

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form ([see an example](#)) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below. Some articles will have been accepted based in part or entirely on reviews undertaken for other BMJ Group journals. These will be reproduced where possible.

ARTICLE DETAILS

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| TITLE (PROVISIONAL) | "I'd like to know what causes it, you know, anything I've done?"- Are we meeting the information and support needs of patients with macular degeneration?: A qualitative study. |
| AUTHORS | Burton, Amy; Shaw, Rachel; Gibson, Jonathan |

VERSION 1 - REVIEW

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| REVIEWER | Stur, Michael Netzhautklinik, Private Office Prof.Stur No competing Interests |
| REVIEW RETURNED | 13-Jul-2013 |

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| GENERAL COMMENTS | <p>This study investigates a very important topic: the question whether patients diagnosed with AMD, treated for "wet" AMD and followed for many years, understand the diagnosis, the recommendations and requirements as well as the possible outcome of AMD. The authors employed a design fitted to this task, and have succeeded in providing very interesting information about the problems the patients with AMD encounter when confronted with the diagnoses and with their individual course of the disease.</p> <p>On first sight one might criticize the small number of patients and the rather informal way in which the answers to the questionnaires were recorded and evaluated. The value of this study, on the other hand, lies in the fact that it provides vivid glimpses of the individual patients experiences, anxieties and frustrations. The study therefore is able to provide important information about the deficits and shortcomings of current patient education, but does not try to give an answer to the question what could be done to improve the situation.</p> <p>This situation, the deficient information about the disease AMD and its consequences may have its cause right with the health care providers and their understandings of the disease. The complexity of AMD is illustrated by the introduction to this paper, when the authors state:</p> <p>„The most common cause of registerable blindness in developed countries is age related macular degeneration (AMD) which has two types: dry and wet. Dry AMD accounts for 80-90% of cases while wet AMD accounts for 10-20%.“</p> <p>This statement is quite incorrect and misleading. It repeats a frequently made mistake, the subsumation of all non-wet cases into a „dry AMD“ class. In fact these „dry AMD“ patients include cases with just a few drusen only as well as cases with advanced geographic atrophy. A better classification would be the grading into early, intermediate and advanced AMD, with an additional sub-</p> |
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classification of advanced AMD into cases with CNV and with geography atrophy. These final stages of AMD, neovascular and atrophic AMD, appear with similar frequency in European populations, as has recently been shown in a large metanalysis of epidemiologic studies investigating the prevalence of AMD (Rudnicka et al., Ophthalmology 2012;119:571–580).

But even the name of the disease is misleading:

- AMD is neither age-related, since its cause is a genetic predisposition and the first signs of the disease can be identified already in the 30s and 40s of an AMD patient,
- nor is it a maculopathy since drusen can develop all over the retina,
- and it is also not a degeneration, since its pathophysiology is quite complex and includes deviations of the complement pathway, accumulation of phototoxic deposits, inflammatory responses and imbalances of the levels of growth factors and its inhibitors.

Beside their diagnosis the patients also received information about the treatment, the necessary follow up visits, recommendations for their diet and possible intake of dietary supplements, the deleterious impact of smoking, the use of the Amsler grid and supportive services including low vision rehabilitation. The authors find that „This may leave patients confused about what is required of them and therefore unable to play an active role in managing AMD.“ One might also ask whether the guidelines, on which this information is currently based, have already been adapted to the current knowledge of the disease:

The introduction of spectral domain optical coherence tomography SD-OCT has radically changed the way we can determine progression of AMD and presents new challenges in the way we use the new technique for the care of the AMD patients. Relying on self reported worsening of visual acuity reportedly reduces the benefit of treatment with ranibizumab and other Anti-VEGF agents, whereas the best results can only be achieved when patients are regularly examined with SD-OCT and treated immediately after disease progression is found. This fact has now been acknowledged and patients treated for neovascular AMD are regularly monitored with SD-OCT. The question is whether this kind of monitoring should not be expanded to patients with early and intermediate AMD as well, since early stages of neovascular AMD do not make any visual symptoms and can only be recognized with repeated SD-OCT exams. Therefore just education about the course of the disease will never be able to provide the best treatment benefit available, which is only achieved when treatment is performed in time before irreversible loss of vision occurs.

Patients with early and intermediate AMD, who still have good vision on both eyes and might have many years before their eyes develop advanced AMD, might be also the ones who might still benefit from stopping smoking, changing their dietary habits and starting supplementation with an AREDS 2 compliant formula. These patients and their offspring are the ones who should be targeted with educational materials and counseling regarding the necessary changes to their “life style”.

