

The Prevalence of Visual Impairment in People with Dementia (the PrOVIDe study): a cross sectional study of 60-89 year old people with dementia and qualitative exploration of individual, carer and professional perspectives

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Scientific Summary

Background

Various conditions cause visual impairment (VI) in older people, yet many cases can be prevented or treated with early detection and correct management. Risks of dementia and VI increase with age so a large proportion of people with dementia may also have VI; UK demographic changes suggest increasing numbers will be affected by both dementia and VI.

A body of evidence exists on the impact of VI on quality of life, the increased risk of falls and higher rates of admission to residential care, but a literature review exposed a dearth of quality evidence on the prevalence of VI among people with dementia. RNIB data suggest many older people do not have regular eye examinations, and uptake among people with dementia is thought to be considerably lower, suggesting that an undefined proportion of older people have VI that could be helped by cataract surgery or by wearing the correct spectacles.

Objectives

Main research questions: What is the prevalence of a range of vision problems in people with dementia aged 60-89 years; and to what extent are these conditions undetected or inappropriately managed?

Primary objectives were to:

1. measure the prevalence of a range of vision problems in people with dementia.

2. compare the prevalences found in objective 1 with published data on the general population in a comparable age range.
3. identify and describe reasons for any under-detection or inappropriate management of VI in people with dementia.
4. recommend interventions to improve eye care for people with dementia and further research in this area.

Secondary objectives were to:

1. identify any differences in the level of undetected or inappropriately managed VI between those living in their own homes and those living in care homes.
2. determine estimates for the percentages of people with dementia likely to be able to perform elements of the eye examination successfully.
3. relate vision problems in people with dementia to data from functional and behavioural assessments.

Methods

Two stages: a cross-sectional prevalence study followed by qualitative research.

Stage 1: 708 people with dementia (389 living at home; 319 in care homes) had a domiciliary eye examination. Inclusion criteria were people with dementia (any type), aged 60-89 years; individuals lacking mental capacity to provide informed consent to participate required a consultee who could consent on their behalf.

Exclusion criteria were individuals who:

- had been in hospital in the preceding two weeks following acute illness, delirium or major infection;

- were participating in a clinical drugs trial: the eye examination involved instilling Tropicamide eye-drops and potential drug interactions could not be determined;
- were unable to understand English, as consent procedures and the eye examination were in English;
- were unable to cooperate with the simplest eye examination procedures.

Participants were recruited from 20 sites in six English regions, with assistance from the NIHR Dementias and Neurodegenerative Diseases Research Network (DeNDRoN).

Stage 2: qualitative data were collected from 119 participants. Interviews were conducted with 36 people with dementia from Stage 1 and eleven care workers. Focus groups were conducted with optometrists (five groups), family carers (five groups) and professional carers (one group). Framework analysis was used to identify, explore and describe issues around detection and management of vision problems among people with dementia from the perspectives of affected individuals, family carers, professional care workers and optometrists.

Results

Key findings - Stage 1:

- Optometrists usually recommend that people have annual sight tests from age 70 onward and every two years before that unless there are clinical reasons for more frequent testing. In PrOVIDe, 22% reported not having had a test in

the last two years: including 19 participants who had not been tested in the last 10 years.

- Prevalence of presenting VI was 32.5% (95% CI 28.7 to 36.5) and 16.3% (13.5 to 19.6) for visual acuity (VA) worse than 6/12 and 6/18 respectively in people aged 60-89 years, generally higher than in comparable data from prevalence studies on the general population after adjustment for age and sex.
- Notably, 51.4% (44.5 to 58.3) and 26.4% (20.7 to 33.0) of participants living in care homes had VI using the VA<6/12 and VA<6/18 cut-offs respectively.
- VI was correctable with an up-to-date spectacle prescription (uncorrected/under-corrected VI) for 14.3% (11.7 to 17.5) of participants for VA worse than 6/12 and 7.7% (5.7 to 10.2) for VA worse than 6/18.
- With the best spectacle correction, VI remained for 18.1% (15.2 to 21.5) and 8.6% (6.6 to 11.3) of participants for VA worse than 6/12 and 6/18 respectively.
- Cataract was the primary cause in 48.0% of post-refraction VI (for VA<6/12 criterion). This VI is potentially remediable. Age-related macular degeneration (AMD) was the primary cause in 36.3%. For VA<6/18 AMD was the cause in 48.9% of cases and cataract in 36.1%.
- Distance VA improved by > two lines (LogMAR chart) post-refraction in 17.8% of participants.
- 16.2% could not read standard newspaper-size print with current spectacles, however almost two thirds of these participants could read this print with up-to-date spectacles.
- While research studies rarely include substantial numbers of people with dementia living in care homes, PrOVIDe had 319 care home residents (44%).

