The questionnaire was not Deaf friendly and did not translate into the cultural side'. 'Most assessment methods for cognitive conditions are delivered orally and therefore not appropriate for Deaf people'.
	Specialist memory clinics and care homes for Deaf people	'The specialist cognitive Deaf clinic is able to recognize specific conditions such as primary progressive aphasia which other teams may not be able to see'. 'He'd been to four care homes but no one in any of them understood BSL'.
4. Navigating the challenges following dementia diagnosis	Experiences of Deaf individuals diagnosed with dementia	'His dementia deteriorated as he wasn't signing with anyone for long periods'.
	Experiences of caregivers	'I learnt about dementia through experience but knew nothing about it before'. 'I couldn't access support groups as no interpreter was present'.

our interview participant P4 (social work professional) commented 'There are a lot of people with mental illness who are Deaf BSL users and we know their outcomes are poor so if you add dementia into the mix… we see the barriers for them in terms of access to information and to services'.

Late diagnosis, misdiagnosis and underdiagnosis

The literature described how Deaf people often experience poor access to accurate and timely diagnoses. Furthermore, within the Deaf community, there is perhaps a greater acceptance of cognitive diversity but with the view that cognitive change is linked to normal ageing. This perspective, along with uncertainty about where to find help, may lead Deaf people to delay seeking support until dementia symptoms become more pronounced. Consequently, Deaf people may postpone seeking support until dementia symptoms are more advanced (Ferguson-Coleman et al., 2014). The interview data reinforced this. P1 (carer/BSL user) discussed how dementia is 'less talked about in the Deaf community… they say dementia is really cruel, it's a horrible disease. I don't think there's any pain. I saw on the TV… they said they weren't in pain… I'm not a doctor so I don't actually know'. This instils fear and deters help-seeking if early symptoms of dementia or cognitive changes arise.

Our interview data also revealed that after previous negative experiences, some Deaf people avoid medical visits as they anticipate a long and arduous process. Thus, serious health issues may go unnoticed and untreated. P5 (social work professional/BSL user) highlighted:

> people with BSL being their first language sometimes struggle to read English words in written form, they don't understand what it means, and they have to get in touch with someone who can support them with understanding…so they try to avoid it…and give up because it's just too difficult for them. With hearing people, you just share information, they can hear it everywhere, so it's a difference with how information is accessed.

Misdiagnosis poses another serious concern for Deaf people. P8 (consultant nurse) elaborated on this:

> because [there are] no other services [Deaf] people are referred to, we picked up two women in their fifties and they [both] had an undiagnosed learning disability… it's shocking how many people, teachers, and social workers ignore them… how many times do they have contact with people that no one ever picked up this difficulty?

P8 also mentioned a Deaf patient who had remained undiagnosed with encephalitis for 30 years. These patients were initially referred for memory issues and suspected dementia, whereas they had been affected by a different condition for much of their lives.

Complex challenges in accessing healthcare

Access to information and healthcare services

A 'hearing person' refers to someone who has the ability to perceive sounds and typically relies on auditory communication, primarily using spoken language. Hearing people will often contact their General Practitioner (GP) by telephone. In contrast, 45% of Deaf people visit in-person to book appointments, as telephone communication is not feasible (SignHealth, 2014). However, 44% of Deaf people reported finding it 'difficult or very difficult' to contact their GP, and 41% were unable to access other health services (SignHealth, 2014). In a survey of 744 respondents, 16% were offered telephone appointments despite being unable to use the phone, and 43% had their name called out at the GP surgery when it was their appointment, consequently leading to missed appointments (Bailey, 2018). Hearing people can access mainstream health education *via* speech, writing radio, television, and websites (Alexander et al., 2012). In contrast, culturally and linguistically accessible information in sign language, and informal caregiving training and support groups, are scarce for the Deaf community (Kushalnagar et al., 2023).

