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Thomas Pocklington Trust
Housing and support for people with sight loss

An investigation of the circumstances of older people with sight loss: analysis of the English Longitudinal Study of Ageing

This publication summarises findings from research conducted by Dr Edlira Gjonça and Professor James Nazroo, Department of Epidemiology and Public Health, University College London.

Summary

This paper aims to describe the socio-demographic characteristics of people with sight loss, their health and wellbeing and their socio-economic circumstances. It is based on the research study 'An investigation of the circumstances of visually impaired older people: Analysis of the English Longitudinal Study of Ageing'.[1] The full findings of this study can be found in the report with the same title produced for Thomas Pocklington Trust.

The exact number of people in the UK with sight loss is not known. More precise information is necessary for understanding the needs of this group.

This study uses data from ELSA, the English Longitudinal Study of Ageing, which surveyed over 11,000 people aged 50 and older living in private households. They were asked to rate their eyesight, among other measures of health and wellbeing.
Among the findings were that:

- just over 4% of people aged 50 or older report that they have poor vision or are registered blind, with a further 12% saying that their vision is fair. These rates rise dramatically in those 70 years and older, and they are higher among women than men.
- one-third of people who said they have poor eyesight did not have a diagnosis for their problem. The most common diagnosis (45% of those with a diagnosis) was reported to be 'cataract'. This is a high proportion, considering that this is a treatable condition.

[1] Gjonça E and Nazroo J (2005) *An investigation of the circumstances of visually impaired people: Analysis of the English Longitudinal Study of Ageing.* Final Report submitted to Thomas Pocklington Trust.

- for almost all outcomes that the study looked into (health, physical and cognitive functioning, economic position and wellbeing), those who reported poor vision or being registered blind were disadvantaged in comparison with those who reported fair vision, who were, in turn, disadvantaged in comparison with those who reported good or excellent vision.
- despite this, those with visual impairments fare quite well in regard to social networks and contacts.

Introduction

In the UK as a whole around 190,000 people are registered as blind and about 160,000 are registered as partially sighted.[2] However, registration rates greatly underestimate the true numbers of people with sight loss. It is thought that the number of people with a sight problem in the UK is actually closer to one million or even up to two million. The lack of complete registration means that not only is this estimate uncertain, but also very little is known about the socio-economic circumstances of this group. There is a lack of data on the demographic profile of those with a visual impairment who are not on the register, and very limited information on their social and economic circumstances. Good information on disability and how this is distributed in the population is vital for understanding the needs of people with impairments and for informing policy responses to population ageing. This paper is an attempt to fill the gap in knowledge about people with visual disability in England.

Data and methods

The study uses data available for the first time, drawn from the English Longitudinal Study of Ageing (ELSA). ELSA is a representative study of 11,392 people aged 50 and older living in private households that was conducted in 2002 and 2003. The ELSA interview collects a considerable array of data on impairment and disability, and on the health, social and economic dimensions of people's lives.[3] ELSA only collects data for people aged 50 and over, which means that the extent of and impact of sight loss among younger people could not be explored here. However, it is known that sight loss is much less common among younger people. This is largely because many eye conditions (such as cataract, macular degeneration, glaucoma or diabetic retinopathy) are age related.

[2] Royal National Institute of the Blind (RNIB) website (2001) Frequently Asked Questions, Factsheets, UK Statistics Summary, www.rnib.org.uk.

[3] Marmot M, Banks J, Blundell R, Lessof C and Nazroo J (2003) *Health, wealth and lifestyles of the older population in England: The 2002 English Longitudinal Study of Ageing*, London: The Institute for Fiscal Studies.

These are conditions with slow and gradual onset, so most people develop visual impairments gradually in later life. Another limitation of the study is that wave one of ELSA only collected data on people living in private households. As it did not cover those living in institutions – and older people with a visual impairment are more likely to be living in institutions – the study might have underestimated their numbers.

