

Dementia Gateway: Sensory loss and dementia

This summary highlights key messages from the research on sensory loss.

Key messages

- There is a lack of prevalence studies of dementia and sensory loss, but clear evidence of an association between visual impairment and dementia, and age-related hearing loss and dementia.
- Visual deficits can be the first or major manifestation that trigger people to seek help regarding Alzheimer's disease, although people are often not aware of the link.
- Recent research has demonstrated strongly that there is a relationship between age-related hearing loss and an increased risk of all different kinds of dementia, not just Alzheimer's disease. However, research is inconclusive whether by improving hearing it is possible to decrease the risk of dementia and/or improve cognitive functioning.
- living with advanced dementia which also include incontinence, malnutrition and frailty.
- Visual and hearing impairments interfere with the assessment and diagnosis of dementia and conversely dementia can affect the assessment of visual or hearing impairment. Cognitive assessments are more complicated to carry out and their results more uncertain.
- The challenges of cognitive assessment and diagnosis of dementia in the case of Deaf people who use sign language are different because of the visual spatial nature of signed languages and the cultural identity of Deaf people.
- Most research and clinical guidelines on dementia fail to consider the role of sensory loss in screening, diagnosis and treatment.

- Visual and hearing impairments form part of a syndrome of conditions often found in people
- The little research that has been carried out with people with dementia and sight loss indicates its profoundly distressing nature and the difficulties of formal and informal carers in helping people to maintain quality of life.
- The small amount of research that has been carried out with Deaf sign language users with dementia and their carers demonstrate that the key barriers are access to information, effective strategies for gaining knowledge about dementia, communicating with professionals and lack of cultural awareness of the needs of Deaf people.
- Guidelines for professional practice tend to assume people with dementia can see and hear, and do not generally address vision- and hearing-related issues.

Introduction

This summary highlights key messages from the research on sensory loss and dementia. It is not intended to be a comprehensive review of literature on this topic. 'Sensory loss' refers to sight, hearing or dual sensory loss. Studies concerning culturally Deaf people who use a signed language such as BSL (British Sign Language) are included, but from the perspective of Deaf people's linguistic and cultural identity status.¹ The perspective of sensory 'loss' is one which is rejected by Deaf communities around the world.²

The material on which the review is based was identified through focused searching of the literature from 2008 to 2014. However, where there is an important piece of work that was published earlier, it will be cited. While the focus of this briefing is on the situation in the UK, the research literature that has been drawn on is international in scope because of the limited amount research literature in this area.

What is the issue?

'Sensory loss' is a general term that hides a vast diversity of experience of sight and hearing. Although some people have lived with sight loss, deafness or both throughout their lives, for the vast majority sensory loss occurs in later life.^{3,4} Dementia is also a condition affecting mainly older people. Consequently, the relationship between dementia and changes in hearing and/or vision is an important focus of concern whether from a causal, diagnostic or care perspective.

Status of the research

Internationally, there is a growing body of research on age-related hearing loss, cognition and dementia. There is minimal research on cognition, dementia and sign language. There is a much larger body of work on vision, sight loss and dementia. There is very little research documenting the lived experience of people with sensory loss who have dementia.

Although there is good quality research on the relationship between hearing loss and dementia, there is some concern that the samples used in the studies are not representative of the diversity of populations in any given country. Also in terms of care and support, the impact of culturally normative practices as an additional dimension in understanding the relationship between sensory loss and dementia has not been explored. An exception is culturally Deaf people with dementia and their carers.

The other main gaps are evidence that might be drawn from evaluation of strategies to promote positive living with sensory loss and dementia, and intervention studies that examine the effectiveness of professional approaches in the care of people with sensory loss and dementia. Research on cognitive assessment for those with visual impairments and people who are sign language users is also very limited.

Implications from the research

Ageing and sensory loss

Most (6.3 million) of the 10 million people in the UK with some kind of deafness are of retirement age, the vast majority of whom will have lost their hearing as part of the ageing process. Similarly, 71.1 per cent of over 70 year-

olds and 41.7 per cent of over 50 year-olds have some form of hearing loss.³ It is estimated that by 2031 there will be 14.5 million people with hearing loss in the UK.³

Twenty per cent of people aged 75 and 50 per cent aged 90 and over are living with sight loss, but only around 7 per cent will have grown up with a visual impairment or a severe visual impairment.⁵ Although there are 360,000 people registered as having irreversible severe or partial sight loss, the RNIB (Royal National Institute for the Blind) estimates that almost two million people live with sight loss. Some of these will have reversible or treatable conditions, for example, refractive errors or cataracts.⁵