Knowledge about dementia varies within the Deaf community, with widespread lack of clarity regarding its origins and progression (Ferguson-Coleman, 2016). Many individuals have either not considered dementia at all, or rely on first-hand experiences with family members for their awareness (Ferguson-Coleman et al., 2014). A qualitative study with Deaf participants uncovered several misconceptions. Some believed that people living with dementia pose a risk to the community and should be avoided. While most people knew there is no cure for dementia, they were not aware of possible measures to reduce risk. Participants were not shocked or worried by their lack of information about dementia (Ferguson-Coleman et al., 2014), which reflects low expectations of acquiring sufficient understanding of health-related topics. While providing information in sign language is crucial, linguistic access alone is insufficient. Cultural considerations are essential to effectively engage Deaf people and raise awareness about dementia aligned to their strengths and values (Young et al., 2018).

While the Accessible Information Standard specifies that information should be provided in BSL to be accessible for Deaf people, interview participants P2 (former carer/BSL user) and P5 noted written information is usually provided in English, rather than in sign language. Although hearing relatives or interpreters assist, this process is often avoided due to its difficulty. P1 described difficult experiences learning how to care for someone with dementia:

> There wasn't much information in sign language at the start, so I didn't know anything about dementia… I knew it was linked to memory loss but couldn't find anything about it to educate myself. I had no tips for managing… my son has done a lot for me, I wanted to do this myself to protect him [her partner] and help him improve, but dementia doesn't improve.

P8 commented how lack of information may result in 'Deaf adults being diagnosed with dementia very late'.

P2 suggested spreading information about dementia *via* 'social media in the form of short video clips in BSL', while P1 felt that 'face-to-face information with an interpreter present' would help educate Deaf people. P4 emphasised that 'the Deaf community should be asked whether information translates well', rather than making assumptions about how information is best received. The British Deaf Association has launched an initiative to promote a better understanding of dementia in BSL (British Deaf Association, 2024). However, our interview data highlights that these resources still do not reach everyone that needs to access to this type of information.

The literature reinforced this, for example, that training on dementia in sign language should be integrated into caregiving training programmes (Kushalnagar et al., 2023). Moreover, mainstream dementia services should review and enhance the accessibility for Deaf people (Ferguson-Coleman, 2016). As Deaf individuals rely on vision for acquiring knowledge, information aiming to raise dementia awareness should exploit Deaf people's visual skills (Young et al., 2014).

Importance of Deaf awareness

Raising awareness about the Deaf community and their culture is essential for enhancing accessibility to services and information. Deaf people report that their health concerns are easily overlooked by non-Deaf healthcare professionals often with considerable distrust towards these professionals due to past communication issues (Ferguson-Coleman et al., 2014). Negative stereotypes and misconceptions can lead hearing people and professionals to attribute cognitive-related abnormalities to the person's Deafness. Subsequently, Deaf people can often feel better equipped to recognise signs of memory or language deterioration in another Deaf person compared to assessments by hearing people, including dementia professionals (Ferguson-Coleman et al., 2014).

Some Deaf community representatives may shield vulnerable members, eg Deaf people living with dementia, from contributing to PPI initiatives focused on improving healthcare accessibility. Their concern is that hearing people may misinterpret these contributions to reinforce negative stereotypes, like associating Deafness with intellectual limitations or communication incompetence (Young et al., 2018), potentially exacerbating stigma surrounding dementia within the Deaf community. P4 (social work professional) described a Deaf couple distancing themselves from the community after one of them was diagnosed with dementia, as they felt that 'people don't understand'. This withdrawal from the community may stem from a lack of knowledge within the Deaf community about dementia and how to support someone living with dementia (Ferguson-Coleman et al., 2014).

P3 explained the difficulty of referring a Deaf individual with memory concerns to the GP for assessment. Often, the referral is 'dismissed and nothing further is done' as the GP feels they 'can't do the assessment' on a Deaf individual. The lack of specialist services leads to uncertainty among healthcare professionals about referrals and P8 described how 'the most shocking thing to me was the number of people that were referred but didn't have dementia'. P8 highlighted the difficulty of implementing Deaf awareness training in hospitals due to high staff turnover and many staff.

