

## E.8.2 Informational needs of people with suspected or confirmed AMD and their family members/carers

RQ3a: What information do people with suspected AMD and their family members or carers find useful, and in what format and when?

RQ3b: What information do people with confirmed AMD and their family members or carers find useful, and in what format and when?

<b>Bibliographic reference</b>	<b>Burton AE, Shaw RL, and Gibson JM. 2013. "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". <i>BMJ Open</i> 3:e003306.</b>
Country/ies where the study was carried out	UK NHS
Study type	Interpretative phenomenological study
Aim of the study	To examine patients' experience of information and support for age-related macular degeneration
Study date	2010
Source of funding	The Aston Research centre for healthy ageing, Aston University
Sample size	13
Inclusion criteria	Patients with age-related macular degeneration who could take part in in-depth interviews.
Exclusion criteria	Not specified
Sample characteristics	Participant ages ranged from 75 to 89 with a mean age of 81.5. Best eye visual acuity ranged from 6/6 to 6/30 while worse eye visual acuity ranged from 6/9.5 to hand movement only. Seven of the participants were eligible for treatment and six were unable to be treated (two due to having dry AMD and three had wet AMD which was too advanced for treatment).
Methods	<p>The interviews were carried out in the patients' homes.</p> <p>In-depth semi-structured interviews were used to explore issues which were important to participants in their own words. The interview schedule included questions focusing on experience of diagnosis and other eye care consultations, the impact of AMD and related vision impairment on daily activities, relationships with and/or support needs from family and friends, and thoughts about the future.</p> <p>Perceptions and experience can change over time and interviews were therefore carried out with each participant on up to three occasions over 18 months to explore perceptions of on-going encounters with healthcare professionals during this time.</p> <p>A thematic analysis was used to examine the data.</p>
Thematic analysis	<p>Four Themes were identified: Sources of information; Equipment and information from support services; Self-advocacy; Future expectations.</p> <p>Theme 1: Sources of information These included books, leaflets, flyers; appointment letters; public events, meetings; verbal information in the clinic or from opticians; information from other people.</p>

Bibliographic reference	Burton AE, Shaw RL, and Gibson JM. 2013. "'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". <i>BMJ Open</i> 3:e003306.
	<p>These sources are not always accurate, which can result in people waiting when they should seek help or having unrealistic expectations of recovery based on anecdotal evidence from friends.</p> <p>"[I see] a black cloud. My neighbour's husband had it and they said it was nothing to worry about at the hospital anyway, you know. But it doesn't last and I've heard a lot of people who say they've had it but it but it went off after years."</p> <p>"Well, [name] had something done to his eye at the hospital, didn't he? Now he can see better..... he had an operation and he can see perfect"</p> <p>Inaccurate information can cause unnecessary distress and fear about going completely blind.</p> <p>"It is really frightening, because I know somebody at one of my groups [...] who says she's got dry macular but..... she's virtually blind"</p> <p>Verbal information provided at hospital was the most common source, but was associated with problems with understanding and retention, which may not be helped by hearing problems or difficulty in understanding the doctor's accent.</p> <p>Written sources could be problematic -patients were confused and overwhelmed by multiple appointment letters/written documents and could/did not always read them.</p> <p>"I have got some leaflets, I haven't read them in ages"</p> <p>'When I read all [these letters] I thought, err [date] [date] [date]....have they slipped up? Which one am I supposed to have?'</p> <p>Group meetings and speeches could be a positive source of information regarding things like attendance allowance that participants may otherwise be unaware of.</p> <p>Conversations with the AMD patients revealed a lack of understanding of the causes of AMD, reasons for processes associated with treatment and unrealistic expectations for the future.</p> <p>The way information was delivered (or not) at the opticians had a big effect on patient perception of their eye problems and emotions surrounding their appointments.</p> <p>Theme 2: Equipment and information from support services</p> <p>Shortages of information were felt prior to diagnosis, following diagnosis and during the course of the disease.</p> <p>The lack of prior awareness of AMD was raised as a factor that made diagnosis more stressful for 9 of the 13 patients and prevented them from having a context to refer to regarding their diagnosis.</p> <p>"one morning that the lampposts were all curly and that really frightened me, but I wasn't sure what it was"</p> <p>"I didn't realise it was so common"</p> <p>Following diagnosis: there was a lack of information and understanding about the causes of AMD, the importance of the use of vitamins and foods to promote eye health, the impact of smoking and how to register as partially sighted.</p> <p>"we don't really know what caused it"</p>

