Abstract

Purpose

Age-related macular degeneration (AMD) is the leading cause of visual impairment in older adults in the UK. This study sought to characterise AMD patients who seek the services of the Macular Society, and determine the level and source of their dietary knowledge.

Methods

A questionnaire was designed, validated and administered to 158 participants. The questions covered demographic data and knowledge of nutrition and supplementation.

Results

The mean age of participants was 79 years, 61% of which were female and 27% were registered visually impaired. Only 55% of the participants thought diet was important for eye health, 63% felt that they had not received enough information about AMD. The participants reported that their information mainly came from non-professional support groups. Most participants identified healthy food, but could not say why, and were not able to identify carotenoid rich foods.

Conclusions

The results will inform design of education and dissemination methods regarding dietary information.

Keywords: age-related macular degeneration, diet, lifestyle factors, nutrition, survey.
Introduction

Age-related macular degeneration (AMD) is the leading cause of visual impairment in older adults (> 50 years) in the UK (RNIB, 2010). Currently, there are several AMD classification schemes which have been developed to try to standardise research and clinical practice. Ferris et al. (2013), proposed a five stage classification scale which has achieved some consensus among AMD specialists: Stage 1) No apparent aging changes, 2) Normal aging changes, known as ‘drupelets’ (small drusen ≤63 µm) 3) Early AMD – medium sized drusen ≤125µm 4) Intermediate AMD - large drusen and pigmentary (hyper or hypo) anomalies and 5) Late AMD – geographic atrophy and/or neovascularisation (Ferris et al., 2013). AMD can cause a gradual loss of central visual function occurring within months, or over many years, and late AMD can cause central visual loss and metamorphopsia within days or even hours. Many AMD patients have been given a simplified classification using the terms ‘dry’ to describe geographic atrophy and ‘wet’ to describe neovascularisation or exudation. Visual loss is strongly associated with a reduction in quality of life as it will limit the ability to perform daily activities. Subsequently, depression often occurs in these patients (Mathew et al., 2011). It has been predicted that the prevalence of AMD will increase significantly by 2020 due to the generalised aging of the population (Owen et al., 2012; Shaw, 2006), but also due to socio-economic factors such as poor nutrition and increased smoking in some areas (Huffman et al., 2012; Wennergren et al., 2013). Therefore it can be expected that there will be a growing need for support services for people with this condition.

Diagnosis for AMD in the UK occurs via an ophthalmologist (RNIB, 2010). Often, after the initial diagnosis, the patient will receive written material regarding the disease from the ophthalmology department. The decision then rests with the ophthalmologist as to whether the patient requires any treatment. This might take the form of anti-vascular endothelial growth factor medications (e.g. Lucentis®) or surgery/laser work to wet AMD conditions, low vision services or placement upon a sight impairment register. If the AMD is of an early or intermediate stage, the patient will have very little contact with any hospital services for some years – if at all – unless the AMD changes to a late stage. Patients are advised to have a yearly eye examination with an optometrist who will monitor the condition, but is often unable to provide physical or psychological help without referral (AOP, 2001).
Whilst specialists agree that smoking has a big impact on AMD and that cessation will halt progression of the disease (Caban-Martinez et al., 2011), there are conflicting research findings and therefore conflicting information provided by eye care practitioners regarding the impact of nutrition on AMD (Kent, 2007).

