



The needs of older people with acquired hearing and sight loss

This publication summarises findings from a research study by Sue Pavey, Dr Graeme Douglas and Dr Liz Hodges from the University of Birmingham and Sarah Bodsworth and Dr Isabel Clare from the University of Cambridge.

The study was funded by Thomas Pocklington Trust with the aims of increasing the knowledge base concerning the experiences, needs and goals of older people with acquired hearing and sight loss, and raising awareness of their needs and those of people living and working with them.

Project methods

The project had two distinct phases. Phase 1 analysed two pre-existing datasets relating to 609 older people with hearing and sight loss – the 'Network 1000 dataset' and the 'Cambridge dataset'.

Phase 2 focused on case studies of 20 people with acquired hearing and sight loss who were recruited via the statutory and voluntary sectors. In-depth life story interviews allowed participants to speak of their past and present lives, and their hopes and/or fears for the future. Further information was gathered from some second interviews and through 'diaries', and some data were also collected from connected family members or professionals. Two 'round table discussions' brought together a range of professionals with an interest in deafblindness to discuss and research the findings.

Findings Phase 1

The Network 1000 dataset allowed a comparison between participants with sight loss only and those with additional hearing loss. Those with hearing loss appeared to differ relatively little from those without hearing loss, with some notable exceptions:

- Participants with hearing and sight loss were older and left their home less often.
- The majority of this group had additional health problems or disabilities.
- Over half wore a hearing aid.
- Difficulties with travel, transport and mobility were common, as well as difficulties with independent living skills and in communication and reading tasks.

The Cambridge dataset measured the psychological health of participants. In summary, the findings indicated.

- Almost 50% of the sample was at or above the conservative threshold that indicates above-normal levels of psychological distress.
- Many felt that their hearing loss was more 'disabling' than their sight loss.
- Issues relating to communication, and resulting isolation and loneliness were identified as key factors.
- Feelings of loss of independence and of dependence on others were commonly expressed.
- Many described difficulty due to lack of awareness and negative attitudes of mainstream service providers and the general public towards hearing and sight loss.

Findings Phase 2

Vision, hearing and other disabilities and health problems

The participants' levels of hearing and sight varied, though none were profoundly deaf. Most had limited knowledge of the cause of their sensory loss. The vast majority reported additional health problems or other disabilities, some of which were clearly very debilitating and had worsened in the previous year. Many were vulnerable to falls at home; few had a system, e.g. personal alarm services, or modifications to their home, e.g. handrails, to reduce their risks.

Most spoke positively about hearing aids and low vision aids which enabled them to do things that were otherwise impossible, like reading their own mail or participating in conversations. Nevertheless, some struggled with the technology and some required further hearing or low vision assessments, particularly as their hearing and sight had deteriorated over the previous year.

Identification

Participants had a relatively low awareness of their registration status as deafblind, which contrasted with a clearer understanding of their registration as blind or partially sighted.

Communication and social interaction

An extremely strong theme was the communication challenges and associated isolation faced by many. Communication in groups was very difficult. Problems with mobility and travel for those who lived alone meant that opportunities for communication were also limited. Use of the telephone was problematic for some, but many had overcome this problem, e.g. by adding amplifiers.

Leaving the home and getting out and about

Participants described many difficulties, including personal/health barriers (e.g. low levels of energy, difficulty walking, and fear of falling) in getting out and about. Nevertheless, many described strategies for travelling, e.g. ringing ahead, asking people for help, using public transport and taxis. People commonly went out with others. Some said that a fear of crime prevented them going outside.

Activities within and beyond the home

Many participants described leisure activities relating to the spoken word, e.g. talking books, radio, and television. People often talked about the importance of having visitors. Contact with religious groups was important to many, in particular the connection this gave to a community of people.

Daily living and sources of support

A key source of support for many participants was family, but some were concerned about 'being a burden'. Many needed support to go shopping. Whilst many were in contact with a support service for people with sensory loss, their needs were not always met and referral routes were not always clear.

Daily living and independent living skills

Participants' hearing and sight loss made many daily living tasks difficult, and this was often exacerbated by additional health problems and disabilities. Of central importance to participants was the wish to retain independence.

Accessing information

Courses for those who are newly registered or diagnosed, usually as visually impaired, were an important source of information for some participants. These courses also provided opportunities for socialising and communication with other people with sensory impairments and sometimes gave partners/carers a greater understanding of sensory loss that helped them facilitate the participant's independence.

Four participants were using computers and it was clear that this offered them many opportunities.

