

Visual Hallucinations in Sight Loss and Dementia

This publication summarises findings from a research review conducted by Joanna Murray, Dr Dominic ffytche and Dr Kate Briggs at the Institute of Psychiatry, King's College London.

The Thomas Pocklington Trust report on the experiences of people with sight loss and dementia and their carers highlighted the incidence of visual hallucinations – the vivid experience of seeing something that is not actually there. These hallucinations led to confusion and distress for the individual and their carers felt uncertain about how best to respond to them. The finding led to the present review of medical and social science literature. The aims were:

- To determine what is known about visual hallucinations in sight loss and dementia and what further research is needed.
- On the basis of current medical and social research findings, to explore the possible development of guidelines for the management of visual hallucinations.

The review found limited knowledge about people with both sight loss and dementia who are affected by hallucinations. The review addressed these questions:

- **What research is needed?** We need to know how frequently the symptom occurs, how it progresses, how it is experienced by individuals and their carers and what management approaches are effective.
- **What other initiatives are required?** Workshops to raise awareness among health and social care professionals and develop inter-agency approaches to the symptom are needed. There is currently insufficient evidence for the development of management guidelines. General recommendations can be made, including dual screening of sight loss and dementia and for reviews of medication and physical health.

- **How many people are affected?** The number of people with visual hallucinations, sight loss and dementia in the UK is somewhere between 35,000 and 118,000.
- **What is the impact of hallucinations?** It is unclear whether the emotional impact of hallucinations in people with both sight loss and dementia will be similar to that experienced in sight loss, similar to that in dementia, or some combination of the two. Hallucinations in people with sight loss alone can lead to a mistaken belief that this indicates mental illness. People with dementia alone may mistake hallucinations for reality, leading to false beliefs and distressing behaviour.
- **Do the hallucinations resolve over time?** 60% of people with sight loss who experience visual hallucinations are free of the symptom by 18 months. In contrast, visual hallucinations in dementia persist. We do not know whether the hallucinations of people with combined sight loss and dementia persist or resolve over time.
- **How best to manage the symptom?** The management approach for visual hallucinations in sight loss is explanation of the symptom and, where appropriate, correction of vision. How hallucinations in people with sight loss and dementia should be managed is unclear. There is little evidence to suggest any particular medication for visual hallucinations in sight loss or dementia and none for both conditions combined.
- **How are people affected identified?** People with visual hallucinations with sight loss are unlikely to have a routine assessment for dementia and people with visual hallucinations and dementia are unlikely to have a routine visual assessment. This means that many cases of visual hallucinations and combined sight loss and dementia are missed.
- **How many people are caring for someone with the symptom?** It is unclear how many carers are involved. The number may be small because hallucinations in someone with sight loss and dementia increase the likelihood of admission to residential care. Or there may be many carers dealing with hallucinations.
- **How are healthcare professionals dealing with the symptom?** The review highlighted a need for training about visual hallucinations generally and for co-ordination between professional groups but found little evidence that either were taking place.

Background

A broad literature review of papers published in medical and social science journals and publications from voluntary organisations was undertaken. The areas covered included:

- Prevalence, risk factors, course and outcome
- Accounts of the experience of hallucinations
- Medical and non-medical interventions, and carer approaches to dealing with the symptom
- The experience and expertise of health and social care professionals in recognising and managing the symptom.

Very little literature was found on visual hallucinations in the setting of sight loss and dementia and the scope of the literature review was widened to include:

- Studies of visual hallucinations in ophthalmological settings (with mention of dementia / cognitive status)
- Studies of visual hallucinations in dementia settings (with mention of visual status)
- Studies of people with visual hallucinations (with mention of visual and dementia status)

215 articles were found and categorised into biomedical, behavioural or social literature and into the ophthalmological, dementia and visual hallucination categories outlined above. The literature on dementia was broadly defined and included Alzheimer's disease, Lewy body dementia, vascular dementia and Parkinson's disease while the literature on sight loss focused on a range of conditions affecting the eye.

Prevalence, risk factors, course and outcome

Visual hallucinations were first recognised as differing from other types of hallucinations in the 1930s. They are found in sight loss related to eye disease, in diseases affecting the brain including the dementias, stroke and Parkinson's disease, in psychiatric illnesses such as schizophrenia, in hospice settings at the end of life and as a side effect of medication. When all such causes are added together, it is estimated that around two million people in the UK have visual hallucinations. Dementia, sight loss and confusional states (typically the result of an infection) are the most common clinical causes.