The Age-Related Eye Disease Study (AREDS) reported that nutritional supplementation in people with intermediate AMD can reduce their risk of progression to advanced AMD by 25% (Kassoff et al., 2001). While the AREDS was in progress, evidence emerged to suggest that the dietary nutrients lutein and zeaxanthin may be more effective than other nutrients in reducing AMD risk or progression due to their antioxidant and photo protective properties (Beatty, Koh, Phil, Henson, & Boulton, 2000). The plausibility for this hypothesis is due to the high concentration of lutein, zeaxanthin, and a related compound meso-zeaxanthin, in the macula, particularly in the fovea, which form the macular pigment (Khachik, Bernstein, & Garland, 1997). The protective properties of the macular pigment are now well established and include the ability to interact with free radicals, prevent lipid peroxidation and filter out incoming, high energy blue light (Alves-Rodrigues & Shao, 2004; Ham, 1983; Junghans, Sies, & Stahl, 2001; RNIB, 2010). Some studies also show a link between increased intake of lutein and zeaxanthin, and higher macular pigment levels (Bhosale, Zhao, & Bernstein, 2007; Vishwanathan, Goodrow-Kotyla, Wooten, Wilson, & Nicolosi, 2009; Wenzel, Sheehan, Burke, Lefsrud, & Curran-Celentano, 2007). Supplementation studies report increases in macular pigment of between 21 and 57% following lutein and zeaxanthin supplementation in people with healthy eyes. Increases in macular pigment of between 24% and 36% have been reported in people with retinal disease. One randomized controlled trial reported an improvement in several measures of visual function in a group of veterans who supplemented with 10 mg of lutein for one year (Richer et al., 2004; Ziemssen, Warga, Bartz-Schmidt, & Wilhelm, 2005). A recent study by Loughman et al. (2012) suggests that supplementation with all three macular carotenoids may offer advantages both in terms of macular pigment optical density (MPOD) response and visual performance enhancement (Loughman et al., 2012). The AREDS team recently released the results for their follow-up study (AREDS 2) which encompassed lutein and zeaxanthin to the original AREDS supplement formulation (Chew et al., 2013). The study found that adding lutein and zeaxanthin did not further reduce the risk of progression to advanced AMD. However, investigators report that lutein and zeaxanthin may be useful substitutes for beta-carotene in the original formulation (Cangemi, 2007). Despite the conflicts,
overall, the research evidence suggests that high macular pigment levels could reduce risk for onset or progression of AMD.

Because xanthophylls are not synthesised by the human body, they have to be acquired either in the diet or by supplementation. Research shows that the highest mole percentage of lutein and zeaxanthin are in egg yolk, maize (corn), spinach, collard greens (like cabbage) and kale (Hosseini, Mosallaei, & Kalameh, 2009; Sommerburg, Keunen, Bird, & van Kuijk, 1998). Maize has been identified as the vegetable with the highest quantity of lutein and orange pepper was the vegetable with the highest amount of zeaxanthin. Amounts of lutein and zeaxanthin are also reported to be present in kiwi fruit, grapes, orange juice, courgettes, and different kinds of squash. Predominantly, leafy green vegetables have a highest content of lutein and zeaxanthin.

Despite the body of evidence in support of a role for dietary modification or nutritional supplementation in reducing risk of progression of AMD, neither patients nor practitioners are clear about what kind of supplements to take, or how foods should be prepared and consumed in order to maximise absorption of useful nutrients (Kent, 2007). To add to the confusion, there are many nutritional supplements aimed at those with AMD currently on the market, with varying degrees of dosage and some without any research basis at all (Arora, Musadiq, Mukherji, & Yang, 2004; Loughman, Nolan, Stack, & Beatty, 2011). Many do not contain the AREDS formulation. Research has shown that given more choices, patients are much more likely to be overwhelmed (Kent, 2007). Supplements are not regulated in the same manner as medication in the UK (EU Directive, 2002) and it is very difficult to identify which supplements are likely to be of any benefit.

Since many local authorities do not have standardised rehabilitation services in place (Gillespie-Gallery, Conway, & Subramanian, 2012), some patients have been turning to non-professional charities, such as The Macular Society, to acquire information and support. The Macular Society is the only national UK charity that is dedicated solely to helping those with diseases of the macula. They provide impartial information and practical support for visually impaired people, their families and carers. They also “provide information for health professionals, campaign for better services, sponsor research and raise awareness of macular degeneration and preventative measures” (The Macular Society, 2013, http://www.macularsociety.org/how-we-help).
The objectives of this study were firstly to find out who pursues the help of a non-professional charity, and secondly, to determine the beliefs and understanding that these AMD patients have about the impact of nutrition on the condition, and where patients have obtained information about nutrition.