The unadjusted rate ratios of all types of VI were two to two-and-a-half times greater for care home residents compared with participants living in their own homes; these higher rates persisted even after age and gender adjustments.

- After adjustment for age, gender and group, cognitive impairment assessed by sMMSE had a significant independent effect for uncorrected/under-corrected VI ($VA < 6/18$) ($p=0.03$) but there was no evidence for an independent sMMSE effect for VI defined as $VA < 6/12$.
- Exploratory analysis found evidence for deficits in some vision-related aspects of function and behaviour in participants with VI vs. those without VI.
- There was no evidence that management of VI in people with dementia differed from the general population of older people. The percentage of participants advised of a change in spectacle prescription post-refraction was consistent with the national figure. PrOVIDe's referral rate (6.7%) was higher than the national figure of (5%) for the population as a whole, possibly due to the older age-profile of PrOVIDe participants.
- When extrapolated to the UK wider population with dementia, following post-stratification calibration and imputation, VI prevalences are higher, with wider confidence intervals, compared to PrOVIDe sample rates.
 - For $VA < 6/12$, extrapolated prevalences for presenting, post-refraction and uncorrected/under-corrected VI were 34.6% (29.3 to 40.3), 22.4% (16.4 to 29.9), and 13.6% (10.5 to 17.4) respectively.
 - For $VA < 6/18$, extrapolated prevalences for presenting, post-refraction and uncorrected/under-corrected VI were 20.3% (16.7 to 24.6), 12.2% (8.8 to 16.6) and 8.3% (5.9 to 11.6).

Key findings - Stage 2:

- Data from all parties revealed gaps in communication. Optometrists are not always informed when an individual has dementia; optometrists explained the importance of knowing this so the examination could be tailored to individual need.
- Stage 1 demonstrated that it was possible for optometrists to conduct most key components of the eye examination on >80% of people with dementia, but carers and care workers were unsure people with dementia could have a full eye examination if they had difficulty answering questions.
- Optometrists are not adequately prepared during training to examine people with dementia; many thought there was a need for additional training and support. They suggested exploring the role of a specialist optometric practitioner or specialist services for older people.
- The need to allow more time when examining people with dementia was identified by all participant groups, but the current examination fee structure militates against this.
- Promoting spectacle wearing among people with dementia can be difficult due to refusal to wear or to missing/broken spectacles, particularly in care homes.
- Carers and care workers had concerns about risks of cataract surgery under either local or general anaesthetic and described the need to balance risks against the benefits and impact on quality of life. However, most people with dementia interviewed said they would want surgery if required. Carers and some optometrists thought current thresholds for cataract surgery should be lower for people with dementia, allowing surgery while the individual was able to consent and better able to cope.

- Almost all people with dementia who were interviewed, and family carers, were unaware of availability of domiciliary eye examinations prior to participation in PrOVIDe.

Limitations

- Sampling bias is possible due to quota-sampling and response bias, with some participants and/or their carers more health-orientated than the general population. PrOVIDe's regional sample may not be fully representative of the general UK population.

Conclusions

Prevalence estimates of presenting VI in those with dementia from PrOVIDe are generally higher, after adjusting for age and sex differences, than estimates from previous population studies of older people which used comparable methods and which either excluded or had low proportions of participants with dementia. The high prevalence of participants with uncorrected/under-corrected VI, the disproportionately high prevalence of VI in care home residents and the high proportion of those with VI due to potentially remediable cataract suggest that eye care for people with dementia could be enhanced by attention to the following:

More eye care information for people with dementia and carers

It was possible for optometrists to conduct key components of the eye examination on >80% of people with dementia, visual fields being the exception. The important health checks of tonometry and direct ophthalmoscopy were possible in >90% of participants. The qualitative finding that some carers and care workers were unsure that people with dementia could have a full eye examination if they had difficulty answering questions indicates a need to increase awareness about the purpose,

scope and limitations of eye examinations to encourage uptake of eye examinations in line with health care recommendations.

