Dementia and Blindness

This publication summarises findings from research conducted by Richard Trigg MSc, Health Psychologist and Roy Jones FRCP, Professor and Director, Research Institute for the Care of the Elderly.

This project examined the information available and issues concerning people who have both dementia and visual impairment. The report has reviewed the research evidence, the number of people affected by both conditions, the problems that those with both conditions may face and areas where intervention may lead to improvements in quality of life.

The study found that:

- there is a lack of reliable data concerning the population in the UK with both visual impairment and dementia
- the potential areas for further research were:
  - epidemiological studies
  - the effectiveness of routine assessments
  - the needs of people with dementia and sight loss
  - optimising vision in people with dementia
  - understanding vision impairments resulting from dementia
  - development of educational programmes
  - rehabilitation techniques
  - environmental design
  - the development of appropriate assessments.
Introduction

Dementia is an acquired and progressive problem affecting thinking processes, the ability to perform everyday activities and behaviour. Vision is one of the primary senses and partial or complete loss of sight will have a major impact on a person’s ability to communicate effectively with others or function independently. There will inevitably be profound practical, emotional, financial and psychological effects for a person who has both dementia and impaired vision. These effects will extend to their family and to society.

The information was obtained from a wide-ranging search of the literature for the period 1981-2004. No comprehensive study was found covering the area of visual impairment and dementia.

Background – Dementia and visual impairment

Dementia is one of the most important causes of disability in elderly people and age is the main risk factor. With the ageing of our population, the number of people with dementia is rising. Alzheimer’s disease is responsible for half to two-thirds of all cases.

Vascular dementia (as a result of stroke disease or problems with the cerebral circulation) is responsible for 10-20% of cases. Dementia with Lewy bodies and dementia associated with Parkinson’s disease is responsible for another 10-20% of cases. Dementia with Lewy bodies is of particular interest because patients also have problems with visual hallucinations. Most people are aware that dementia affects memory but it is the impact on performance of daily activities and problems with behaviour (including aggression, agitation and sleep disturbance) that cause particular difficulties and lead to institutionalisation.

In the UK loss of sight usually happens later in life as part of the ageing process, and more than 12% of people over the age of 75 are visually impaired.

Conditions such as multiple sclerosis, Down’s syndrome and diabetes can cause both visual and cognitive impairment. However, in most cases the two problems, of dementia and visual impairment, develop independently. One UK study reported impaired vision in 28.8% of people who live in the
community in comparison with 34.6% of a control group matched for age. These differences were not significant. A study of visual impairment in nursing home residents in Australia did conclude that residents with dementia were more likely to have blindness (13%) compared with those without dementia (9%). However it is likely that a blind person with dementia is more likely to need nursing home care.

Little attention was paid previously to the possibility of abnormalities in processing visual information in Alzheimer’s disease. There is increasing evidence that there are significant disturbances in visual function in Alzheimer’s disease and other types of dementia. For example there may be problems with visual acuity, contrast sensitivity, colour vision and depth perception. In general these deficits are believed to be more reflective of disturbances in the brain than any specific problem in the eye or the optic nerve.

A visual variant of Alzheimer’s disease has been reported in a small number of people who develop a progressive decline in visual processing that is out of proportion to the difficulties in other aspects of cognition and thinking processes.

There is a clear link between impairment in visual acuity and the occurrence of visual hallucinations. Despite this one study demonstrated that few dementia patients with hallucinations had undergone recent visual assessment. It has also been suggested that there is sufficient evidence of a link between reduced vision and hallucinations in dementia to warrant an experimental study of the therapeutic value of improving vision for these people.

It seems clear that a better understanding of the relationship between visual processing and dementia is essential and that tangible benefits may arise from this knowledge.

**Number of people affected**

No specific figures have been identified from the literature review for the numbers of people with both dementia and visual impairment. It is possible to make a rough estimate of the number of elderly people who have dementia and visual impairment based on the data for the individual problems. A reasonable figure for the prevalence of dementia in people over 75 is 15% of the population.
Prevalence estimates of visual impairment from the Medical Research Council Trial of Assessment and Management of Older People in the Community gives a figure of 12.4%. This would suggest that about 2% of people over the age of 75 are likely to have dementia and visual impairment.