In the ELSA interview, subjective assessments of sight loss have been used, allowing for a comprehensive assessment of the relationship between sight loss and the outcomes covered. Respondents were asked to evaluate their eyesight using glasses as usual. The sample is divided into those who report good, very good or excellent eyesight, those who report fair eyesight and those who report poor eyesight or being registered blind. The use of a self-reported measure of impairment, rather than an objective measure of visual acuity, is perhaps less than ideal. However, it is a direct measure of respondents' own sense of their visual impairment and is likely to correlate strongly with objective tests. Our analyses have shown that this measure can be useful in assessing the circumstances of people with visual disability.

Results

Prevalence of sight loss

The study found that 4% of respondents report having poor eyesight or that they are registered blind, while a further 12% report having only 'fair' eyesight. The majority, 84%, report having excellent, good or very good eyesight. However these prevalences vary greatly by age and gender.

Age was found to be a strong determinant in the prevalence of visual disability. Figure 1 shows clearly the increase in prevalence of sight loss by age. The figure shows the prevalence by 5-year age groups. Two levels of sight loss are shown, with the dark part of each bar on the graph representing those who describe themselves as having poor vision, or as registered blind, and the paler part showing those who report having fair vision, as opposed to good, very good and excellent vision. The chart shows the expected exponential increase in rates of visual impairment, with rates becoming particularly high from the age of 70 onwards. While 2% of respondents aged 50-59 reported having poor eyesight or being registered blind, this proportion is higher for respondents aged 60-64 (3%) and even higher for respondents aged 80 and over (13%).

Figure 1: Prevalence of sight loss among those aged 50 and older by visual impairment and age

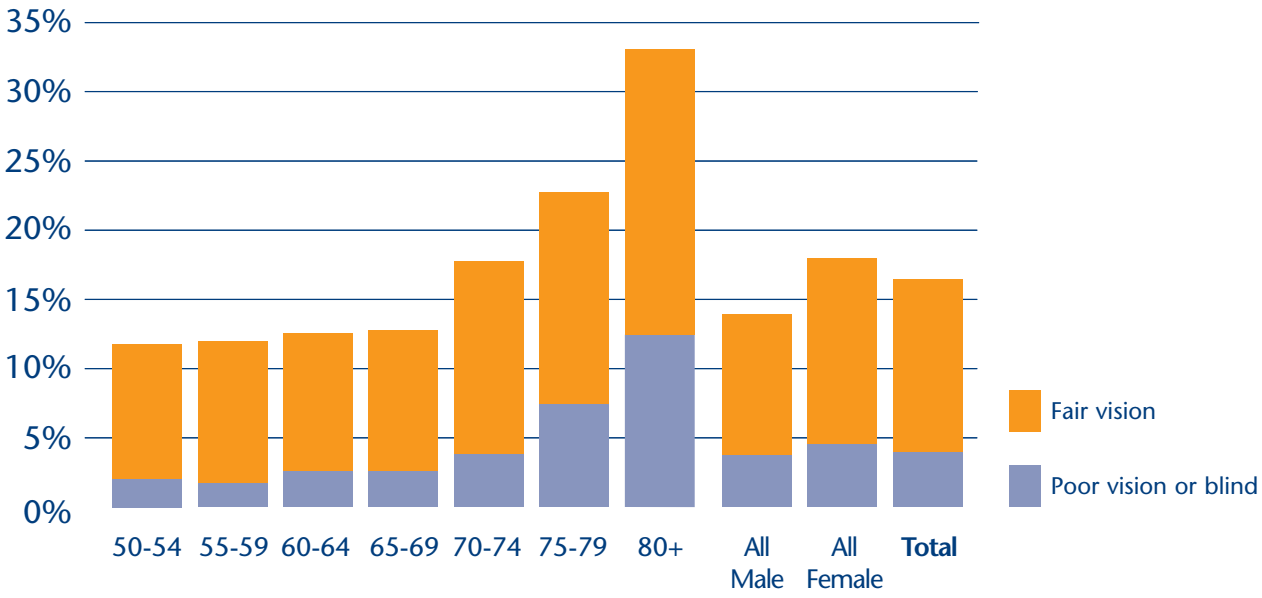


Figure 1 also shows some gender differences in the prevalence of sight loss (the three right-hand side bars), with females reporting higher visual disability rates than men. For example, while 3.5% of the male respondents report having poor eyesight or being registered blind, for the females this figure is 4.7%. Other studies also report that women have higher levels of vision impairment.[4]

