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## Formal and informal care utilisation amongst elderly persons with visual impairment

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## **Formal and informal care utilisation amongst elderly persons with visual impairment**

### **Abstract**

**Objective:** To examine the determinants of formal and informal care utilisation amongst persons with (age-related macular degeneration) AMD.

**Design:** Cross sectional hospital based study.

**Setting:** Hospital eye clinic in Northern Ireland.

**Participants:** 284 persons aged 50 years and above.

**Main outcome measures:** Participants were asked questions about their care, living arrangements, eyesight-related ability to self-care, and eyesight-related need to be more careful whilst undertaking everyday tasks.

**Results:** The percentage of older persons receiving formal and informal care rose with the level of visual impairment with 34.9% and 37.3% of those with no visual impairment receiving formal and informal care respectively compared with 51.6% and 69.9% of those with moderate visual impairment and 55.6% and 88.9% of those with severe visual impairment. Three factors - age, best corrected distance visual acuity in the better eye, and living alone - were significant predictors ( $p < 0.05$ ) of care utilisation. The likelihood of a person utilising formal care rose with increasing age, severity of visual impairment and living alone. There is an approximate one-to-one trade-off between age and visual acuity such that a difference in one line of vision is equivalent to

approximately one year of life to the affected individual in terms of its impact on the probability of care utilisation.

**Conclusions:** Care utilization is predicted by age, visual acuity in the better eye, and living arrangement. These findings question the validity of the current practice of defining the need for statutory services on the basis of visual acuity alone. These data may have implications for cost utility analyses of new therapeutic developments in macular degeneration.

## **Formal and informal care utilisation amongst elderly persons with visual impairment**

### **1. INTRODUCTION**

The late stages of age-related macular degeneration (AMD) are the major cause of blindness among those aged 50 years and over in the developed world.<sup>1,2</sup> Severe visual impairment associated with late stage AMD affects 0.2% of those aged 55-64, almost 5% of those aged 75-84 and 13% of those aged 85 and above.<sup>3</sup> As AMD is a bilateral process, that it should have a severe adverse impact on the individuals' health-related quality of life and ability to live independently when advanced disease affects both eyes is not surprising.<sup>4-11</sup> To date there has been few systematic attempts to better understand the contribution of AMD related visual impairment to the utilisation of formal and informal care amongst affected individuals. One study - the Blue Mountains Eye Study - has shown a greater reliance on both community and family support.<sup>12</sup> Evidence from this study has also demonstrated that decreased vision may be a contributing factor to subsequent nursing home placement.<sup>13</sup> As the population ages and the prevalence of AMD increases, clearly a better understanding of the impact of the disease on the utilisation of formal and informal care is important. In this paper we examine the determinants of formal and informal care utilisation amongst elderly persons with AMD.

## **2. METHODS**

### **Subjects**

A total of 284 individuals were recruited through a hospital eye clinic in Northern Ireland. The inclusion criteria were (a) aged 50 years and above; (b) not cognitively impaired with ability to give informed written consent; and (c) a diagnosis of late AMD in at least one eye. Data collection took place between November 2000 and February 2003. The study was approved by the Research Ethics committee of The Queen's University of Belfast and adhered to the Tenets of Declaration of Helsinki on the participation of human volunteers.

### **Instruments**

A set of structured questions was used to acquire information on independent living (Q1), self reported visual disability (Q2 and Q3), formal and informal care utilisation (Q4) and transfer payment utilisation (Q5) (Table 1). Formal care utilisation referred to (a) home help provided by social services, (b) private home help (paid by the individual), and (c) attendance allowance (a social benefit given to those who are aged 65 or over and need help with personal care because of an illness or disability). Utilisation of informal care was defined as support provided by family or friends.