**Methods**

**Participants**

A total of 158 participants were recruited between January 2012 and March 2012. Recruitment was via the Macular Society helpline volunteer worker. Patients aged over 55 years of age who contacted the Macular Society helpline between January 2012 and March 2012 were asked if they would like to take part in a telephone survey (once they had received all the assistance they needed from the Macular Society). Pre-requisites for potential participants were that they should be aged over 55 years and have been diagnosed with a form of AMD; exclusion criteria were the inability to hear and reply to questions in English over the telephone. No attempt was made to define and categorise the amount of visual loss the participant had, as the objective was to assess typical patients seeking the Macular Society services.

**Ethics**

The procedures followed were in accordance with the ethical standards of the Aston University Ethics Committee on human experimentation that conform to the Declaration of Helsinki 1975, revised Hong Kong 1989.

**Survey Design**

A systematic literature review of research on AMD patient’s perceptions of nutrition and AMD was conducted of the following databases: Web of Knowledge, The Cochrane Library, Optics Infobase, Ovid Journals, PsycArticles, NCBI databases and Wiley Online Library. The following key-terms were used: “Age-related macular degeneration”, “Nutrition”, “Survey”, “Attitudes”, “Behaviours” and “Diet”. This review did not identify any existing measure of patient’s perceptions of nutrition, but found most surveys looked at nutritional behaviours (Montgomery et al., 2010). As a result, a 36 question cross sectional survey was designed to explore nutritional habits, supplement usage, physical abilities in food preparation and cooking,
and sources of knowledge in order to ascertain the beliefs AMD patients have, and compare their beliefs with
their behaviours. Not all the results of the 36 questions are covered in this paper. Because the survey was
exploratory, it was designed mainly with open ended questions in order to ensure responses reflected
participants’ true beliefs. In addition, some closed ended questions were included with response scales to
grade participants’ feelings.

The survey was then piloted on eight AMD participants, from the Macular Society, to test the reliability,
comprehensibility, and understanding among an informed population. This ‘face validity’ (i.e., does the
questionnaire appear correct at face value) was the only means of validation that it was possible to perform,
due to a lack of other instruments to compare the results with. Initially, the eight patients completed the
survey via a telephone interview. Three weeks later, the patients attended a focus group that had two parts:
firstly, the participants completed the survey once more. Next, the participants had a recorded, guided
informal discussion structured by a moderator – the volunteers were asked to comment on how easy the
questions were to understand and opinions on the topics covered. The results of this meeting were analysed
to further refine the survey, which was altered accordingly (e.g. the terms ‘wet’ and ‘dry were employed to
coincide with many patient’s understanding of AMD classification, extra options were added to some
questions, some questions were removed or re-worded and additional instructions were added). The final
survey (see Appendix 1.) was then administered to the cohort.

The initial questions covered demographic topics such as gender, age, employment, social history, type and
length of time with AMD and visual impairment registration. Opinions on diet and supplementation were
obtained, with particular interest in whether participants could identify lutein and zeaxanthin rich foods (e.g.
kale) amongst other vegetables. Participants were also asked where they had acquired any information about
the condition from (for instance, an ophthalmologist, optician, Macular Society etc). The questions
subsequently focused on perceived state of vision and health, and ability to perform preparation and cooking
of food. Participants also provided a food diary for 24 hours, as studies have shown there is less measurement
error in food recording than in food frequency questionnaires, and the ability to study associations between
diet and chronic diseases is slightly easier with food diaries (Bartlett & Eperjesi, 2004; Block, Hartman, &
Dresser, 1986). The results of the questions relating to cooking abilities, perceived health and vision states and
the food diary is beyond the scope of this paper and will be discussed in a future paper.
If a patient agreed to take part, their name and contact details were taken by the helpline worker. The potential participants were read an information factsheet informing them what the survey would involve, how long it would take and how the information would be stored. If the patient decided to participate, an oral informed consent was obtained over the telephone and they were advised that they could withdraw at any time. Usually an appointment was scheduled for a future telephone interview or the interview began immediately if the patient wished.