Participants in the ELSA study were also asked whether they had a diagnosed eye problem. A third of those who reported their eyesight as poor, or that they are registered blind, did not report a diagnosis for their problem. The main diagnosis reported was 'cataract', followed by 'macular degeneration', 'glaucoma' and 'diabetic eye disease'. Fewer than half of those diagnosed with cataract had had surgery. The number of people reporting more than one diagnosis for their visual impairment was small – 2.6%.

Health and wellbeing

The first wave of ELSA collected self-reports on general health, longstanding illness and quality of life. Respondents rated their health as excellent, very good, good, fair or poor. All respondents also had to say whether they suffered from any illness or disability that affected them over a long period of time. Those who reported that they were suffering from a longstanding illness were asked whether the illness limited their activities in some way. Quality of life

[4] Tate R, Smeeth L, Evans J and Fletcher A (2005) *The prevalence of visual impairment in the UK. A review of the literature*. Report commissioned by the Royal National Institute of the Blind.

was measured using the CASP-19 in the self-completion booklet.[5] This contains 19 questions on four sub-domains of quality of life: Control, Autonomy, Self-realisation and Pleasure. The scale was dichotomised at the mean to divide the sample between those with worse-than-average quality of life and those with better-than-average quality of life.

Table 1 shows the prevalence of a selected range of health-related outcomes from the ELSA study by level of sight loss. The findings are shown for three broad age groups (because of the relationship between age and visual impairment on the one hand, and age and the other health outcomes on the other) and for the population as whole. For each age group there is a direct correlation between visual impairment and the outcome, with higher levels of visual impairment related to poorer outcomes. Looking at the 'Total' column, two-thirds of those reporting poor vision or that they are registered blind have fair or poor health and over two-thirds report that they have a longstanding illness that limits their everyday activities. In most cases these rates are well over twice those found among those who report their vision as excellent or good. The measure of quality of life also shows a marked inequality, with one-third of those with poor vision or registered blind having a good score on the quality of life measure, compared with two-thirds of those with good or excellent vision. These findings are present in each age group.

Table 1: Health and wellbeing by visual impairment

		Cell percentages			
	Age	**50-59**	**60-74**	**75+**	**Total**
Reported fair or poor health	Excellent/good vision	17.9	23.0	27.7	21.8
	Fair vision	46.7	55.0	56.5	52.9
	Poor vision or blind	58.4	69.7	60.9	63.3
Reported longstanding illness	Excellent/good vision	45.0	55.5	60.2	52.3
	Fair vision	63.5	72.9	72.0	69.8
	Poor vision or blind	76.2	88.2	82.8	83.2
Reported limiting longstanding illness	Excellent/good vision	24.7	31.0	40.5	30.3
	Fair vision	43.3	56.5	56.1	52.4
	Poor vision or blind	62.7	74.1	72.5	71.2
'Good' quality of life*	Excellent/good vision	66.3	67.2	51.5	64.3
	Fair vision	39.5	42.7	40.2	40.9
	Poor vision or blind	42.2	33.9	30.0	34.6

*Assessed using the CASP-19 scale[6]

[5] Hyde M, Wiggins RD, Higgs P and Blane DB (2003) *A measure of quality of life in early old age: the theory, development and properties of a needs satisfaction model [CASP-19]*, Ageing and Mental Health, 7: 186–94.

[6] Hyde M *et al*, (2003) op.cit.

Physical and cognitive function

The study also looked at the physical and cognitive function of people in different visual impairment categories. It is important to study these aspects, especially in older people, not just because of the increase in prevalence of physical, cognitive or visual problems with age, but also because these problems have a profound influence on the quality of life of older people, and they have common underlying causes.