Lack of Deaf awareness may also pose difficulties in obtaining consent or assessing the capacity of Deaf individuals for treatment. One published case described a Deaf patient in the emergency department who was labelled a 'poor historian' due to communication failures, which were not related to his cognitive ability but rather to inadequate communication methods like shouting and written English (Abou-Abdallah & Lamyman, 2021). Deaf people have recounted distressing interactions during consultations where their pleas for help were ignored, leaving them confused about their diagnosis, treatment plan, and medication use (Sheppard, 2014). In one study, 28% of participants left their GP appointment unsure about their diagnosis and 19% unclear about their medication (Bailey, 2018; SignHealth, 2014).

Interview participant P5 explained how Deaf people need to 'assert their rights, which some people perceive as aggression'. Similarly in the literature, where the relative of a Deaf individual diagnosed with dementia recounted an incident when the doctor 'laughed at her concerns and told her she was being silly' and was reluctant to refer her to a specialist (Parker et al., 2010). Consequently, Deaf individuals may be labelled as 'difficult to treat'. Interview participant P3 (social work professional) discussed how this can lead to disengagement from healthcare professionals, making it more challenging for Deaf individuals to access health services.

In the UK, Deaf awareness training is available to all healthcare workers, but is under-utilised (Abou-Abdallah & Lamyman, 2021). Making it a mandatory module in university or foundation induction, ideally led by a Deaf community member, could enhance communication and trust between the Deaf community and healthcare professionals (Alexander et al., 2012). From our interviews, P1 underscored its potential benefits for care home staff as it would 'help them be more confident communicating with Deaf people'. A key area for improvement identified in a report by the British Deaf Association on enhancing care homes for Deaf people with dementia was the need for better BSL and Deaf cultural training for care home providers (British Deaf Association, 2022). Collaboration between healthcare services and Deaf community charities, suggested by P6 and P2, could address Deaf service users' needs and raise awareness of Deafness and dementia. This approach could encourage the Deaf community to 'get more involved and help remove barriers'. Additionally, efforts from staff and service providers are essential to establish positive relationships with Deaf patients, particularly in primary care (SignHealth, 2014). In fostering a culture of inclusivity, P1 suggested the impact of learning relevant signs like 'dinner' and 'toilet' would contribute to facilitating positive interactions with Deaf patients.

Communication with healthcare staff

Communication issues between Deaf individuals and healthcare professionals are evident. Only 25% of Deaf people expressed 'trust and confidence' in their doctor compared to 67% of the general population (SignHealth, 2014). Many Deaf people feel uncertain about trusting their doctor to correctly diagnose issues, often leaving consultations with doubts about being fully understood (Ferguson-Coleman et al., 2014). This is often due to the absence of an interpreter during consultations, and doctors providing information in written English which Deaf individuals may struggle to understand (Ferguson-Coleman et al., 2014). Negative healthcare experiences among the Deaf community typically stem from poor communication, leading to reliance on lip-reading and written information, leading to misunderstandings and potential medical errors (Alexander et al., 2012).

P1 described communication issues in care homes, with limited BSL knowledge among staff:

> There were lots of mistakes when trying to communicate with X [her partner]…when he was trying to let them know he wanted the toilet and he would shout…he was signing 'T' and they thought he was signing for tea. There was a lot of communication breakdown, I think that added to the frustration for X as well and sometimes he would wave to staff because he wanted to say something…and they would just ignore him, walk past, but they would talk to other people…but I'd have to get their attention to tell them X needs the toilet.

To encourage patient-centred care for Deaf individuals, the communication preference for each patient must be determined. A communication plan, recorded and flagged in the patient's record, should be agreed. This plan should cover the patient's preferences regarding communication during consultations, how to be addressed in the waiting room, and how results are conveyed (SignHealth, 2014). Middleton et al. (2010) provided a several tips for communication, eg ensure the person knows what is being discussed; use cues, gestures, signposting and writing when required; but the most important consideration remains empathy with the hearing impaired person.

Access to interpreters during consultations is key for effective communication with Deaf patients but interpreters are often in short supply and require advance booking (Alexander et al., 2012). Consequently, patients frequently resort to family/friends to interpret, which compromises privacy and autonomy, places an emotional burden on relatives, and poses the risk of missing key information, as professional interpretation is necessary to convey complex health information (Parker et al., 2010; SignHealth, 2014).