Table 1: Questions used to elicit information on formal and informal care utilisation

Questions	Responses
1. What best describes your living environment?	<ol style="list-style-type: none"> <li>1. Live alone</li> <li>2. Live with spouse</li> <li>3. Live with a relative or friend</li> <li>4. Live in residential home or sheltered accommodation</li> <li>5. Live in fold</li> <li>6. Other (please state)</li> </ol>
2. My eyesight prevents me from attending to my own needs.	<ol style="list-style-type: none"> <li>1. Strongly agree</li> <li>2. Agree</li> <li>3. Neither agree or disagree</li> <li>4. Disagree</li> <li>5. Strongly disagree</li> </ol>
3. I feel I have to be more careful because of my eyesight.	<ol style="list-style-type: none"> <li>1. Strongly agree</li> <li>2. Agree</li> <li>3. Neither agree or disagree</li> <li>4. Disagree</li> <li>5. Strongly disagree</li> </ol>
4. Please indicate any outside help you receive.	<ol style="list-style-type: none"> <li>1. Home help provided by social services</li> <li>2. Private home help</li> <li>3. Meals on wheels</li> <li>4. Day centre attendance</li> <li>5. Family or friends</li> <li>6. Other (please state)</li> </ol>
5. Do you receive any of the following benefits?	<ol style="list-style-type: none"> <li>1. Income support</li> <li>2. Attendance allowance</li> <li>3. Assistance with rent/rates</li> <li>4. Disability living allowance</li> <li>5. Other (please state)</li> </ol>

### Measures of vision

Each participant had distance and near visual acuities and contrast sensitivity measured on each eye separately, according to a specified protocol and under standard conditions of illumination, as previously described.<sup>14</sup>

## **Statistical methods**

The Statistical Package for Social Sciences (SPSS) version 11.5 was used to record, retrieve and analyse data. Data on socio-demographic characteristics, namely, age and gender, and visual acuity of the sample population were examined through simple descriptive statistics. Subjects were assigned to three levels of care utilisation depending on their response to Q4 in table 1. The three levels of care utilisation were no utilisation of care services at all (level 1), utilisation of informal care (level 2), and utilisation of formal care with or without informal care (level 3). All nominal and ordinal variables were recoded into dichotomous dummy variables for the purpose of the analysis (see Appendix). An ordinal regression model using Cauchit link function was used to estimate the relations between the three levels of care and all possible explanatory variables which included age, gender, living arrangement, distance visual acuity in the better eye, eyesight-related ability to self-care, and eyesight-related need to be more careful whilst undertaking everyday tasks.

## **3. RESULTS**

Table 2 displays the summary statistics for the sample population. There were a total of 284 participants with an average age of 75.1 years. One third of the participants lived alone (36.3%) and two thirds lived within social groups: (45.4% with their spouse, 13% with a relative or friend and 5.3% in residential accommodation).

On classifying participants into three groups based on DVA in the better eye (table 3), those with an acuity equal to or better than logMAR 0.3 (6/12 Snellen) who represented the no visual impairment group, had the least use of formal and informal care and transfer payments. Participants who were moderately visually impaired (logMAR 0.4 to 0.9) and severely impaired (logMAR 1.0 or worse) proportionately made greater use of formal and informal care and transfer payments. Those who were severely visually impaired were statistically more likely to use informal care than those who were moderately visually impaired (z score = 1.98) but were not different from each other in the use of formal care or transfer payments (z scores are 0.46 and 0.00 respectively).

Table 2: Socio-demographic and visual acuity characteristics of participants

Age at recruitment (years)		
Range	51.00 – 99.00	
Mean (SD)	75.10 (8.01)	
Gender		
Female (%)	172 (60.6)	
Male (%)	112 (39.4)	
Living arrangement		
With spouse (%)	129 (45.4)	
Alone (%)	103 (36.3)	
With a relative or friend (%)	37 (13)	
Supported/sheltered accommodation (%)	8 (4.2)	
Others (%)	3 (1.1)	
	Better eye	Worse eye
Distance visual acuity (logMAR)		
Range	-0.20 – 1.60	0 – 1.70
Mean (SD)	0.37 (0.38)	0.99 (0.53)
Median	0.30	1.00
Near visual acuity (logMAR)		
Range	0 – 1.70	0.10 – 1.70
Mean (SD)	0.66 (0.47)	1.25 (0.47)
Median	0.60	1.40
Contrast sensitivity (logMAR)		
Range	1.80 – 0	1.65 – 0
Mean (SD)	1.16 (0.34)	0.75 (0.48)
Median	1.20	0.75

Table 3: Utilisation of care services and transfer payments by distance visual acuity (DVA)