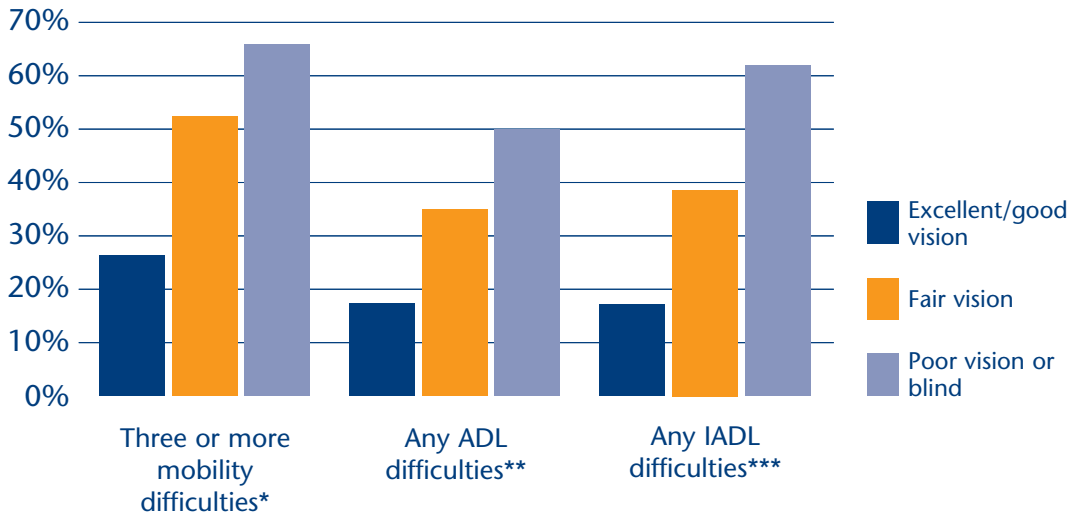
Information regarding physical function of ELSA respondents was based on self-reports. The core questions about physical function in ELSA fall into one of three domains: mobility; activities of daily living (ADLs) or self-care activities; and instrumental activities of daily living (IADLs) or activities necessary for independent living in a community. In addition, ELSA participants were asked about problems with falls and hearing. Respondents aged 60 years or over were asked whether they had fallen in the last two years and, if so, how many times and whether in any of the falls they had injured themselves seriously enough to need medical treatment. Respondents were also asked to self-rate their hearing (using a hearing aid as usual) according to the following five response categories: excellent, very good, good, fair or poor.

Figure 2 shows the prevalence of mobility difficulties, and difficulties performing activities of daily living (ADL) and instrumental activities of daily living (IADL) by level of visual impairment.

Figure 2 shows clearly that for all three outcomes respondents who report having poor vision or that they are registered blind are more likely to have difficulties compared to those with excellent or good vision. Among those reporting poor vision or that they are registered blind, about two-thirds report three or more mobility difficulties, almost half report one or more ADL difficulty and almost two-thirds report one or more IADL difficulty. Analyses showed that these findings were consistent across age groups; that is, they were not a product of the increasing prevalence of both mobility difficulties and sight loss with age.

The study also found that people with greater visual impairment were more likely to have suffered falls. While 30% of people who have excellent, very good or good vision have fallen, this proportion is larger for people who report fair vision (42%) and even larger for people with poor vision or who are registered blind, among whom almost half had fallen in the last two years (47%). In addition, among those who had fallen those who reported poor vision or that they were registered blind had also had the largest number of falls. Again, these findings were consistent across age groups.

Figure 2: Mobility and activities of daily living by visual impairment



* Mobility includes: walking 100 yards; sitting for about two hours; getting up from a chair after sitting for long periods; climbing several flights of stairs without resting; climbing one flight of stairs without resting; stooping, kneeling, or crouching; reaching or extending your arms above shoulder level; pulling or pushing large objects like a living room chair; lifting or carrying weights over 10 pounds, like a heavy bag of groceries; picking up a 5p coin from a table.