A lack of evidence in relation to visual hallucinations in the specific context of combined sight loss and dementia was found. Between 10% and 20% of people with sight loss have visual hallucinations and 60% of those are free from hallucination at 18 months. Around 20% of people with dementia have visual hallucinations, but unlike the visual hallucinations of sight loss, the hallucinations in dementia tend to persist over time and become increasingly distressing to the individual and their carer. Sight loss increases the risk of visual hallucinations in dementia. The review findings suggest that visual hallucinations, sight loss and dementia occur together more frequently than previously recognised. We predict that around 30% of those with combined sight loss and dementia will have visual hallucinations (35,000 people in the UK). Sight loss and dementia may act together to cause visual hallucinations, and in this case it is possible that 100% of people with the two conditions combined have visual hallucinations (118,000 people in the UK).

The experience of hallucinations

People with sight loss experience simple hallucinations (e.g. flashes, patterns and colours) and complex hallucinations (e.g. figures, faces and objects). The hallucinations are not associated with false beliefs or explanations (delusions) or a persistent failure to recognise that the experiences are not real. However, people may be reluctant to tell anyone about the hallucinations for fear of being seen to have a serious mental illness or dementia. In dementia, it may be difficult to distinguish hallucinations from other types of abnormal experiences such as delusions (persistent false beliefs). Unlike in sight loss, where simple and complex hallucinations occur, only complex hallucinations occur in dementia. The complex hallucinations are associated with hallucinations in other senses (e.g. heard voices), and delusions, and the experiences are often believed to be real. These hallucinations have been linked to more severe behavioural problems and a more rapidly advancing dementia, and may lead to a move to residential care.

Clinical and other interventions

In sight loss, recommended management for hallucinations is to inform people and treat the underlying eye condition. Medication has little role to play, although all medications and general health should be reviewed to exclude other possible causes of hallucinations. Some people find that moving their eyes, changing light conditions or focusing attention elsewhere stops an ongoing hallucination. In dementia, recommended treatment is to minimise confrontation, for example by directing conversation elsewhere. Medication is used. It is unclear which is most appropriate. Recent evidence cautions against the use of atypical antipsychotics because of an increased risk of stroke. As in sight loss, medication and general health should be reviewed.

Current evidence suggests that the management of hallucinations in people with combined sight loss and dementia will be different from that for people with either sight loss or dementia alone. If the hallucinations of sight loss and dementia are more like those of sight loss, management will include reassurance and education about the hallucinations, and optimising vision. If the hallucinations are more like those of dementia, management will involve avoiding confrontation by not talking about the symptom and, if appropriate, medication.

The research findings highlighted the issue of identifying people with visual hallucinations, sight loss and dementia. People with visual hallucinations assessed by an ophthalmologist are unlikely to be screened for dementia and people with visual hallucinations assessed by an old age psychiatrist are unlikely to be screened for sight loss. There is potential for misdiagnosis. For example, someone with sight loss may wrongly be diagnosed as having dementia or the diagnosis of dementia may be missed in someone with sight loss.

It is unclear how many family carers are supporting people with visual hallucinations, sight loss and dementia in the community, and therefore little is known about how they manage visual hallucinations. A recent report identified this problem among family carers and suggested that mental health professionals could guide them in managing the symptom.

The experience and expertise of health and social care professionals

There is currently an absence of evidence as to whether different health and social care professionals dealing with visual hallucinations, sight loss and dementia are aware of the symptom or have relevant expertise and training to manage it. The review did not identify any initiatives, guidelines or evidence of co-ordinated working between relevant professions in relation to visual hallucinations in sight loss and dementia.

Recommendations for future work

Research is needed in the following areas.

- A study of visual hallucinations in sight loss and dementia to establish the rates, needs and experiences of people with the condition. People could be identified through screening for sight loss in dementia services or memory clinics and screening for dementia in eye clinics. A study of visual hallucinations and the impact on family carers over time would provide important information on support needs.
- A survey of expertise in professional groups encountering people with sight loss and dementia to assess current practice and awareness of visual hallucinations. Such a study would need to enlist the help and support of various professional bodies.
- Studies to compare the impact of the different management approaches on people with sight loss and dementia.
- Effective approaches to the management of visual hallucinations in sight loss and dementia require clarification. Current knowledge makes it possible to make only general recommendations regarding identification of the symptom, co-ordinated responses and raising awareness and sources of further advice.

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How to obtain further information

A report in the form of an Occasional Paper entitled '*Visual Hallucinations in Sight Loss and Dementia*' by Joanna Murray, Dr Dominic ffytche and Dr Kate Briggs is available from:

Thomas Pocklington Trust
5 Castle Row, Horticultural Place, London W4 4JQ

Telephone: 020 8995 0880

Email: info@pocklington-trust.org.uk

Web: www.pocklington-trust.org.uk

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

The full report entitled '*Visual Hallucinations in Sight Loss and Dementia: A Review of the Literature*' is also available on request, using the above contact details.

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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