Dual sensory loss (hearing and vision) affects 250,000 people in the UK, of whom 222,000 are over the age of 70.⁶ It is estimated that by 2030 the number of deafblind people will increase by 60 per cent, with the largest increase among older age groups.³

Prevalence of dementia and sensory loss

There are many articles reporting the prevalence of dementia and visual impairment separately which show both conditions increasing as the population ages. However, no recent local or national prevalence studies in the UK report how common dementia and visual impairment are together, except where authors have examined the prevalence of dementia in those with specific eye diseases. For example, a study of age-related macular degeneration demonstrated that over three years 14.4 per cent of the study population declined cognitively.⁷ Nonetheless, it has been estimated that 2.5 per cent of people over the age of 75 have a severe visual impairment and dementia.⁸

There are no prevalence studies of dementia among Deaf people who are BSL users and extrapolations of likely

numbers are hampered by inaccurate population statistics for Deaf people who are BSL users in the UK.⁹ However, a recent study has estimated that there are between 675 and 1350 Deaf people (who are BSL users) with dementia in the UK currently.¹⁰

The prevalence of dementia and hearing loss is also not firmly established. However, the increasing evidence of the clear link between hearing loss and cognitive decline, and hearing loss and dementia (see below), suggest that co-occurrence of dementia and hearing loss is more common than previously thought. No published data are available on the co-occurrence of dual sensory loss and dementia in the UK.

Age-related hearing loss and dementia

There is a clearly established link between age-related hearing loss and decline in cognitive functioning.^{11, 12} The underlying explanation for this link concerns changes in how the brain functions both as we age and as we lose our hearing.^{13, 14, 15, 16} This is because making sense of what we hear does not just depend on the quality of our hearing, but also on the capacity of the brain to interpret those sounds and in particular to interpret the speech signals that it receives.¹⁴ Age-related hearing loss can result in shrinkage of the auditory cortex.¹⁶ Also, parts of the brain that are not usually used to process speech signals are recruited to do so as the brain has to work harder to make sense of speech as hearing declines.^{12, 15} Consequently, brain resources usually used for thinking, organisation and remembering functions can become reallocated to speech processing tasks, thus reducing cognitive functioning overall or in some specific aspects.^{12, 15}

Recent research has demonstrated strongly that there is a relationship between age-related hearing loss and an

increased risk of all different kinds of dementia, not just Alzheimer's disease.^{14, 15, 16, 17, 18} Some studies have shown that increased risk of dementia is related to the degree of hearing loss¹⁵, others to the degree of difficulty in speech processing (for example, understanding speech in background noise).^{13, 14} One study estimated that people who did very poorly (less than 50 per cent correct) on specific tests of speech in noise and speech processing had a 7- to 12-fold increase in risk of receiving a diagnosis of Alzheimer's disease in the subsequent 3 to 10 years.¹⁴

Loss of hearing can affect social functioning and social relationships as a result of difficulties in interaction and communication.¹⁹ This has also been identified as an important factor in the relationship between hearing loss and dementia because of the impact of social isolation on cognitive decline and personal wellbeing.^{17, 19} In much rarer cases, the cause of a neurodegenerative condition which includes dementia will also include hearing loss, for example as a result of a specific gene mutation.²⁰

These findings have led to a call to include tests of cognitive functioning in regular audiology appointments when age-related hearing loss is being assessed.¹⁹ This is because age-related hearing loss is now seen as an important potential predictive indicator of the onset of dementia, but at the moment the accuracy of the predictive value has not fully been investigated.¹⁴ It is not clear whether hearing loss should be regarded as a component within an early stage of dementia or whether it is risk factor open to modification.^{17, 18}

Dementia and visual impairment

Dementia and visual impairment have been found to be associated by showing that people with dementia are

more likely to report functional limitations such as vision impairment than people without dementia.^{21, 22} Worse visual acuity scores have been found to be associated with lower cognitive scores or more severe dementia.²¹ This suggests that there is similar pathophysiology between the two conditions, but it is unclear whether one leads to another.²¹ In some studies visual impairment has been found to predate loss of cognition.²³

Advanced dementia and visual impairment are commonly found with other conditions including incontinence, delirium, falls, hearing impairment, sarcopenia, malnutrition and frailty.^{24, 25} Complete consensus on which conditions to include in this list has yet to be reached by health care professionals and without agreement there could be confusion in communication about them.^{24, 25} These groups of conditions or diseases are called 'geriatric syndrome' and is an emerging area for research.^{24, 25}