** ADLs include: dressing, including putting on shoes and socks; walking across a room; bathing or showering; eating, such as cutting up food; getting in or out of bed; using the toilet, including getting up or down.

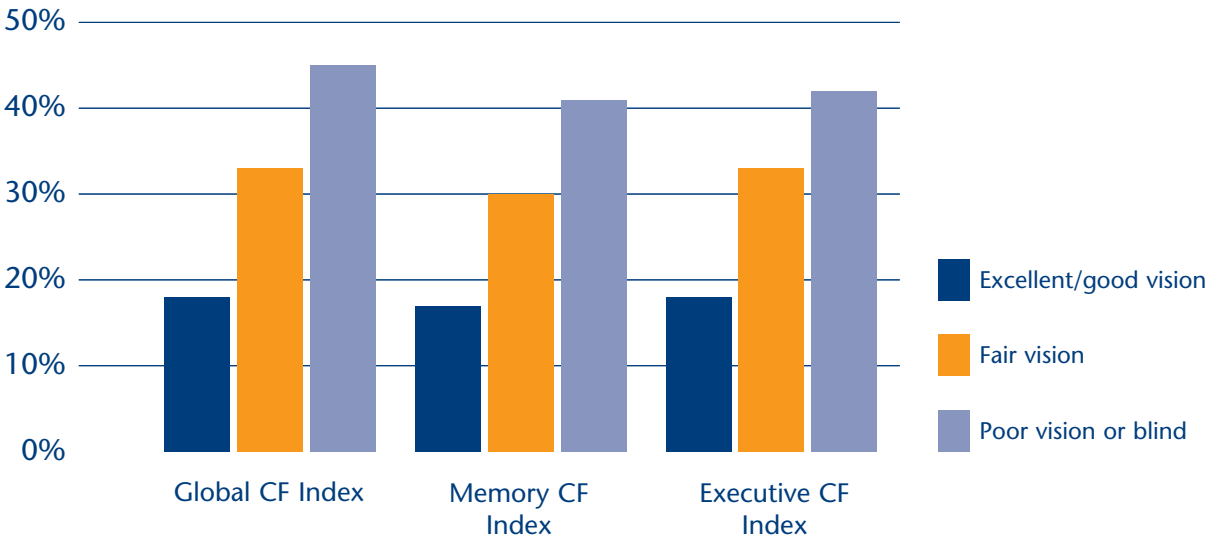
*** IADLs include: using a map to figure out how to get around in a strange place; preparing a hot meal; shopping for groceries; making telephone calls; taking medications; doing work around the house or garden; managing money such as paying bills and keeping track of expenses.

It is known that the percentage reporting fair or poor hearing increases with age, but our analyses show that the hearing disability increases in line with sight loss as well. Whilst only 4% of people who report having excellent, very good or good vision report having poor hearing, this proportion for people who have poor vision or are registered blind is 21% and these higher rates were present across age groups.

Cognitive function was also measured in ELSA, using a number of objective tests. The cognitive processes that were assessed include: learning and memory; word-finding ability; executive function (or strategic thinking); speed of processing; and numerical ability. Using responses to these tests, a memory index, an executive function index, and a global cognitive index, which combines the other two indices, were derived.[7] These three indices were used in the analyses.

Analyses of cognitive performance by visual ability showed that people in the better visual ability group also had better cognitive performance. Figure 3 shows results only for the bottom quintile (20% of the sample) of the Global Cognitive Function Index, the Memory Cognitive Function Index and Executive Function Index. The figure shows a similar pattern for the three cognitive function indexes. Clearly for every cognitive performance test the proportion of people who perform badly is much higher in those with higher visual impairment. This pattern persisted across age groups; that is, it was independent of age effects.

Figure 3: Bottom 20% of Global, Memory and Executive Function indexes by visual impairment category



Some of the tests of cognitive function required that the person is able to see well to perform them. However, this is not the case for the memory index, so the fact that this index functions similarly to the other indices suggests that the pattern of findings is genuine.