Access to and participation in clinical services

Many participants reflected upon both negative recollections (e.g. insensitive staff, lack of continuity, poor communication) and positive recollections (e.g. 'wonderful' staff) of services received. Some found visits to hearing specialists and the maintenance of hearing aids difficult due to their sight loss. Many seemed vague about the services on offer relating to hearing loss and there was a lot of confusion about referral routes for hearing aids, the boundaries between NHS and private services, and costs. Many participants were unclear and passive about referral routes to general clinical services and there were a number of examples of difficulty in accessing those. There were mixed experiences of hospital admissions; most were negative and often linked to staff not identifying their communication needs.

Social and emotional needs

Many participants felt negative about their current life and prospects for the future; this seemed particularly true of those who lived alone. Unsurprisingly, given the age of this group, experience of bereavement was common. Key coping strategies appeared to be drawing upon positive memories and religion, the latter playing a strong role in many of the participants' lives. Many felt they lived day to day and coped with anxieties about the future by refusing to reflect on it.

Many expressed anxiety about the possible deterioration of their health and sight, about becoming a burden upon their families, particularly their children, and about not being able to stay in their own homes.

Care homes

Participants seemed overwhelmingly negative about moving into a care home. This seemed to be linked to feelings of losing independence.

Views of some participants' families

Interviews with families indicated the daily support they gave to participants. Various issues would relate to carers generally, e.g. the need for respite care, and advice and support about the caring role. A particularly relevant issue was that the spouses were vulnerable to ageing and complications of deteriorating health and disabilities. It was clear that participants with spouses had more comprehensive care and companionship, and appeared happier, than those who lived alone. However, there was a feeling that this support was delicately balanced.

Professionals' views of services

Responses from a small sample of professionals illustrated a range of ways of managing caseloads and using registers of deafblind people. Encouragingly, the services offered mirrored many of the issues and needs raised by participants, but time and resources did not allow professionals to assess needs adequately, or provide resources for each person in the depth required. Awareness training of staff in allied sectors was seen as an important role (e.g. for generic staff in day centres, residential homes and hospitals), but scarce resources and high caseloads meant this work was infrequent.

Discussion

Findings show the difficult circumstances that many people with hearing and sight loss experience, whether due directly or indirectly to their sensory loss. The secondary data analysis demonstrated that many older people with hearing and sight loss appear to experience levels of psychological distress that are higher than similarly aged people without sensory impairments. This offers a powerful backdrop to the data gathered in the case studies – it is hardly surprising that people

with hearing and sight loss may suffer psychological distress given that many of the research findings could be associated with feelings of isolation, lack of control and depression.

The findings reinforce the Department of Health definitions of the impact of hearing and sight loss through a focus on access to information, communication and mobility.

Difficulties in these areas, and across the themes in the research, interact and may be mutually reinforcing. People in the group were at a time in their lives when bereavement was experienced or feared, and this concern was exacerbated by the implications of loss of support from partners, loss of independence and the ability to live in their own home. Many feared they would become so dependent that they would have to move to a care home.

Undoubtedly, the research findings provide clear evidence of people facing very difficult challenges. Nevertheless it would be simplistic to ignore the positive findings. Most notably, participants often showed remarkable resourcefulness, pragmatism and determination. For many the companionship of a partner or family was crucial. Many valued support from services, but not all had received such support.

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How to obtain further information

A report in the form of an Occasional Paper entitled 'The needs of older people with acquired hearing and sight loss' by Sue Pavey, Dr Graeme Douglas, Dr Liz Hodges, Sarah Bodsworth and Dr Isabel Clare is available from:

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Copies of the two reports that inform this publication are available to download from <http://www.education.bham.ac.uk/research/victar/research.shtml> and are entitled as follows:

1. Secondary data analysis with a focus upon the needs of older people with acquired hearing and sight loss: An analysis of the 'Network 1000' and 'Cambridge' datasets.
2. The needs of older people with acquired hearing and sight loss: findings from 20 case studies.

Copies of this report in large print, audio tape or CD, Braille and electronic format are available from Thomas Pocklington Trust.

Background on Pocklington

Thomas Pocklington Trust is a leading provider of housing, care and support services for people with sight loss in the UK. Each year we also fund a programme of social and public health research and development projects.

Pocklington's operations offer a range of sheltered and supported housing, residential care, respite care, day services, resource centres and volunteer-based community support services.

We strive to improve continuously the quality standards in our operational centres to meet the changing needs and expectations of our current and future service users. We are proud to be an Investor in People and a Positive about Disability organisation.

Our research and development programme aims to identify practical ways to improve the lives of people with sight loss by improving social inclusion, independence and quality of life, and improving and developing service outcomes as well as focusing on public health issues.

In this publication, the terms 'visually impaired people', 'blind and partially sighted people' and 'people with sight loss' all refer to people who are blind or who have partial sight.



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