Visual manifestations in dementia

Inconsistencies in definition and differences in terminology and tests make it difficult to draw conclusions from the research on all types of dementia and visual manifestations. However, it can be said, in Alzheimer's disease, there is damage to the visual pathway from the eyes to the brain.²⁶ People who have brain (cortical) changes in Alzheimer's disease present with vague visual complaints including difficulties with reading or driving.²⁷ The prevalence, associations and prognosis of these changes, including the implications for vision, have yet to be explored fully through research.²⁸ Reviews of the literature discuss how visual deficits are often the first or major manifestation of specifically Alzheimer's disease

reported by patients but people are generally unaware of the link.^{27, 28}

Other dementias may manifest more visuo-perceptual deficits compared with the memory deficits typical of Alzheimer's disease.²⁹ These are: Parkinson's disease dementia, dementia with Lewy bodies and posterior cortical atrophy (PCA).³⁰ Visual hallucinations have been reported in these conditions and range from feelings of presence, perceptual disturbances such as seeing faces in patterns, to complex visual hallucinations, for example seeing people or animals in the home. These have been found to vary across and within diseases, making assessment of prevalence difficult.³¹ Other visuo-perceptual disorders reported commonly are reduced visual acuity, poor contrast sensitivity, reduced visual attention and disrupted visuo-spatial function.²⁷

Dementia diagnosis and assessment – and sensory loss

Sensory loss interferes with accurate assessment of cognition and dementia because of its effects on professional judgement, test administration and the accuracy of test results.

Hearing loss and cognitive assessment

One study of over 2000 patients found that people with hearing difficulties were more likely to be falsely judged as having dementia than those without, although results were not checked against a gold standard diagnostic assessment.³² Similar effects on doctors' judgements have been reported on an individual case basis.³³ The effect of hearing loss on MMSE (Mini Mental State Examination) performance has produced a variety of results. One study of the use of the MMSE with people with a moderate or severe hearing loss has shown a

preference for a written (rather than verbally administered) MMSE, although no discernible difference in scores.³⁴ Another demonstrated that hearing loss has an impact on cognition (as measured by the MMSE) in populations without dementia, to the extent that 'reduction in cognitive performance associated with a 25 dB (decibel) hearing loss was equivalent to the reduction associated with an age difference of 6.8 years'.¹⁷ Difficulties in understanding test administration instructions have also been highlighted as a potential confounder in assessments of people with hearing loss.³⁵

Sign language and cognitive assessment

For a Deaf person who uses a signed language such as BSL or ASL (American Sign Language), the MMSE is not an accurate or acceptable way to assess whether that person has dementia.^{36, 37} It is not a test in the person's strongest or preferred language, and therefore may operate more like a test of language competence. If administered through an interpreter, some of the items will not work in the same way – their interpretation into a visual language can give away the answer. For example, the instruction to draw a particular shape or hands on a clock will be interpreted by showing the shape or the position of the clock hands when it is rendered in BSL. There are also other issues of cultural appropriateness that arise from questions that assume an individual has grown up hearing or shares common knowledge and reference points with the majority culture.^{36, 38, 39} A cognitive screen in BSL has now been developed after first investigating in BSL normal parameters of ageing and cognition among Deaf people.⁴⁰

Visual impairment and cognitive assessment

Visual assessment is compounded by dementia as it is difficult at times to discern whether the outcome of an assessment is because of lack of cognition or actual visual impairment or a combination of both.⁴¹ People with dementia and visual impairment do not tend to have regular eye tests even though they have an eye condition.⁴¹ Research has recommended that the uptake of eye tests needs to be improved in this group of people.⁴¹ A few studies have validated visual acuity tests in people with dementia.⁴² More research is required in this area to help optometrists to accurately assess and intervene to improve the quality of life of people with dementia.⁴¹

Care, support and decision making

Deaf people (BSL users) who have dementia

Deaf people who are BSL users have severely restricted access to information about dementia, care and support options in their preferred and strongest language, BSL. Consequently, the level of awareness of and knowledge about dementia in the Deaf community is quite low.⁴³ The provision of information in written English does not solve the problem, both because it is not Deaf people's preference and because levels of literacy in English are low among Deaf people.⁴⁴ Lack of information affects Deaf people with dementia and their care partners' abilities to make decisions about how they might want to be supported because they are unaware of the choices and options available.⁴³ The translation into BSL of standard information for the general public about dementia has been shown to be insufficiently effective, unless the form of information and knowledge exchange is made culturally appropriate.¹⁰

Residential care is problematic for Deaf BSL users because of a lack of provision where BSL is used and the low levels of awareness of Deaf people's cultural needs to be with others who share the same values, traditions and life experiences.⁴⁵ Isolation, fear and language deprivation have been reported as a result of being a lone Deaf BSL user in an otherwise mainstream (hearing) residential provision.^{9, 45}

