

People with dementia and sight loss: a scoping study of models of care

This publication summarises findings from a short scoping study conducted by Dr Ruth Bartlett (Division of Dementia Studies) and Dr Declan McKeefry (Division of Optometry) at the University of Bradford.

Background

People with dementia and sight loss

Previous research at Kings College, London has highlighted that few studies and reports address the needs and experiences of people with dementia and serious sight loss, yet both problems are common in older people and in particular among those living in long-term care facilities.

The study reported here follows on the previous research to consider sensitivity to sight loss in models of dementia care.

Summary Findings

- The enriched model of dementia care does not take sufficient account of the physical environment to make it sensitive to particular issues facing people with dementia and sight loss.
- Other models of dementia care practice have the potential to be more sensitive to sight loss issues.
- In the broader dementia care literature on best practice, opportunities for raising awareness about the needs and entitlements of people with dementia and sight loss are overlooked.

- Whilst sight loss issues are generally overlooked in the dementia care literature and models, practitioners who work with people with dementia and sight problems on a day-to-day basis are trying to find effective ways of supporting individuals.
- There are varying degrees of sensitivity and awareness about sight loss issues amongst practitioners.

Models for working with people with dementia

In the context of health and social care, a model is a framework for organising and transferring important ideas into practice. There is no model of practice for working with people who have both dementia and sight problems. Several models of practice are considered appropriate for work with people with dementia; the most widely used in UK dementia care is the enriched model (also known as dialectic model), which Professor Tom Kitwood developed in the early 1990s and which has since been embedded in dementia policy in the form of person-centred care. The enriched model of practice is based on the idea that a person with dementia is affected by the following factors:

- cognitive impairment
- physical health
- personal biography
- individual personality
- social environment.

Taking all these factors into account is regarded as best practice in the field of dementia care.

In the broader literature on best practice in dementia care, it is generally assumed that dementia is a person's primary or only health concern. More established work on psycho-social interventions (such as reminiscence and music therapy) focuses on how best to help and support people in dealing with dementia-related issues such as memory loss and agitation. Similarly, newer work on cognitive rehabilitation techniques, such as memory training and cognitive stimulation therapy, focuses on improving cognition. In addition, knowledge is growing in regard to how best to adapt the environment to decrease confusion and promote orientation. The evidence base for how best to work with people who have both dementia and sight problems is sparse.

Models for understanding dementia

Models for understanding dementia are disputed. The traditional model for understanding dementia in Western societies has been the medical model – that is, as a neurological disorder affecting cognition and other cranial powers. In recent years this understanding of dementia has been challenged by researchers on several counts, including the following.

- Because dementia affects vision so much, it should be regarded as a visuo-perceptual as well as a neuro-cognitive condition.
- Non-Westernised communities and sub-cultures view dementia in different ways. For example, within African and some Indian sub-cultures, dementia is regarded as a religious or mystical experience, and many South Asian and Indian communities do not have a specific word for 'dementia'. Instead, memory loss and confusion are seen as an inevitable and normal part of the ageing process.
- The impact of poor care practices is not taken into account.

Aims and objectives

The main aim of this scoping study was to assess the extent to which existing models of best practice in dementia care were sensitive to sight loss issues. A further aim was to identify and propose ways of increasing sensitivity to sight loss issues in existing models of dementia care practice.

Specific objectives of the study were to:

- review the literature on best practice in dementia care
- review the scientific research on sight loss and people with dementia
- examine how sensitive models of dementia care practice are to sight loss issues
- explore how sensitive dementia care providers are to sight loss issues.

Methods

The study collected data in three ways:

- searching databases for academic literature
- interviewing seven practitioners
- auditing working practices in four care homes for older people.

Findings

- The enriched model of dementia does not take sufficient account of the physical environment to make it sensitive to particular issues facing people with dementia and sight loss.
- Other models of dementia care practice, and in particular the Nightingale-based model, are potentially more sensitive to sight loss issues.
- In the broader dementia care literature on best practice, opportunities for raising awareness about the needs and entitlements of people with dementia and sight loss are overlooked. The prime focus is dementia and so issues related to memory rather than sight loss are at the forefront of people's work, and it is generally assumed that people can see.
- Whilst sight loss issues are generally overlooked in the dementia care literature, care workers who work with people with dementia and sight problems on a day-to-day basis are trying to find effective ways of supporting individuals.
- There are varying degrees of sensitivity and awareness about sight loss issues amongst practitioners, particularly with regard to the following issues:
 - colour and contrast
 - getting to know a person
 - the provision of information
 - wearing of spectacles
 - preventative measures such as regular eye tests.

Recommendations

Develop and pilot a more integrated sensory model of practice

A sensory model of care practice should be developed and piloted in a dementia care setting. This model would integrate the elements of the enriched and Nightingale-based models.

Work with other key stakeholders to set up a network of practice

As a result of this scoping study, there is a database of over 30 individuals from around 10 different organisations – all of whom are interested in improving practice for people with dementia and sight problems. A network of practice should be set up which involves other stakeholders in order to inform a community of those interested in both dementia and sight loss issues.

Produce guidance on how to create an inclusive notice board

Guidance should be written primarily for managers, activity co-ordinators and social care facilitators, and contain practical details, including how to relay information in different forms and media.

Provide specific guidance for care home inspectors

A checklist should be developed to provide guidance to care home inspectors about good practice in meeting the specific support needs of residents who are both cognitively and visually impaired. At the very least, inspections should check whether residents have had a regular eye test.

Design a large-scale inter-disciplinary programme of research

A large scale inter-disciplinary study should be designed which seeks to address pressing and persistent problems such as spectacle-wearing and providing information in different formats.

Seek to influence the implementation of the National Dementia Strategy (NDS) for England

The NDS aims to raise awareness and transform health and social care services for people with dementia by setting up a core national team and regional support teams to lead on innovative programmes of work, such as structured peer support and learning networks, and the establishment of new roles such as the dementia advisor. This provides an ideal opportunity to influence debate and practice; for example, it might be possible for someone with a background in sight loss issues to participate in implementation team meetings at either a national or regional level.

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How to obtain further information

A report in the form of an Occasional Paper entitled '*People with dementia and sight loss - a scoping study of models of care*' by Dr Ruth Bartlett and Dr Declan McKeefry, is available from:

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

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Web: www.pocklington-trust.org.uk

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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