Patients with advanced AMD, on the other hand, need quite different information. They need to know how often they have to return for follow up visits and where to get supportive services, but should not

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| | <p>be pressed to change their diet and to stop smoking completely, when there is little proof that these drastic measures can still make a difference for the course of their AMD.</p> <p>In conclusion, the study presented provides important insight into the challenges of caring for patients with AMD. When planning new educational programs one should keep in mind that education alone is not sufficient, and that initiatives improving the information of the patients have to happen hand in hand with expansion and continuous refinement of the services providing care for patients with all stages of AMD throughout the primary, secondary and tertiary branches of the healthcare system.</p> |
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| REVIEWER | <p>Emily Boxell Royal Holloway, University of London UK</p> <p>I am a PhD student funded by the Macular Society investigating the experiences of patients with Macular degeneration at diagnosis, treatment and rehabilitation.</p> |
| REVIEW RETURNED | 27-Aug-2013 |

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| THE STUDY | <p>-There is some published literature in the field that has not been discussed. Information provision has been briefly looked at before but with visually impaired participants in general (e.g. Douglas et al., 2010) or within the diagnostic consultation only (see Mitchell et al., 2002,) where lack of information has been linked to patient dissatisfaction. A brief critical review of this literature with a concluding sentence on the need for this current research is needed.</p> <p>- Please could the authors add a sentence stating why qualitative methodology is best placed to examine their aims.</p> <p>-In addition to providing more information on the background and research aims, I feel that the reader may benefit from an explanation of how the interview questions were designed with examples of these questions. This will help link the background, research aims and method together. Were the interviews semi-structured?</p> <p>-Additionally there appears to be no explanation provided as to why participants were followed up over a 18 month period. Please could the authors clarify this.</p> |
| RESULTS & CONCLUSIONS | <p>-The authors point to the finding that information provision can affect patients well-being (see pg 15, line 10.) This is an important finding and could add gravitas to the current research if expanded on.</p> <p>-Pg 18, line 21- Typo- "...appointments to assess THEIR physical, social and psychological needs."</p> <p>-Would the quote used in the title and in Box 2 ("I'd like to know what causes it, you know, anything I've done?" Cathleen)- be more appropriate under the sub-theme of cause attributions?</p> |
| REPORTING & ETHICS | <p>Only issue would be for the authors to clarify why participants were followed up more than once to ensure a good reason for this and for any burden that may have been caused to the participant because of this.</p> |
| GENERAL COMMENTS | <p>This is a well written paper based on an important topic for ophthalmology practice. The research uses qualitative methodology to investigate information provision to patients with age-related macular degeneration (AMD) both inside and outside the hospital setting.</p> <p>The findings on self-advocacy were particularly new and interesting and I think the use of qualitative methodology was a good choice to</p> |

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| | <p>pick up on the problems patients face with this. The findings provide a good basis for avenues for further research and interventions of benefit to AMD patients. I can see how further research may use these results combined with the wider literature, for example on barriers existing for detection of symptoms for other conditions. Perhaps a discussion of this could be included in the discussion section if space allows.</p> <p>Currently there is no mention in the discussion about the important role that the Macular Society and other vision charities can play in providing information and support to patients with Macular degeneration. Ophthalmologists can't be expected to provide all the help and support that patients might need, but are able to pass on the details of these charities to patients when they are diagnosed (indeed this is in the RCOphth guidelines.) Peer support from support groups may lead to better adjustment to Macular degeneration, something which ophthalmologists cannot provide themselves.</p> <p>One final comment- given that the RCOphth guidelines were published in 2009 and the interviews for the present research were conducted in 2010, this may not have allowed enough time for the guidelines to be translated into practice so we should be wary of drawing any firm conclusions from these data about "current" practice. As nearly 3 years have passed since the data were collected, experiences of patients with AMD may now be different. This is a limitation not recognised by the authors, however I believe the results do provide a good starting point to investigate the issues raised further.</p> <p>Minor comments: pg2, line 42, the word recognise should contain an "s" rather than a "z"</p> <p>Tables- check pseudonyms are in brackets. pg 9, line line 7-12, repetition of the quote from "Mary" (it is in the table too.) I don't think this quote is needed twice. Also this quote isn't exactly the same in text as in the table ie.in text- "[I had] a black cloud." In table- "[I see] a black cloud." Is this a typo?</p> <p>Title on pg2 does not match title on pg 1.</p> <p>pg 10, theme titled "equipment and information from support services"- if appropriate, could "equipment" be changed to "low vision aids" if this is what the authors are referring to?</p> <p>Also check use of speech marks e.g. on pg 12 line 5 (quote from Hermione.) Should this also read "I know IN many ways..."? pg 15, line 17- should this read "there appear to be deficiencies..."? Also check use of apostrophes e.g. pg 16, line 45 - should read: "patient's perspective" ?</p> <p>References: Douglas, G., Pavey, S., Corcoran, C. & Eperjesi, F. (2010) Individuals recollections of their experiences in eye clinics and understanding of their eye condition: results from a survey of visually impaired people in Britain. <i>Ophthalmic and physiological optics</i>, 30, 748-757. Mitchell, J., Bradley, P., Anderson, S.J., ffytche, T & Bradley, C. (2002) Perceived quality of health care in macular disease: a survey of members of the Macular disease society. <i>British journal of Ophthalmology</i>, 86, 777-781.</p> |
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1: Prof Michael Stur