Improving hearing and the impact on dementia

For those living with dementia and hearing loss the question arises as to whether improvements in hearing can have a beneficial effect. Evidence is limited, but one study demonstrated that, for some people with a mild or moderate hearing loss, consistent hearing aid use while not improving symptoms of dementia will nonetheless improve general wellbeing.⁴⁶ Improving hearing aid use has been shown to have beneficial effects on social connectedness, communication and quality of life of people with dementia and their carers.⁴⁷ Failure to attend to hearing needs can aggravate some behavioural problems experienced by people with dementia.⁴⁸ Also, simple checks to see whether someone's hearing is affected by ear wax and ensuring its removal have also been shown to be helpful improvements for people with dementia.^{46, 49} Among the 330,000 older people living in residential care environments in the UK today, over 250,000 are estimated to use or be able to benefit from a hearing aid.⁵⁰ However, hearing care in residential care environments has been shown to be in need of improvement with residents' hearing loss commonly remaining undetected and a widespread lack of attention to the benefits of hearing aid use.⁵⁰

Interventions to delay or improve the cognitive status of people with dementia and visual impairment

Ironically, people without dementia are more likely to have visited medical professionals for the treatment of vision-related conditions even though those with dementia could have severe sight problems.^{22, 23} Preventative interventions which treat eye conditions may therefore delay or even prevent progression to dementia, although few studies have demonstrated this yet.²¹ Small-scale studies indicate that it is possible to intervene and reverse cognitive decline and improve other outcomes like quality of life in people with dementia and visual impairment.⁵¹ More research is required to test whether:

- psychological interventions, such as counselling, are helpful in treating those with visual hallucinations
- detecting and treating correctable ocular factors, for example age-related macular degeneration (AMD) or cataracts, are successful in delaying cognitive decline
- adjusting the physical environment may help to reduce the person's distress.⁵²

More intervention studies are needed to test the effectiveness of professional approaches in care of people with dementia and visual impairment.

Models of care for people with dementia and visual impairment

A scoping study reviewed eight models of care for people with dementia and found that they did not usually consider visual impairment.⁵³ For example, a widely used model of care, the person-centred care model – while recognising

the impact of health conditions – fails to take into account the physical environment and therefore may not be particularly useful for people with visual impairment and dementia. On the other hand, another model reviewed in the study (the 'Nightingale model of enriched care') considers how to enhance the environment to maximise the person's capabilities, and as such was found to be more appropriate for someone with dementia and visual impairment. The authors suggest these models could be integrated to make a sensory model of care which would help identify and address visual problems.⁵³ Other guidelines for practice on dementia care also neglect visual impairment, working on the premise that people can see.⁵³

The visual manifestations described above can affect how people with dementia interpret their surroundings leading to adverse outcomes, including distress. Particularly poor design features are, for example, patterned carpets and mirrors. However, there are no recommended environments which are effective for all – and further research is required to inform guidelines on creating environments for people with dementia which take into account visuo-perceptual difficulties.²⁶ One recommendation is that architects should continue to involve those who have experience of working in care settings.²⁶

Visual impairment, cognitive impairment, age, living with others, impaired walking and cancer are key influencing factors in people being admitted to nursing homes.⁵⁴ However, managers of dementia care homes report they do not know how to carry out simple eye tests, were generally unaware of residents' current visual status and did not know age affects vision.²⁶ In residential care settings in Spain, when compared to people without

dementia, people with dementia and high co-morbidity reported the most compromised health status especially in those with sight, oral and genito-urinary problems.⁵⁵

Service user voices

There is very little research evidence generated by people with sensory loss who either have dementia or who are carers of those who do. This is a major gap in our understanding of dementia and sensory loss.

Evidence from carers who are sign language users indicate that a key barrier faced is the inability of professionals to communicate with them or services to prioritise their communication access for support and information.^{39, 43, 56} For the Deaf person with dementia, maintaining contact with others who are BSL users and being cared for in a way that puts Deaf identity and cultural affiliation at the centre is significant.^{10, 39, 43, 45, 57}

In relation to visual impairment, the combined effect of dementia and visual impairment is profoundly disorientating and isolating for the person concerned, and places an enormous burden on informal and formal carers and services.^{58, 59} Professional carers from the field of sight loss report feeling ill-equipped to take on the mental health aspects of care whereas dementia care professionals think that needs relating to visual impairment are overlooked in the mental health services.⁵³ Joint working is recommended between sight loss and mental health services to overcome these shortcomings in service delivery and to better support informal carers.⁵³

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