[7] Steel N, Huppert F, McWilliams B and Meltzer D (2003) *Physical and cognitive function in Health, wealth and lifestyles of the older population in England: The 2002 English Longitudinal Study of Ageing,* London: The Institute for Fiscal Studies.

Social networks and participation

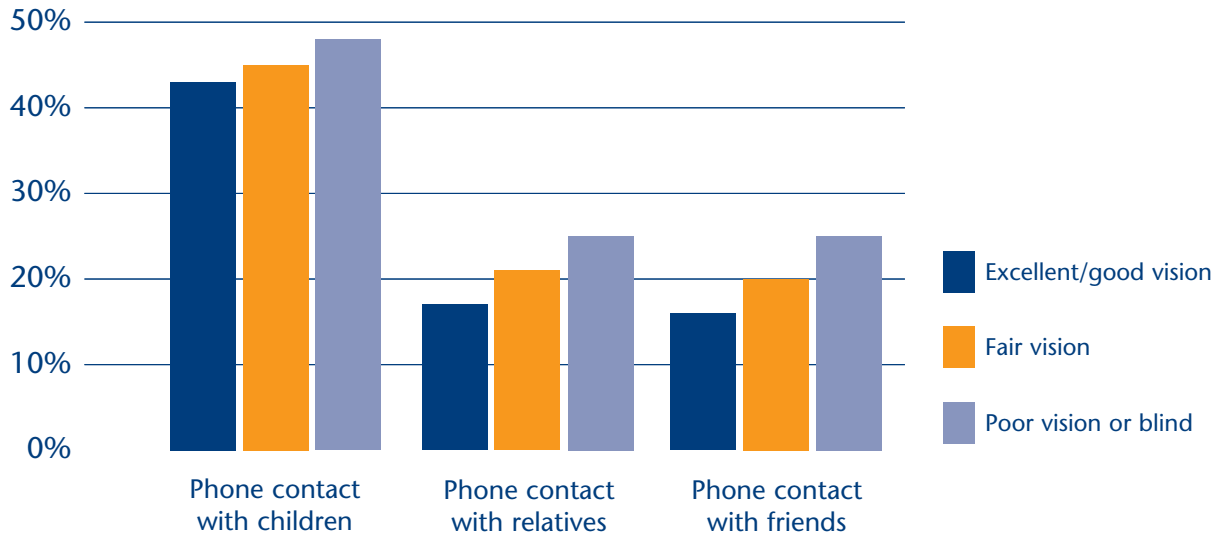
Social networks and relationships with others represent a key resource for older people, and research suggests that social relationships have a measurable impact on physical and psychological health. Generally, older people who have more social ties and who have more support available to them are in better health than their more isolated counterparts.[8] The ELSA self-completion questionnaire included a series of detailed items on respondents' social relationships. The first set consisted of 'social network' questions, which addressed the frequency with which the respondent has contact with children, other relatives, and friends. The second set consisted of 'social support' questions, which were concerned with the quality of the respondent's social relationships covering the same groups. In order to assess social participation, respondents were also asked whether they were members of any of the following organisations: political party; trade union or environmental groups; tenants' groups or residents' groups; Neighbourhood Watch; church or other religious groups; charitable associations; education, art or music groups, or evening classes; social club; sports clubs, gym or exercise classes; or any other organisations, clubs or societies.

Looking at this marker of social participation – being a member of an organisation – the study found that two-thirds of those who have poor vision or who are registered blind say that they are not a member of an organisation, compared with just one-third for those with excellent or good vision, and the pattern of this relationship remained across age groups.

Figure 4 shows one of the markers of social networks – the frequency of phone contact with children, relatives or friends. The figure shows the proportion of respondents who say that they speak on the phone three or more times a week to these three groups. Interestingly, it was found that people in the poor vision or blind category had more phone contacts than people in other visual impairment categories. As Figure 4 shows, people in the poor vision or blind category report slightly higher frequency of talking three or more times a week to children, relatives or friends. In absolute terms, relatives or friends are contacted less frequently by phone, but the pattern is the same as that of contact with children. There was also a very similar pattern when it came to the frequency of meeting with children, relatives or friends: people with higher visual impairment were likely to have a higher frequency of meetings (not shown in the figure). As for other analyses, these findings were present across age groups.