The Equality Act 2010 and NHS England (2018) require providers to supply an interpreter to prevent discrimination in healthcare. Some older Deaf patients are unaware of their right to language provision and the opportunity to book interpreters, as qualified BSL interpreters were not commonly available for healthcare appointments previously (Ferguson-Coleman et al., 2020). However, awareness of this right does not always ensure its provision. Among 744 respondents, 68% who requested a BSL interpreter for their GP appointment did not receive one, and 41% of those who did found the interpretation quality inadequate (Bailey, 2018). Securing an interpreter may not guarantee effective understanding, quality interaction, or accurate and clear interpretation [9, 30]. P5 explained that 'even if information is given *via*…interpreter, some medical terminology is hard to understand'. This lack of understanding can be because of a low fund of health literacy (Pollard & Barnett, 2009).

Having the same interpreter for all appointments is preferred, as it limits access to personal information to just one extra person. Challenges arise when the preferred interpreter is unavailable, as this would require sharing personal information again with a new BSL interpreter. P1 stated that 'nothing feels private', and often attends appointments alone when their preferred interpreter is unavailable: 'If the interpreter I normally use is away, it's hard to communicate and often I will say I understand something even if I don't'. For P5, it is 'difficult to maintain an interpreter for every consultation if a Deaf person is referred to a different service', affecting their continuity of care. P1 and P8 emphasised that this contributes to appointment cancellations or delays, healthcare costs, and hinders access to essential health information. This creates additional barriers to obtaining information, particularly for accessing support groups for health-related issues. P2 highlighted: 'it's difficult to access information, you can't go to support groups and because they don't really book interpreters, so they don't get any information that way… so they don't have access there'.

Specialist dementia services for Deaf people

Appropriate assessment for Deaf people

The Mini-Mental State Exam (MMSE; Folstein et al., 1975) is often used to assess cognitive function. It is available in over 50 languages, but there is just one study of its validity and reliability in older Deaf Americans (Dean et al., 2009). American Sign Language (ASL) is a different language from BSL, and ASL speakers may not be able to understand BSL (and *vice versa*). In this study involving 117 older Deaf American participants, the mean performance score fell below the 'normal' range, potentially influenced by cultural and linguistic factors rather than solely cognitive impairment. Translating the test to American Sign Language (ASL) presents challenges due to grammatical and structural differences leading to potential misunderstandings of tasks. Specific words do not translate directly into ASL, which could affect comprehension and overall test score. Therefore, responses may make sense in ASL, but the test-taker may not receive credit if scored using English grammar. The most accurate results were obtained when the test was given by qualified professionals proficient in ASL with a background in cognitive assessment of Deaf adults (Dean et al., 2009).

P6 (audiologist) acknowledged that 'the majority of cognitive assessments are not appropriate for Deaf adults' as most are delivered orally and therefore inaccessible and unvalidated for the Deaf community. While visual tools offer an alternative, visual impairments among older adults could compromise results. Testing semantic understanding differs for Deaf individuals, as P8 explained that certain signs might overlap with the action they are asked to perform in some tests. For instance, the BSL sign for 'screwdriver' is the same as the action of using one.

Considering the experiences of Deaf people during assessment and subsequent diagnosis is also important. P1 described receiving the dementia diagnosis:

> [The doctor] said he had got dementia and that was it. I didn't get anything at the time he was diagnosed, and I don't think there was an interpreter either. The appointment came in late and I couldn't

> get an interpreter so it was a bit of a breakdown…we just got told he had dementia and if I had an interpreter I probably would have asked more questions.

P2 had a similar experience: 'The doctor was like give her some medication and get her out of the way…rather than supporting and understanding'.