Visual acuity group (logMAR)	Formal care (%)		Informal care (%)		Transfer payments (%)	
	Yes	No	Yes	No	Yes	No
DVA -0.2 – 0.3	52(34.9)	97(65.1)	56(37.3)	94(62.7)	66(44.9)	81(55.1)
DVA 0.4 – 0.9	48(51.6)	45(48.4)	65(69.9)	28(30.1)	63(69.2)	28(30.8)
DVA 1.0 or worse	15(55.6)	12(44.4)	24(88.9)	3(11.1)	18(69.2)	8(30.8)

The ordinal regression model found three explanatory variables that were statistically significant, namely, age, living alone, and distance visual acuity in the better eye (table 4). The explanatory variables contributing to the model were in order of importance (as assessed by a Wald test) age, distance visual acuity in the better eye and living alone status. All three variables have positive parameter estimates. Individuals who were older, more visually disabled and living alone, were more likely to fall into level 3 of care utilisation i.e. formal care with or without informal care, compared to level 1 or 2.

Table 4: Determinants of utilisation of formal care with or without informal care

Determinant	Parameter estimate	95% CI
Age	0.082*	0.041 – 0.122
Distance visual acuity in the better eye	0.932*	0.303 – 1.560
Live alone	0.664*	0.182 – 1.146

\*p < 0.05

Table 4 shows the determinants of utilisation of formal care with or without informal care. On examining the parameter estimates for age and distance visual acuity in the better eye there was a one-to-one trade-off between these two variables. As the parameter estimate for visual acuity is the coefficient in the log-odds model for a 10 line loss in visual acuity, the effect of a 1-line loss would

be 1/10 of this or 0.093. This coefficient is approximately equal to the effect of ageing by one year (0.082). Thus a one line loss vision is equivalent to being a year older in terms of the 'care burden'.

#### **4. DISCUSSION**

The existing body of research on the utilisation of care services amongst visually impaired elderly persons remains very limited. It has been shown that visually impaired elderly persons are more likely than those who are not visually impaired to draw on help offered by the state and their informal support network.<sup>12</sup> However, it is unclear whether there exists a particular factor or set of factors that may trigger the need for care. Our analysis has shown that proportionately more of the subjects received informal care from their families or friends than formal support.

Our analyses have also provided some insight into the determinants of care utilisation. The ordinal regression model showed that age, distance visual acuity in the better eye and living alone status were significant determinants of care utilisation. In particular, the likelihood of a person with AMD moving from a state of not utilising care (level 1) to utilising informal care (level 2) and finally to utilising formal care with or without informal care (level 3) increases with age, severity of visual impairment in the better eye, and when the person lives alone. This pattern likely reflects differences in the factors governing access to formal care (or used to assess access) and consequent differences in the role of formal and informal care. It would appear that formal care (such as a home help) may

be triggered by general indicators of greater vulnerability (such as increasing age and living alone) and reduced ability to self-care and independent living brought about increased visual impairment and consists of assistance with specific tasks at scheduled times such as that required for cooking or cleaning. On the other hand, persons who are younger with better vision and live with someone are more likely to tap into informal care or require no care at all. Informal care may provide less specific assistance in case a need arises at times that may be more difficult to predict – perhaps offering a watching role for example. This is not to understate the importance of such care. In the absence of informal carers to meet such needs, especially when individuals live alone, they may find their continued independence impossible to sustain precipitating entry to a nursing home or other care establishment or increasing the need for some form of help offered by social services.

Clearly further work is required in this area to gain a better understanding of the needs of visually impaired older persons as well as the impact of supporting AMD patients on informal caregivers. The present study has shown that the needs for the visually impaired will be more accurately assessed when the cumulative effect of age, visual acuity and living arrangement status are taken into account. Given that an improvement of even one line in acuity is equivalent to one year of life in terms of its impact on the probability of care use, the findings of this study provide a further impetus to minimize vision loss in AMD.

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**Competing Interests** – None declared

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## **Appendix**

With reference to Table 1, the variables were recoded as follows:

- a) Q1, responses 2 to 6 recoded as 0 (do not live alone) and response 1 recoded as 1 (live alone).
- b) Q2 and Q3, responses 3 to 5 recoded as 0 (no) and responses 1 and 2 recoded as 1 (yes).