[8] House JS, Landis KR and Umberson D (1988) *Social relationships and health*, Science, 241: 540–5.

Figure 4: Percentage of respondents who speak three or more times per week with children, relatives or friends, by visual impairment



Economic position and housing

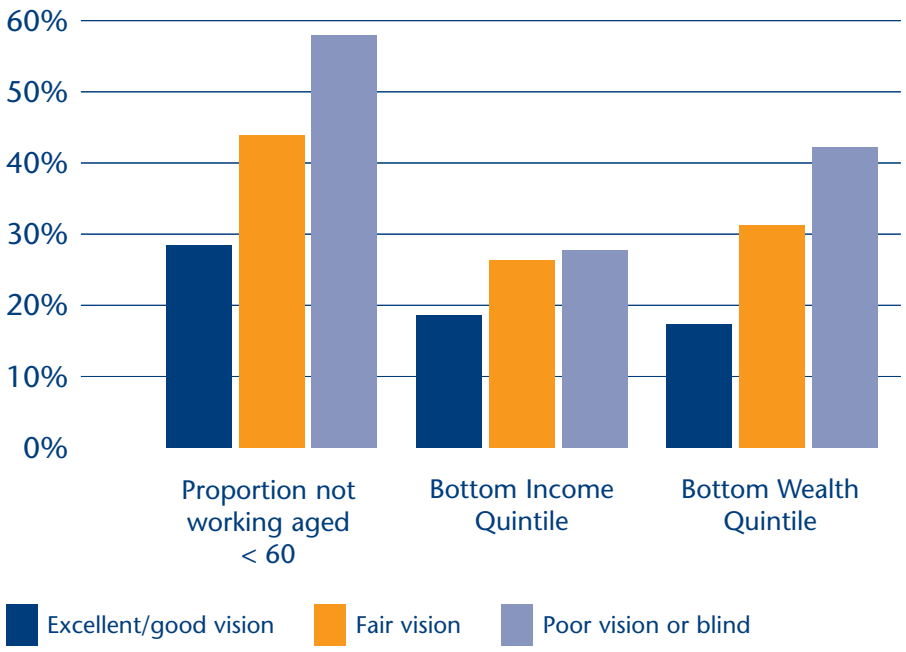
One of the most important issues in the debate on the ageing population is whether individuals will have adequate economic resources to maintain sufficient standards of living in retirement. This question is perhaps more pertinent to those with visual impairments. In part, economic resources depend on employment history. A series of questions were asked about this in the ELSA interview, which were used to allocate occupational categories reflecting current or past (for no longer employed respondents) employment. These were then used to derive a socio-economic classification (NS-SEC) covering five categories: managerial and professional; intermediate; small employers and own-account workers; lower supervisory and technical; and semi-routine. In addition, the ELSA data included direct measures of economic wellbeing, including current income, accumulated assets and wealth, how well respondents managed financially, and home ownership.

The study found that more people who have excellent or good vision are classified as managerial and professional (30%) than people who have fair vision (19%) or who have poor vision or are registered blind (12%). Similarly, fewer people who have excellent or good vision are classified as being in lower supervisory, technical or semi-routine occupations (45%) than people who have fair vision (57%) or who have poor vision or are registered blind (58%). These differences were consistent across age groups.

Figure 5 shows three markers of economic position by reported self-assessed visual impairment. The first marker is participation in paid employment, with only those aged 50-59 included (60 is state pension age for women, and a large proportion of men are no longer in paid employment in the 60 to 65 age range – 65 is the state pension age for men). For all groups the graph shows that a considerable proportion of people are not in paid employment – 28% of those reporting good or excellent eyesight, for example. The rate rises with increasing visual impairment, so almost three-fifths of those with poor vision or who are registered blind, are not in paid work.