They were then contacted at a convenient time by one of four Macular Society employees who would administer the telephone interview and fill in the survey online at the same time (Bristol Online Surveys). The telephone interview lasted approximately 25 minutes, and was not recorded. Each volunteer was trained (by RS) to ask the questions only, without bias, and if the participant had any questions regarding the survey, they were given the author’s contact details, although no participant made any contact.

Data Analysis

The results were analysed to find the mean, median and standard deviation using the software Microsoft Excel. Data from Excel was then used to create charts, and used in statistical software IBM SPSS (version 20) to draw comparisons between supplement cost and usage using chi-square statistics. Qualitative data was grouped into categories and general themes were extracted to then use in SPSS.

Results

Sample Characteristics

Table 1 shows the demographic characteristics of the sample. The gender distribution of the 158 participants showed that there were significantly more females (61%) in the sample than males (39%) (chi-square p= 0.05). The participants ranged in age from 56 to 95 years; the median age was 80 years. There was a nearly even split between ‘wet’ (47%) and ‘dry’ types of AMD (49%), with a small percentage of participants who were unsure of their AMD classification. The median duration of having the condition was 5 years, ranging from 1 to 25
years. The majority of participants lived in their own home – either rented, mortgaged or owned outright, and participants mainly either lived with their partner or alone. The majority of participants were not registered partially sighted or blind, although there was a trend for those participants that had the condition for longer to be on a register (Kruskal Wallis H p= 0.09).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percentage of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living Arrangements</td>
<td></td>
</tr>
<tr>
<td>Own home</td>
<td>88%</td>
</tr>
<tr>
<td>With family/friends</td>
<td>3%</td>
</tr>
<tr>
<td>Sheltered accommodation</td>
<td>7%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
</tr>
<tr>
<td>With</td>
<td></td>
</tr>
<tr>
<td>Partner</td>
<td>50%</td>
</tr>
<tr>
<td>Alone</td>
<td>47%</td>
</tr>
<tr>
<td>Other family members</td>
<td>4%</td>
</tr>
<tr>
<td>Registration</td>
<td></td>
</tr>
<tr>
<td>Blind</td>
<td>16%</td>
</tr>
<tr>
<td>Partially sighted</td>
<td>21%</td>
</tr>
<tr>
<td>None</td>
<td>63%</td>
</tr>
<tr>
<td>Supplement price</td>
<td></td>
</tr>
<tr>
<td>No cost</td>
<td>17%</td>
</tr>
<tr>
<td>£1-5</td>
<td>10%</td>
</tr>
<tr>
<td>£6-10</td>
<td>21%</td>
</tr>
<tr>
<td>£11-15</td>
<td>24%</td>
</tr>
<tr>
<td>£16-20</td>
<td>12%</td>
</tr>
<tr>
<td>£20+</td>
<td>17%</td>
</tr>
</tbody>
</table>

Table 1. Demographic characteristics of participants.

Patient’s perceptions of diet and eye health

When asked their overall opinions on diet and health, 87% of participants believe that diet affects general health, and 68% believe that diet affects eye health.

Figure 1 shows the beliefs that participants held about specific foods: leafy green vegetables, which are good sources of lutein and zeaxanthin, other fruit and vegetables, and dairy products. Participants were asked if they believed each food was beneficial for eye health, and if they answered ‘Yes’, they were asked why they thought so.
Figure 1. Participant’s beliefs about the eye health benefits of several foods. ‘Yes’ indicates the participant believed the food was beneficial, ‘No’ indicates the participant did not believe that the food was beneficial, and ‘DK’ indicates the participant didn’t know.

As shown, the majority of participants were accurate in their perceptions of the food which would be beneficial for eye health. Leafy green vegetables such as spinach, cabbage and kale were identified as being beneficial by over 80% of participants. Ice-cream was identified as not beneficial for eye health by 72% of participants. For mango, bilberries and peppers, 25% or more participants answered ‘don’t know’, and responses were more mixed. Males responded with ‘Don’t know’ on average 10% more than females.