Better communication between carers, optometrists and other health care professionals

Qualitative data revealed communication gaps between optometrists and those caring for people with dementia, and between optometrists and other health care professionals. Ensuring optometrists know when they are dealing with someone with dementia would enable them to tailor the examination to meet individual's needs. This includes involving a family member whenever possible, something family carers identified as being highly relevant. Where individuals having an eye examination are accompanied by a professional care worker it is important the care worker knows the individual and has relevant information to hand. Optometrists should ensure they contact the care home for further information if necessary.

Tailoring the eye examination, spectacle dispensing and treatment of eye conditions to meet the needs of the individual

Improving VA, identifying possible causes of VI and referring patients for medical intervention when necessary are the main responsibilities of the optometrist when examining an older person with dementia. However, the needs of the individual and quality of life issues should be considered by the attending optometrist and discussed with carers. This may impact decisions regarding the desirability of subjecting an individual to a full eye examination if this is likely to cause substantial distress, minimising unnecessary changes when prescribing and dispensing spectacles, and possible referral for cataract surgery.

Professional development and guidance for optometrists

PrOVIDe was led by the College of Optometrists, the professional, scientific and examining body for optometry in the UK, working for the public benefit. More than 70% of UK optometrists are members, which positions the College to increase professional awareness of eye care for people with dementia by providing information, guidance and opportunities for professional development.

Recommendations for research

Further improvements to eye care for people with dementia could emerge subject to the outcomes of further recommended research.

1. Development of an eye care pathway

Research conducted into the development of an eye care pathway for people with dementia, considering what should happen in terms of eye care when an individual is diagnosed with dementia. This could include the following questions;

- What information do individuals and carers need to promote uptake of eye examinations?
- What are the barriers and facilitators to providing continuity of eye care?
- What modifications are required to the current structure for General Ophthalmic Services sight test funding in both community and domiciliary practice? This could include establishing minimum requirements for an ocular health check when there are difficulties completing a full eye examination, and providing adequate remuneration for the extra time often required for examination of people with dementia.

- In acknowledgement of the problems regarding spectacles for people with dementia (increased incidence of spectacles being broken or lost) should there be additional financial support for spectacle provision? For example, should there be financial subsidies to provide spectacles made from materials less likely to break?
- Should the threshold for cataract surgery be lower for people with dementia?

The last research question is related to the second area of research recommendations.

2. Early intervention for cataract

People with dementia interviewed for PrOVIDE said they would have cataract surgery if needed. Carers described balancing the risks, burdens and benefits of cataract surgery against the impact on quality of life. The potential for different outcomes in decision-making depending on who is responsible suggests it would be preferable for the decision to be made while an individual had mental capacity to decide. This generated the second research recommendation, that there should be research into the effects of early cataract intervention for people in the early stages of cognitive impairment.

3. The specialist optometric practitioner role

Research is needed to explore the potential of developing the role of a specialist optometric practitioner for people with dementia. This would include establishing competencies for the role, training requirements and feasibility. Initial research should consider the level of interest from the optometric profession and consider if

this dementia role could be accommodated within the alternative of a specialty for working with older people. Research should also explore the role's positioning in the current mixed economy of health care provision i.e. would specialists be independent practitioners or employed by the NHS in hospital, or in community/domiciliary settings.

Eye care for other vulnerable groups

PrOVIDe study findings suggest almost 25% of participants had not had an eye examination in the previous two years and that eye care for people with dementia could be improved. Critically, *none* of the participants in Stage 1 living in their own homes were aware that a domiciliary sight test was possible. Therefore research should also be conducted into the prevalence of undetected/ uncorrected VI and provision of eye care for other vulnerable groups. PrOVIDe study findings regarding the lack of awareness of domiciliary eye care suggest one such target group would be older people with chronic illness and disability who have difficulty accessing community-based optometric practice.

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