The other two sections of the graph show more direct assessments of economic position – levels of income and levels of wealth. Both show the proportion of people who are in the bottom age-related quintile of income and wealth – by definition 20% of the sample should be in the bottom quintile. There are marked inequalities in this, with increasing proportions in the bottom quintile for increasing levels of visual impairment. Although these differences are present for both income and wealth, the differences are larger for wealth, with more than 45% of those reporting poor vision or being registered blind in the bottom quintile, compared with just under the expected 20% in the excellent or good vision group. Wealth for this age group reflects lifetime earnings and so, perhaps, lifetime disadvantage.

Figure 5: Economic position by visual impairment



ELSA respondents were asked how they manage financially. In this outcome, once more, people with better vision also say that they manage better financially. Analysis showed that 67% of respondents who reported excellent, very good or good vision said that they manage very well or well, compared with 51% of people who report poor vision or who are registered blind.

Housing tenure is another indicator of economic position and wealth that was analysed. The study found that only 44% of people who have poor vision or who are registered blind own their accommodation outright, compared with 56% of people who report excellent, very good or good vision. Most importantly, 41% of people with poor vision or registered blind are renting their accommodation, a high proportion when compared with 17% for people with excellent, very good or good vision and 31% for people with fair vision. Looking at whom the accommodation is rented from, the analyses show that people who report poor vision or that they are registered blind are more likely to rent their accommodation from the local authorities or housing associations (92% with poor/blind vision vs. 85% with excellent/very good/good vision).

Conclusions

This study is among the first to explore the circumstances of people with sight loss in a nationally representative sample. As such the findings are novel and important.

The study focused on the demographic profile and social circumstances of older people in England who have a self-assessed visual impairment. It aimed to describe the demography of people with visual impairments; how sight loss relates to health, physical functioning, hearing and cognitive impairments; as well as the social and economic circumstances of those with such impairments.

Just over 4% of people aged 50 or older, and living in private households, report that they have poor vision or are registered blind, with a further 12% saying that their vision is fair. These rates become dramatically larger in the 70 years and older population. One-third of people who reported to have poor eyesight did not have a diagnosis for their problem. The most common diagnosis (45% of those with a diagnosis) was reported to be ‘cataract’. This is a high proportion, taking into account the fact that this is a treatable but disabling condition. Campaigns should target older people to raise awareness of poor vision in later life and the potential for improving visual impairment through cataract surgery. Strategies are needed in order to improve screening of the older

population for visual impairment. Research on barriers to service utilisation and access may help inform the development of such services.

For almost all outcomes that the study looked into, those who reported poor vision or being registered blind were disadvantaged in comparison with those who reported fair vision, who were, in turn, disadvantaged in comparison with those who reported good or excellent vision. This inequality was present for health, quality of life, mobility, social participation, and economic wellbeing, and was consistent across age groups; that is, it was independent of age. The extent of this relative disadvantage is large and a cause for great concern. In contrast, assessments of social networks indicate that those with visual impairments fare quite well. Why those with sight loss perform poorly on health, quality of life, economic outcomes and measures of social participation, but well on measures of social networks, is worthy of further investigation. What is clear is that the findings indicate a strong association between sight loss and social exclusion and poverty.

It is worth restating that the level of sight loss identified in the study, even though based on a subjective measure, suggests that this is a significant issue among the older population, especially since the prevalence increases dramatically with age. There is a clear policy imperative to address the inequalities faced by people with such impairments.

Despite the limitations of this study, we can be confident of two broad messages that come from the findings presented here, and the broader analysis upon which they are based. First, inequality by visual impairment was present for most outcomes, showing clearly the disadvantage of people with sight loss. Second, those with visual impairments fare quite well in regard to social networks and contacts.

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How to obtain further information

The full report, and a summary report – in the form of a 'Research Findings' – entitled *An investigation into the circumstances of older people with sight loss: Analysis of the English Longitudinal Study of Ageing* by Dr Edlira Gjonça and Professor James Nazroo, are available from:

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

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 £600,000 to fund 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, 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 outcomes 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.

Thomas Pocklington Trust

Housing and support for
people with sight loss

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