When asked why they felt a particular food was valuable for eye health, the majority of participants (81%) struggled to verbalise why they held that belief. Of those that did express the reasoning behind their beliefs, the majority of the responses had nothing to do with nutrients. Only 2% of those that felt spinach and kale are beneficial for eye health knew that they contain lutein. Some participants responded that leafy green vegetables were known to be good for eyes (spinach 5%, kale 3%, and cabbage, 6%), while others merely responded that coloured foods were good for eyes (carrots 2%, peppers 5%, and mango 1%). Some participants (1%) responded that spinach and kale contained iron, which was why they felt it would be beneficial for eye health. One percent of participants felt that carrots were beneficial because they contained carotene, and that peppers were beneficial because they contained vitamin C. Participants also included the following reasons for carrots: “They help you see in the dark” (6%), “war propaganda” (6%), “We were told to
eat them by parents” (6%). One percent of participants responded that their optician had told them that mango was good for eye health. Participants also responded that they had “read it was beneficial somewhere” for some foods (peppers 1%, bilberries 5%).

As mentioned earlier, no participant felt that ice-cream was beneficial for eye health. Of the participants that felt that cheese was beneficial for eye health (18%), none could give a reason why.

Nutritional supplementation

The participants were asked who they had discussed nutritional supplementation with - 30% of the participants had discussed it with their ophthalmologist, 15% with their optometrist and 8% had consulted their GP.

Participants were asked if they currently took a nutritional supplement(s). Of those that responded ‘yes’ (79%; of males and 79% of females), the majority (60%) took the supplement once per day. The most popular brand of ocular supplement used was I-caps [Alcon] (24%), followed by PreserVision [Bausch&Lomb] (19%), Ocuvite [Bausch&Lomb] (14%), Viteyes [Viteyes] (14%), Macushield [Macuvision] (11%), Retinex [Healthspan] (8%), Visionace [Vitabiotics] (5%), and Vitalux [Novartis] (3%). Some patients took more than one brand with a variety of dosing methods.

- Figure 2. Reasons for not taking Nutritional Supplements.

Those that responded that they did not take a nutritional supplement (33 participants - 21% male and 21% female) were asked to describe these reasons as shown in Figure 2. The majority felt that they were not sure
of the effectiveness of supplementation, but many listed an ‘other’ reason for not taking supplements (but did not provide an explanation for what that reason might be).

The participants were asked how much money would they be willing to spend on a supplement (per month or 30 day’s supply) if they had proof of its worth. The results are shown in Table 1. The supplement usage data were cross-tabulated with the amount of money participants were willing to spend on a monthly supplement, using chi-square statistics. The results show a significant association between those that do take supplements being willing to spend more money on supplements, and those that do not take supplements are willing to spend less money on supplementation (p≤0.000). Of the participants that did not take supplements, 67% were not willing to spend any money on supplementation even if they had proof of its worth.

Patient information

Figure 3 displays the opinions that the participants held about AMD and living with the condition. Over half the participants (51%) believed that AMD patients do not receive enough information about nutrition and lifestyle choices; an additional 12% strongly believed this. The participants were asked where they had received information on AMD from – (they were allowed to pick more than one option): 40% of participants had received information from their ophthalmologist. As expected, 92% had received information from organisations such as The Macular Society. Just over half of the cohort believed that AMD could be prevented by lifestyle choices such as nutrition.
Discussion

The demographic data has shown three interesting findings:

Firstly, research has shown that females (especially in this age-group) are more likely to ask for and utilise health care services (Cameron, Jing, Manheim, & Dunlop, 2010; Vaidya, Partha, & Karmakar, 2012), so it could be speculated that more females than males seek out the services of the Macular Society.