| Comment | Author Response |
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| <p>The complexity of AMD is illustrated by the introduction to this paper, when the authors state:</p> <p>„The most common cause of registerable blindness in developed countries is age related macular degeneration (AMD) which has two types: dry and wet. Dry AMD accounts for 80-90% of cases while wet AMD accounts for 10-20%.“</p> <p>This statement is quite incorrect and misleading. It repeats a frequently made mistake, the subsumation of all non-wet cases into a „dry AMD“ class. In fact these „dry AMD“ patients include cases with just a few drusen only as well as cases with advanced geographic atrophy. A better classification would be the grading into early, intermediate and advanced AMD, with an additional sub-classification of advanced AMD into cases with CNV and with geography atrophy. These final stages of AMD, neovascular and atrophic AMD, appear with similar frequency in European populations, as has recently been shown in a large metanalysis of epidemiologic studies investigating the prevalence of AMD (Rudnicka et al., Ophthalmology 2012;119:571–580).</p> <p>But even the name of the disease is misleading:</p> <ul style="list-style-type: none"> - AMD is neither age-related, since its cause is a genetic predisposition and the first signs of the disease can be identified already in the 30s and 40s of an AMD patient, - nor is it a maculopathy since drusen can develop all over the retina, - and it is also not a degeneration, since its pathophysiology is quite complex and includes deviations of the complement pathway, accumulation of phototoxic deposits, inflammatory responses and imbalances of the levels of growth factors and its inhibitors. <p>Beside their diagnosis the patients also received information about the treatment, the necessary follow up visits, recommendations for their diet and possible intake of dietary supplements, the deleterious impact of smoking, the use of the Amsler grid and supportive services including low vision rehabilitation. The authors find that „This may leave patients confused about what is required of them and therefore unable to play an active role in managing AMD.“ One might also ask whether the guidelines, on which this information is currently based, have already been adapted to the</p> | <p>We agree with the points raised by this reviewer and hope the highlighted changes we have made within our paper addresses all of the concerns raised.</p> |

current knowledge of the disease:

The introduction of spectral domain optical coherence tomography SD-OCT has radically changed the way we can determine progression of AMD and presents new challenges in the way we use the new technique for the care of the AMD patients. Relying on self reported worsening of visual acuity reportedly reduces the benefit of treatment with ranibizumab and other Anti-VEGF agents, whereas the best results can only be achieved when patients are regularly examined with SD-OCT and treated immediately after disease progression is found. This fact has now been acknowledged and patients treated for neovascular AMD are regularly monitored with SD-OCT. The question is whether this kind of monitoring should not be expanded to patients with early and intermediate AMD as well, since early stages of neovascular AMD do not make any visual symptoms and can only be recognized with repeated SD-OCT exams. Therefore just education about the course of the disease will never be able to provide the best treatment benefit available, which is only achieved when treatment is performed in time before irreversible loss of vision occurs.

Patients with early and intermediate AMD, who still have good vision on both eyes and might have many years before their eyes develop advanced AMD, might be also the ones who might still benefit from stopping smoking, changing their dietary habits and starting supplementation with an AREDS 2 compliant formula. These patients and their offspring are the ones who should be targeted with educational materials and counseling regarding the necessary changes to their "life style".

Patients with advanced AMD, on the other hand, need quite different information. They need to know how often they have to return for follow up visits and where to get supportive services, but should not be pressed to change their diet and to stop smoking completely, when there is little proof that these drastic measures can still make a difference for the course of their AMD.

In conclusion, the study presented provides important insight into the challenges of caring for patients with AMD. When planning new educational programs one should keep in mind that education alone is not sufficient, and that initiatives improving the information of the patients have to happen hand in hand with expansion and continuous refinement of the services providing care for patients with all stages of AMD throughout the primary, secondary and tertiary branches of the healthcare system.

