

The social care and support needs of adults with concurrent dementia and visual impairment

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Background

- 100,000 people in the UK aged 75+ have concurrent dementia and sight loss
- Lack of understanding of the social care and support needs of this group
- Previous research focused on:
 - Separate conditions
 - Care home setting
 - Physical environment

Project aims

- To investigate how best to provide care and support for adults living with sight loss and dementia in a range of housing settings
- To develop evidence-based practice guidance for people with these concurrent conditions

Methodology

- Scoping literature review
- Qualitative interviews with people with dementia and sight loss and/or their carers
- Qualitative focus groups and interviews with professionals
- Cost of providing care in different housing settings
- Consensus event to present emerging themes

Interviews and focus groups

University	Regions	People with dementia and/or carers	Professionals
Bournemouth	Dorset, Somerset, Wiltshire, Hampshire	9	11
Worcester	West Midlands and South West	8	19
York	Yorkshire, Lancashire, Manchester	9	17
Totals	-	26	47

- Ethical approval: Social Care Research Ethics Committee
- Thematic analysis of transcripts using NVivo 10

Social care needs of people with dementia and sight loss

- Needs and coping strategies may differ depending on when (and which order) individual develops each condition
- Difficulties remaining independent
- Frustration at needing to accept help
- Care needs were exacerbated by having both conditions as well as comorbidities

Example

"But with Pops you see, his sight, he hasn't got that visual has he, that visual aid to react to his memory, to kick in that memory....With Dad, even if he had something like a switch on the wall in places like this that told him what day it was, by the time he got to the door he'd've forgotten, so that is another difficult thing that, you know, it's so difficult to actually stimulate the brain and the memory, because of the lack of sight... Because we'll be asked the same question, 2 minutes later, all through Saturday won't we?"

Social care needs of carers

- Concern about ability to care when partner's condition deteriorates
- Coping strategies included:
 - Taking on additional household tasks
 - Obtaining equipment and aids

Current models of care

- Formal support provided by paid care workers
 - e.g. help with activities of daily living, medication, and respite care
- Informal support provided by family and friends
 - e.g. grocery shopping, housework, managing bills, and respite care
- Emergency or additional support provided by neighbours
- Difficulty addressing the needs of both conditions at the same time
 - Dementia services more suitable for people with sight loss than vice versa
 - Dementia aids can be visual, while sight loss aids may be simplified and not recognised by people with dementia

Barriers to providing high quality, cost effective social care and support

- Formal care
 - Inconsistency of service provision due to time and financial constraints
 - Difficulty obtaining diagnoses for both conditions
 - Lack of awareness of what is available
 - Professionals focus on own area and rarely consider both conditions together
 - Lack of joint working between professionals
- Aids and equipment
 - Difficulty getting used to new appliances/devices
 - Difficulty using aids due to either condition

Facilitators to providing high quality, cost effective social care and support

- Early/timely diagnosis and signposting
 - Access suitable medication or interventions
 - Able to access services sooner
 - Enhance the impact of rehabilitation through a greater range of options
 - Facilitate planning and preparation for the future
- Long-term approach to providing care and support services
 - Enables professionals to see the bigger picture and develop trust with individuals
 - Consistency of staff providing care
- Knowledge and training of professionals

Recommendations

- A timely diagnosis for both conditions, followed by appropriate support and information
- Greater focus on holistic care rather than on one condition over the other
- Professionals should have opportunities to improve their own knowledge of the 'other' condition and how dementia and sight loss interact
- There is a need to promote joint working and information sharing with other professionals and services in their local area
- Equipment and environmental adaptations should be introduced as early as possible, enabling them to become embedded into daily routines

Thank you

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Association for Dementia Studies
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www.worcester.ac.uk/discover/association-for-dementia-studies.html

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