The BSL Cognitive Screening Test (BSL-CST) was developed to ensure cultural and linguistic accessibility for cognitive assessment in the Deaf community. Rather than attempting to translate spoken language tests, it was developed with BSL and Deaf culture as the foundation and uses BSL videos without English language requirements (Atkinson et al., 2015). Similar to standard cognitive tests like the MMSE, it assesses memory, visuospatial domains, language, and executive functioning (Denmark et al., 2016). The BSL-CST shows validity and reliability across a wide demographic of Deaf sign language users. However, it needs validating with participants presenting with milder cognitive impairment than in the original sample (Atkinson et al., 2015). The BSL-CST has potential for earlier diagnosis and tailored treatment planning for Deaf people; however, it requires BSL proficiency or accurate administration and interpretation. It has not been validated for use by clinicians without sign language proficiency (Harris et al., 2021).

Specialist memory clinics and care homes for Deaf people

In 2011, the first specialist cognitive clinic for Deaf BSL users was established in the UK to address diagnostic challenges, improve communication between practitioners and Deaf patients, and reduce health inequalities (Harris et al., 2021). An interpreter who has been fully trained in all aspects of the BSL-CST assessment attends all consultations. For patients referred to the clinic with a prior diagnosis, this was changed in 67% of cases, and significant comorbidities are frequently identified, eg 36% affected by hypertension and 14% with diabetes (Harris et al., 2021). P8 described how such a clinic could detect 'specific conditions such as primary progressive aphasia, which other teams may not be able to see'. P8 emphasised the value of Deaf clinicians as cultural insiders who can discern subtle details that might be overlooked by other professionals. However, with only one clinic nationally, patients have to travel, particularly challenging for older people. Moreover, many GP practices are unaware they can make direct referrals to this clinic. Consequently, numerous Deaf people who could benefit from the clinic are perhaps not referred (Harris et al., 2021).

P4 described how many Deaf individuals lack knowledge about addressing memory concerns within their community. This could result from lack of knowledge about dementia, uncertainty in communication, or not knowing where to refer people. In response, P5 implemented a face-to-face drop-in service for the Deaf community, addressing concerns about memory difficulties and health-related issues through effective signposting. Being a BSL user and a member of the Deaf community, P5's involvement fosters trust among Deaf people about health concerns. As this is a novel service that is not mirrored across the UK, it highlights the lack of parity within the Deaf community.

For Deaf people living with dementia, finding a suitable care home is challenging. In the literature, a Deaf daughter seeking a care home for her Deaf mother with dementia recounted staff mistreatment towards Deaf residents, including shouting and rough handling (Parker et al., 2010). P1's partner attended four care homes but 'no one understood BSL in any of them'. P1 and P5 found that any care home with services or staff for Deaf residents was either too far away or 'very expensive'. Consequently, Deaf individuals may end up in environments where their communication needs are unmet, leading to potential isolation and health problems.

Due to insufficient awareness of the needs of Deaf residents, family members and friends often have to take on the responsibility of being vigilant and regularly ensuring that the well-being and needs of the Deaf person in the care home are being addressed. There is very little information in BSL to help Deaf people make informed decisions about care homes. Moreover, Deaf family and carers often feel alienated from the processes surrounding assessment and decision making about whether someone should move into a care home. This is due to the absence of a BSL interpreter, or assumptions that they can understand written English. The lack of an interpreter partly arises due to the fact that care homes care homes may not recognise the necessity of booking an interpreter, lack knowledge on how to do so, or are unaware of their obligation to provide one. Social workers and care home staff sometimes find it easier to communicate with hearing person in the family rather than directly with the Deaf primary caregiver, leaving Deaf individuals feeling marginalised (British Deaf Association, 2022).

P1 described communication issues in care homes, with limited BSL knowledge among staff:

> There were lots of mistakes when trying to communicate with X [her partner]…when he was trying to let them know he wanted the toilet and he would shout…he was signing 'T' and they thought he was signing for tea. There was a lot of communication breakdown, I think that added to the frustration for X as well and sometimes he would wave to staff because he wanted to say something…and they would just ignore him, walk past, but they would talk to other people…but I'd have to get their attention to tell them X needs the toilet.