Secondly, only 37% of the participants were registered on a visual impairment register, despite 47% of participants having ‘wet’ AMD (although this was self-reporting and the severity was not assessed). The Royal National Institute of the Blind (RNIB)’s survey into certification and registration in 2011 (Boyce, 2012), shows a steady decline in the number of registrations per year despite the fact that the prevalence of visual impairment is increasing (Owen et al., 2012; RNIB, 2010). They attribute this decrease in registration not to a lack of interest in registration by the patient, but rather to the length of time it takes to complete the Certificate of Visual Impairment (CVI) by the professionals involved.

Finally, nearly half the participants lived alone – this can have a huge impact on their quality of life. One study (Vale, 2004) has shown that 63% of all blind and partially sighted people live alone – a higher figure than the ‘normal’ sighted elderly population. It would have been useful to find out if participants had a mobility issue, as this may have affected why the participants had chosen to seek the Macular Society’s services – a helpline is easier to access than physically going to see an Ophthalmologist or Optometrist for advice, and this could explain why patients did not report sourcing their information from an ophthalmologist or optometrist.

The cohort was a group of highly motivated individuals who had taken the initiative to contact the Macular Society but still felt that they needed more advice, particularly relating to nutrition. Although some of the participants needed to rely on others for support and felt they had considerable visual impairment, the desire to remain independent and improve their vision is evidenced through seeking the services of the Macular Society, and using other healthcare professionals such as dieticians and specialist doctors.
This sample may not represent all patients seeking services from organisations like the Macular Society. Access to other organisations would provide a more rounded view. It would be important to find out the opinions of those with AMD who have not sought support from non-professional organisations, and this will form the next step to the overall project.

Patient’s perceptions

This study provides a clear picture of the perceptions of diet and eye health among a sample of AMD patients. The majority of participants agreed that specific foods can affect general health, and participants also agreed that specific foods affect eye health. The results of the specific food questions show that the majority of participants felt that the vegetables and fruit were beneficial for eye health, and these perceptions were generally accurate. However, apart from a few individuals who mentioned specific nutrients in regard to specific foods (e.g., lutein in kale), most participants were not able to identify why these foods helped promote eye health, or gave vague responses such as “I read it somewhere”. This suggests that participants, who would be expected to be well-informed, were not clear about the links between diet and eye health.

Information

The majority of participants reported that they did not have enough information on nutrition and its relationship to AMD. As expected, all participants reported that they had received information from organisations such as the Macular Society. In contrast, not all the participants reported getting information from their ophthalmologist, which is consistent with previous studies (Dahlin-Ivanoff, Sjöstrand, & Klepp, 1998; RNIB, 2013). The data reported here shows that there are clear gaps in the knowledge patients have of AMD risk factors (Sushma, Lamkin, Albanese, Edward, 2010). A lack of information might also explain why four percent of the participants were not sure what type of AMD they were suffering from. Patients appear to be actively seeking advice but not all are getting it from sources such as ophthalmologists or optometrists. These findings are similar to results from the Royal College of Ophthalmologists audit of AMD services in March 2009 (Amoaku & Hubbard, 2009) which found that there was an insufficiency of resources to deliver adequate AMD Services. Lawrenson and Evan’s survey (2012) of eye professionals (Lawrenson & Evans, 2013) showed that although over 60% of respondents reported that they frequently provide dietary and supplement advice to patients with established AMD and those at risk of AMD, the nutritional advice given only consisted of leafy
green vegetables and oily fish recommendations, and type of supplement recommended did not comply with
current best research evidence, based on the findings of the Age-Related Eye Disease Study (AREDS). Only one
in three optometrists regularly assessed smoking status and advised on smoking cessation (Lawrenson &
Evans, 2013). The results reported in the present study reinforce those of the survey and the Royal College of
Ophthalmologists, and provide further evidence that greater support and information provision for AMD
patients is needed.