This figure is likely to be conservative because of the links previously mentioned between dementia, particularly Alzheimer’s disease, and visual problems. It is also likely to be an under-estimate in that the studies of visual impairment will not have accounted for individuals who are deemed to be untestable and it is likely that this group would have included subjects with dementia.

**Difficulties in assessment of people with both problems**

As drug treatments become available for people with dementia, accurate and earlier diagnosis is becoming increasingly important. Similarly, early diagnosis of eye conditions is essential for treatment and prevention. Diagnosis of dementia usually involves the performance of some form of memory and cognition test. In one study, the most common cause of poor performance other than dementia on a standard test was poor vision or blindness. The Mini-Mental State Examination is one of the most widely used screening tests for dementia. A version for blind people has been developed and found to be valid but it deserves more widespread application.

Standard tests of vision are rarely carried out when people are assessed for dementia. In addition a person with dementia may find it difficult to describe problems and fluctuations in visual functioning. On the other hand it is more difficult to assess the memory and cognitive functioning of a person with significant visual problems. Equally an overestimate of cognitive impairment may be made if an elderly person is tested in conditions where the lighting is poor.

There is agreement between the literature and the people consulted for this report that it is vital that eyesight is optimal in people who also have dementia.
Problems of having both conditions

The degree to which a person with dementia is able to cope with cognitive impairment is likely to be influenced by visual impairment and vice versa. For example people with dementia have an increased risk of falls as do people with significant loss of vision. The risk of falls is increased in people with impaired depth perception and impaired contrast sensitivity; both factors may be altered by conditions such as Alzheimer’s disease. People affected by both conditions may be more susceptible to noise, changes in light intensity and in understanding and learning how to use new equipment.

The use of compensating mechanisms to help visually impaired people overcome their visual deficits will be significantly affected by problems with memory and thinking processes.

Independence in carrying out everyday activities is known to be an important component of quality of life for people with dementia. Visual impairment will have a significant additional negative impact.
Conclusions and suggestions for potential research projects

The most striking conclusion from this review is that there continues to be a lack of formal research on this population. Information regarding people with dementia and visual impairment can generally only be found in studies examining one of the two conditions. There are few documents that address the characteristics and needs of people with both conditions. Yet both problems are very common in older people particularly those in residential and nursing homes.

Finally, this review suggests some areas for potential future research:

- there is a lack of reliable data concerning the population in the UK with both visual impairment and dementia
- there is a need to assess the effectiveness of routine assessments
- there is little information on the experiences and needs of people with dementia and sight loss
- there is a need for research to assess the impact of optimising vision on the occurrence and severity of hallucinations in people with dementia
- there is little understanding of vision impairment resulting from dementia
- there is a need to improve educational programmes for care staff
- current models of rehabilitation need to be reviewed
- the environmental settings and requirements should be reviewed
- assessments need to be sensitive to the difficulties that can occur through impaired contrast sensitivity or acuity.

Authors:
Richard Trigg MSc, Health Psychologist
Roy Jones FRCP, Professor and Director

The Research Institute for the Care of the Elderly
St Martin’s Hospital, Bath BA2 5RP
Background on Pocklington

Thomas Pocklington Trust is the leading provider of housing, care and support services for people with sight loss in the UK. Each year we also commit around £300,000 to fund social and public health research and development projects on sight loss issues.

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

A Positive about Disability and an Investor in People organisation, we are adopting quality assurance systems for all our services to ensure we not only maintain our quality standards, but also seek continuous improvement in line with the changing needs and expectations of our current and future service users.

We are working in partnership with local authorities, registered social landlords and other voluntary organisations to expand our range of services.

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, improving and developing service outcome as well as focusing on public health issues.

We are also applying our research findings by way of pilot service developments to test new service models and develop best practice.