Navigating the challenges following dementia diagnosis

Experiences of Deaf individuals diagnosed with dementia

Deaf people with dementia commonly experience communication difficulties as the condition progresses, including subtle signing errors, such as altering the shape or articulation of a sign or using vague gestures when unable to recall a specific sign (Denmark et al., 2016). Deteriorating hand mobility and visuospatial deficits further complicate signing (Rantapää & Pekkala, 2016). For Deaf individuals, sign language is a fundamental part of their culture and community. For a person who is Deaf with dementia, the impact on sign language caused 'deep sadness and despondency' (Kolberg et al., 2024; Young et al., 2014). Subsequently, many individuals become withdrawn and engage in fewer conversations (Ferguson-Coleman et al., 2020; Parker et al., 2010). Isolation may be exacerbated by limited dementia awareness within the Deaf community. For example, some people with cognitive difficulties in later life experienced rejection from their community, with life-long friends no longer visiting them. Some were asked to leave events because their behaviour was perceived as disruptive or embarrassing (Ferguson-Coleman et al., 2014).

P1's partner experienced isolation in the care home:

> I know dementia won't improve but…with hearing people, they're all singing and clapping and they can listen to music but my husband just sat there and couldn't hear the music…and he struggled to get involved…I think they just kind of left him there…because

> he was Deaf, not so much his dementia and I'm not blaming them I think they just forget he's Deaf and think he doesn't want to get involved because he hasn't heard them.

P1 said their partner's 'dementia deteriorated' because he 'wasn't signing with anyone for long periods', ultimately resulting in his hospitalisation after being misunderstood as violent. Thus, communication barriers and isolation for Deaf individuals with dementia may exacerbate their condition.

Experiences of caregivers

Deaf caregivers face challenges caring for their relatives with dementia due to limited information in sign language. In a previous interview study, participants described making quick decisions based on the immediate situation, inadvertently leading to safeguarding issues, such as leaving their partner with dementia alone in the car or at home to attend the local Deaf club (Ferguson-Coleman et al., 2020). These decisions were not based on neglect but on lack of available information. In our data, P1 described how they 'learned about dementia through experience but knew nothing about it before'. Moreover, P2 'couldn't really find any information [in BSL]. There are support groups in the area but there weren't any interpreters so I can't access them'. While hearing caregivers may benefit from support groups, Deaf people encounter cultural differences and feeling that they must constantly clarify their Deaf identity can be stressful (Ferguson-Coleman et al., 2020).

Some Deaf individuals advocate for Deaf people with dementia to remain at home where caregivers understand their needs (Parker et al., 2010; Rantapää et al., 2024). Yet, care homes may be necessary, which can be emotionally challenging for caregivers, especially where care homes are not Deaf-friendly. P1 described her feelings:

> they left my husband out [of games] and I had to encourage him to get involved so I could show everyone that he can do some of the games because I think they look at him and think he can't do it… sometimes because he is Deaf it was easier to leave him out. I felt hurt when I saw that…they couldn't look after him in the care home…he's left there on his own and it's difficult. [In one care home] he fell five times, it broke my heart…I couldn't understand how he was falling, and I was crying and upset about it, thinking about if he was safe at the care home. I stopped eating, and my husband wasn't eating well anyway… I was just worried.

Discussion

This study is a novel synthesis of published literature and qualitative interview data, describing several key health issues experienced by older Deaf people, particularly those living with dementia and their families. Both the literature and interview data consistently highlighted poorer health outcomes in the Deaf community compared to the general population, exacerbated by underdiagnosis of conditions like diabetes and cardiovascular disease (Emond et al., 2015; SignHealth, 2014). Deaf people can be reluctant to seek healthcare due to communication issues and previous negative experiences (Sheppard, 2014). A scarcity of accessible information in BSL, few professional interpreters, and limited Deaf awareness among healthcare staff all contribute to communication barriers. Consequently, Deaf people have insufficient information about dementia, creating a detrimental cycle wherein they are less likely to seek healthcare and subsequently face delays in diagnosis (Powell et al., 2022). Both the literature and the interview data illuminated a lack of dementia assessment methods and services that are appropriate for Deaf people. Although the BSL cognitive screening test improves diagnosis accuracy, it can only be used by clinicians proficient in BSL (Atkinson et al., 2015). Moreover, the only dementia assessment service for Deaf people in the UK, presents travel challenges for elderly individuals. Few assessment alternatives tailored to the Deaf community were found in the literature.