Nutritional supplementation

Over 75% of participants reported taking a nutritional supplement (mainly on a once-per-day basis) – this is a
larger number than other studies into supplement usage have found (Block et al., 2007) (Bartlett & Eperjesi,
2004; Denison et al., 2012). The majority of patients that were taking ocular supplements were not taking an
exact AREDS formulation, and were taking an incorrect dosage or combining it with one or two other brands
with the same formulation (maybe believing that more might be better). This pattern of supplementation
could reflect a lack of information from healthcare professionals, with only a third of patients having discussed
nutritional supplementation with their ophthalmologist, while some participants had not discussed
supplementation with anyone at all. Those participants in our study that reported not taking any supplements
listed the primary reason as not believing they would be effective, and hence were unwilling to spend much
money on an unproven supplement. The high number of nutritional supplements marketed towards people
with AMD makes it difficult for both patients and health professionals to navigate this issue for the prevention
or treatment of the condition (Kent, 2007). There are currently no clear supplement guidelines for health
professionals to use; The College of Optometrists advises that patients should eat a healthy diet and to stop
smoking, adding that there “is no definitive scientific evidence of the effectiveness of nutritional
supplements”, but patients should speak to their optometrist for supplement advice (The College of
Optometrists, 2011). Some institutions might have been waiting for the results of AREDS 2, but since the
AREDS 2 results have been released, there is a need for unified guidelines for all health professionals. When
asked how much participants would be willing to pay for an effective nutritional supplement, only one quarter
responded that they would pay more than £11 per month, and there was a significant correlation between
those who did not take supplements and those that were not willing to spend any money on supplements.
In conclusion

The development of this survey has created a new measure that can be used again. The study has identified that AMD patients have a definite lack of information and understanding of the link between AMD and nutrition, and this needs to be corrected. The results of this study will inform the design of more effective education and dissemination methods, and help to outline guidelines for health professionals.

Declaration of Conflicting Interests

The authors declare no conflict of interest and have no proprietary interest in any of the materials mentioned in this article.

Acknowledgements

This study was conducted with support from the Macular Society, but not funded by the Macular Society.
References


Appendix 1. Survey Questions.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>How old are you?</td>
<td>Male, Female</td>
</tr>
<tr>
<td>Would you describe yourself as...</td>
<td>Alone, With partner, With family, With friends, Other (please specify)</td>
</tr>
<tr>
<td>Do you live...</td>
<td>In own residence, In family/ friend's residence, In sheltered accommodation, In nursing home, Other (please specify)</td>
</tr>
<tr>
<td>What is, or was your main occupation</td>
<td>Extremely good</td>
</tr>
<tr>
<td>How would you describe your general health today? How would you describe your vision today?</td>
<td>Extremely good</td>
</tr>
</tbody>
</table>
### Table: Food Preparation and Shopping

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have the eye condition age-related macular degeneration?</td>
<td>Yes, No, Have not heard of this condition</td>
</tr>
<tr>
<td>If Yes, how many years have you had it in total?</td>
<td></td>
</tr>
<tr>
<td>What type of age-related macular degeneration do you have?</td>
<td></td>
</tr>
<tr>
<td>Are you on any visually impaired register?</td>
<td>Sight impaired (partially sighted), Severely sight impaired (blind), Neither</td>
</tr>
<tr>
<td>Who MOSTLY prepares your food?</td>
<td>You, Partner, Family member, Care giver, Other (please specify)</td>
</tr>
<tr>
<td>Who MOSTLY cooks your food?</td>
<td>You, Partner, Family member, Care giver, Do not eat cooked food, Other (please specify)</td>
</tr>
<tr>
<td>What prevents you from preparing food (select all that apply)</td>
<td>Visual impairment, Physical impairment, Nothing, Other (please specify)</td>
</tr>
<tr>
<td>Are you able to cook a hot meal on your own?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>What prevents you from cooking food (select all that apply)</td>
<td>Visual impairment, Physical impairment, Nothing, Other (please specify)</td>
</tr>
<tr>
<td>Who MOSTLY does your food shopping?</td>
<td>You, Friend, Family member, Care giver, Other (please specify)</td>
</tr>
<tr>
<td>Where do you get your food from? (select all that apply)</td>
<td>Supermarket, Local grocers/ corner shop, Internet, Meals on wheels</td>
</tr>
</tbody>
</table>