Reviewer 2: Emily Boxell

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| <p>There is some published literature in the field that has not been discussed. Information provision has been briefly looked at before but with visually impaired participants in general (e.g. Douglas et al., 2010) or within the diagnostic consultation only (see Mitchell et al., 2002,) where lack of information has been linked to patient dissatisfaction. A brief critical review of this literature with a concluding sentence on the need for this current research is needed.</p> <p>References: Douglas, G., Pavey, S., Corcoran, C. & Eperjesi, F. (2010) Individuals recollections of their experiences in eye clinics and understanding of their eye condition: results from a survey of visually impaired people in Britain. <i>Ophthalmic and physiological optics</i>, 30, 748-757. Mitchell, J., Bradley, P., Anderson, S.J., ffytche, T & Bradley, C. (2002) Perceived quality of health care in macular disease: a survey of members of the Macular disease society. <i>British journal of Ophthalmology</i>, 86, 777-781.</p> | <p>A brief reference to this literature has now been incorporated within the introduction section of the paper.</p> |
| <p>Please could the authors add a sentence stating why qualitative methodology is best placed to examine their aims.</p> | <p>A comment regarding the ability of semi-structured interviews to capture information important to the participants in their own words has been added to the participants and method section.</p> |
| <p>In addition to providing more information on the background and research aims, I feel that the reader may benefit from an explanation of how the interview questions were designed with examples of these questions. This will help link the background, research aims and method together. Were the interviews semi-structured?</p> | <p>A little more has been added in relation to explaining the semi-structured interviews used in response the previous point. Due to space restrictions a full description of the interview schedule would be unsuitable but a reference to the thesis from which this data comes has been referenced to sign post the reader to further information about this.</p> |
| <p>There appears to be no explanation provided as to why participants were followed up over a 18 month period. Please could the authors clarify this.</p> <p>Only issue would be for the authors to clarify why participants were followed up more than once to ensure a good reason for this and for any burden that may have been caused to the participant because of this.</p> | <p>Further information explaining the purpose of this is included in the participants and methods section.</p> <p>Participants reported actually enjoying the opportunity to 'chat' with the researcher and therefore there was little burden resulting from involvement in the research.</p> |
| <p>Pg 18, line 21- Typo- "...appointments to assess THEIR physical, social and psychological needs."</p> | <p>Amended</p> |
| <p>Would the quote used in the title and in Box 2 ("I'd like to know what causes it, you know, anything I've done?" Cathleen)- be more appropriate under the sub-theme of cause attributions?</p> | <p>Amended</p> |
| <p>Currently there is no mention in the discussion about the important role that the Macular Society and other vision charities can play in providing information and support to patients with Macular degeneration. Ophthalmologists can't be expected to provide all the help and support</p> | <p>A section with reference to third sector support such as that provided by the Macular Society has been added to the discussion.</p> |

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| <p>that patients might need, but are able to pass on the details of these charities to patients when they are diagnosed (indeed this is in the RCOph guidelines.) Peer support from support groups may lead to better adjustment to Macular degeneration, something which ophthalmologists cannot provide themselves.</p> | |
| <p>given that the RCOph guidelines were published in 2009 and the interviews for the present research were conducted in 2010, this may not have allowed enough time for the guidelines to be translated into practice so we should be wary of drawing any firm conclusions from these data about "current" practice. As nearly 3 years have passed since the data were collected, experiences of patients with AMD may now be different. This is a limitation not recognised by the authors, however I believe the results do provide a good starting point to investigate the issues raised further.</p> | <p>A statement addressing this point has been included in the limitations section.</p> |
| <p>Minor comments: pg2, line 42, the word recognise should contain an "s" rather than a "z" Tables- check pseudonyms are in brackets. pg 9, line line 7-12, repetition of the quote from "Mary" (it is in the table too.) I don't think this quote is needed twice. Also this quote isn't exactly the same in text as in the table ie.in text- "[I had] a black cloud." In table- "[I see] a black cloud." Is this a typo? Title on pg2 does not match title on pg 1. pg 10, theme titled "equipment and information from support services"- if appropriate, could "equipment" be changed to "low vision aids" if this is what the authors are referring to? Also check use of speech marks e.g. on pg 12 line 5 (quote from Hermione.) Should this also read "I know IN many ways..."? pg 15, line 17- should this read "there appear to be deficiencies..."? Also check use of apostrophes e.g. pg 16, line 45 - should read: "patient's perspective" ?</p> | <p>Amended</p> |

VERSION 2 – REVIEW

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| REVIEWER | <p>Boxell, Emily Royal Holloway I am funded by the Macular Society to conduct research on the patient experience of living with Macular Degeneration.</p> |
| REVIEW RETURNED | 14-Oct-2013 |

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| GENERAL COMMENTS | <p>An interesting read. Looking forward to reading the follow up research from the authors.</p> |
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