The study has several strengths. The qualitative interviews drew upon expertise by experience and profession, with diversity in location, gender, and profession, thus capturing a range of stakeholder perspectives. Furthermore, the study provided first-hand experiences from Deaf people, including those caring for someone with dementia, often lacking in prior research. We interviewed people using BSL with support from professional interpreters, which is another strength, as BSL users are often not involved in research, and professional interpreters are scarce even in clinical appointments.

While interviewing a member of the Deaf community living with dementia would have been ideal, recruitment for both dementia and Deafness is highly challenging. Another limitation was the sparse literature addressing the intersection of Deafness and dementia. To compensate, the inclusion criteria were extended from 10 to 15 years, although older studies often lacked coverage of recent technological advances (eg appointment booking apps, social media). Nonetheless, both older and more recent studies often identified the same key issues, indicating slow progress to improve healthcare for Deaf people.

An important gap in the literature is a lack of accurate figures on the older Deaf population, making it hard to estimate the prevalence of dementia. While Deaf people may exhibit higher rates of dementia risk factors, the comparison of dementia rates between the Deaf and hearing populations remains unclear at present. Additionally, future research should explicitly clarify whether they include participants from the Deaf community and/or participants with hearing loss who do not identify as culturally Deaf. In this review, only papers explicitly centred on the Deaf community were included.

Studies included in the literature review had inadequate representation of diverse populations. Older Deaf people may be reluctant to participate due to mistrust and concerns about reinforcing negative stereotypes held by the hearing population. There is scant literature regarding older Deaf people from ethnic minorities, leading to under-representation of their unique experiences. There are no intervention studies addressing dementia in the Deaf community. Research involving diverse participants is needed to provide a more nuanced understanding of the experiences of older Deaf people. This could be achieved by involving 'cultural insiders' in conducting and leading research to facilitate open communication and establish trust (eg Suwankhong & Liamputtong, 2015). A co-production approach, partnering with Deaf people affected by dementia, to define research questions and design studies and services is crucial for sharing power and ensuring alignment with Deaf people's needs. Promoting and funding such research would contribute valuable insights into effective strategies for assessing and managing dementia among Deaf individuals.

This research has important clinical implications. Interventions and Deaf awareness training are needed to facilitate effective communication between health and social care staff and Deaf patients. Both parties should be informed of patients' right to interpreters during clinical consultations. Information should be delivered in BSL and clearly signposted, eg through short BSL videos and collaborating with Deaf charities to promote awareness of health topics like dementia. Screening and assessment methods for dementia must be culturally sensitive and tailored to Deaf individuals, with clear guidelines and ample time to deliver a diagnosis. Implementation and accessibility of the validated BSL-cognitive screening test would help facilitate accurate and timely diagnoses.

Care homes with Deaf residents should ensure they have suitable resources and facilities to provide quality care. This could reduce negative outcomes (eg isolation, stress) in Deaf residents and their relatives. Deaf caregivers face challenges accessing dementia support groups due to interpreter availability and because their experiences may differ from those of hearing caregivers. Therefore, specialised Deaf support groups are required.

Finally, enhancing Deaf representation in healthcare and increasing involvement in research can significantly improve awareness and outcomes for Deaf people. To achieve this, initiatives aimed at making healthcare education and career opportunities more accessible to the Deaf community should be prioritised (Abou-Abdallah & Lamyman, 2021).

In conclusion, this paper highlights the challenges faced by older Deaf individuals within the health system, particularly regarding dementia diagnosis and management. The need for improvements is evident: greater availability of interpreters, access to health-related information in BSL and the implementation of Deaf awareness training for healthcare staff and students are crucial steps forward.

This novel synthesis of a literature review and qualitative interview data provides a nuanced understanding of the experiences of Deaf individuals and their caregivers. By addressing these barriers and promoting accessibility in education and training, we can create a more inclusive environment that supports the Deaf community across various areas of life, including healthcare.

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