---

**Key:**
- **Good**
- **Satisfactory**
- **Poor**
- **Extremely poor**
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the most important factor that dictates what you eat?</td>
<td>Cost, Preference, Habit, Ability to cook or prepare it, Ability to acquire it, How it affects your health, Other (please specify)</td>
</tr>
<tr>
<td>Would you like to change your diet in any way?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>What prevents you from changing your diet?</td>
<td>Visual impairment, Physical impairment, Nothing, Other (please specify)</td>
</tr>
<tr>
<td>Please could you describe what you ate yesterday (Breakfast, Lunch, Dinner, Snacks - your interviewer will describe portions).</td>
<td>Mostly cooked, Mostly raw, No vegetables eaten yesterday</td>
</tr>
<tr>
<td>Were the vegetables eaten yesterday (if any)...</td>
<td>Mostly cooked, Mostly raw, No vegetables eaten yesterday</td>
</tr>
<tr>
<td>Please state how strongly you agree or disagree with the following statement:</td>
<td>Strongly agree, Agree, Neither, Disagree, Strongly disagree</td>
</tr>
<tr>
<td>There are specific foods that can affect your health.</td>
<td><strong>Agree</strong></td>
</tr>
<tr>
<td>Please state how strongly you agree or disagree with the following statement:</td>
<td>Strongly agree, Agree, Neither, Disagree, Strongly disagree</td>
</tr>
<tr>
<td>There are specific foods that can affect your EYE health.</td>
<td><strong>Agree</strong></td>
</tr>
<tr>
<td>Do you think any of the following foods are beneficial for eye health... and why</td>
<td>Carrots, Ice-cream, Spinach, Cabbage, Kale, Bilberries, Cheese, Peppers, Mango</td>
</tr>
<tr>
<td>Which, if any, of the following vegetables did you eat last week? (select all that apply)</td>
<td>Carrots, Peas</td>
</tr>
<tr>
<td>Spinach</td>
<td>Cabbage</td>
</tr>
<tr>
<td>--------------</td>
<td>--------------</td>
</tr>
</tbody>
</table>

**Have you ever discussed taking a nutritional supplement with a health specialist or advisor?**
- **Yes**
- **No**

**If yes, who?**
- Ophthalmologist
- GP
- Optician
- Specialist doctor
- Nurse
- Herbalist
- Pharmacist
- Dietician
- Helpline worker
- Other (please specify)

**Do you currently take any nutritional supplements?**
- **Yes**
- **No**

**If yes, what supplements do you take?**

**How often do you take the supplements listed above?**
- More than twice per day
- Twice per day
- Once per day
- Once per week
- Other (please specify)

**If you answered No, Can you give a reason for not taking a nutritional supplement?**
- Too expensive
- Not sure if effective
- Fear/ experience of side-effects
- Worry about interaction with other drugs
- Too much trouble
- Other (please specify)

**How much money would you be willing to spend on a monthly basis on a nutritional supplement which promised good results?**
- No money
- £1-5
- £6-10
- £11-15
- £16-20
- £20+

**Please state how strongly you agree or disagree with the following statement:**
- **Strongly agree**
- **Agree**
- **Neither**
- **Disagree**

**Age-related macular degeneration patients are given enough information on how nutrition affects their eye health.**

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where have you received information on age-related macular degeneration from? (select all that apply)</td>
<td>Ophthalmologist, Optician, Internet, Newspapers, TV, Organisations such as the Macular Society, Other (please specify)</td>
</tr>
<tr>
<td>Do you believe that age-related macular degeneration can be prevented by lifestyle choices such as nutrition?</td>
<td>Strongly agree, Agree, Neither, Disagree, Strongly disagree</td>
</tr>
<tr>
<td>Which changes to the way that you live do you think could affect age-related macular generation?</td>
<td></td>
</tr>
</tbody>
</table>