Bibliographic reference	Burton AE, Shaw RL, and Gibson JM. 2013. "'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". <i>BMJ Open</i> 3:e003306.
	<p>"I'd like to know what causes it, you know, anything I've done"</p> <p>'I was advised to take those [I-caps] and that's supposed to help it not get any worse"</p> <p>The lack of understanding of the purpose of medical procedures was also raised with people spending many hours at the hospital without understanding what the procedures and tests were trying to achieve. Letters often failed to clearly explain the purpose of an appointment.</p> <p>'I'm going, as I say I'm going up there next month. I don't know what the procedure is going to be, but they don't tell you do they? They don't tell you."</p> <p>"I have to go next month, I'm supposed to have the other eye done. Well, this is what I could assume, it might be about today I don't know."</p> <p>People were reported to have given up favourite pastimes in order to preserve their remaining vision, suggesting a fundamental communication problem regarding the nature of the disease that is not helped by some medical practitioners referring to AMD as "wear and tear and your age".</p> <p>"I keep sort of thinking oh I will [do some painting] and I think no, I sort of put a limit on how much I use my eyes a lot, does this make sense to you?"</p> <p>People were either unaware of support groups or worried that these groups were for people who were overwhelmed by having AMD and thus would be depressing to attend.</p> <p>"Interviewer: Is there any support you'd like to receive that you are not receiving and that would help you? Rick: I don't know what that would be, support there is."</p> <p>During the disease course: different information was needed at different points in the disease course and needed to be tailored to the person's disease stage. Early AMD patients needed information about monitoring their condition and spotting changes; wet AMD patients needed to know about available treatments and outcomes; patients with advanced disease needed to hear about support services and equipment.</p> <p>"He said that you could be registered as part-sighted. Well what does that mean? What does it do? Does it open the door for different things?"</p> <p>Theme 3: Self-advocacy</p> <p>Patients with early or advanced dry AMD or untreatable wet AMD who were not being monitored regularly by medical staff had been told to seek help at the Emergency department (ED) if any further vision problems occurred, but they were mainly uncertain of what sort of changes to look out for and what constituted a serious enough change to necessitate a visit to the ED. In addition, they associated the ED with accidents and were reluctant to attend it for a change in vision, highlighting the need to explain the expanded role of the modern ED to them.</p> <p>Patients felt unable to identify advancing vision loss and unqualified to determine when a change was severe enough to merit them seeking help. The language used by the clinician to describe vision changes was not accessible to the patients and did not fit with their understanding of the condition.</p>

<b>Bibliographic reference</b>	<b>Burton AE, Shaw RL, and Gibson JM. 2013. "'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". BMJ Open 3:e003306.</b>
	<p>"I'm not sure what I'm looking for."</p> <p>"I mean it's fine isn't it, for someone to say to you, well you would notice a change because.... But you can't be sure...I'm not sure what I'm looking for! I mean obviously if I suddenly couldn't see or some dramatic change, but would it be as dramatic as that?"</p> <p>Some patients worried about seeking help unnecessarily and wasting scarce NHS resources.</p> <p>Theme 4: Future expectations- fear and uncertainty, and hope.</p> <p>The approach to the future taken by a patient was dependent on the type of AMD they had and the level of uncertainty surrounding their future. This fear could be reduced by the availability of accessible, accurate information.</p>
Author's comments	<p>Patients with early and intermediate AMD may benefit from advice regarding smoking cessation and the use of vitamins/nutritional advice, but if patients are unaware of the purpose of these recommendations they may be less likely to adhere to them.</p> <p>Changes due to AMD may be attributed to ageing and wear and tear leading to confusion.</p> <p>Patients were not adequately informed about the course of disease progression and would have benefited from support and advice from health care professionals with a better understanding of what it is like to live with AMD.</p> <p>Patients often lack the ability to self-advocate and the lack of continuity between the NHS and support services complicates matters. The authors recommend a more structured pathway to ensure patient access to relevant services (including counselling and support services) at the correct times.</p> <p>The way information was provided was also problematic as patients often forgot the verbal information delivered at diagnosis and written documents could be hard for them to access.</p> <p>Conclusion: AMD patients have a range of information needs that change over the course of the condition.</p>
Quality Assessment	<p>Was there a clear statement of the aims of the research? Yes</p> <p>Is a qualitative methodology appropriate? Yes</p> <p>Was the research design appropriate to address the aims of the research? Yes</p> <p>Was the recruitment strategy appropriate to the aims of the research? Yes</p> <p>Was the data collected in a way that addressed the research issue? Yes</p> <p>Has the relationship between researcher and participants been adequately considered? Unclear</p> <p>Have ethical issues been taken into consideration? Yes</p> <p>Was the data analysis sufficiently rigorous? Unclear - Sufficient primary data was provided to support analysis so not downgraded</p> <p>Is there a clear statement of findings? Yes</p> <p>How valuable is the research? High value</p>

<b>Bibliographic reference</b>	<b>Burton AE, Shaw RL, and Gibson JM. 2013. "'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". <i>BMJ Open</i> 3:e003306.</b>
	Overall quality: High

<b>Bibliographic reference</b>	<b>Crossland MD, Helman CG, Feely MP, Gould ES, Rubin GS. 2007. Why did I lose vision? A qualitative study of patient perceptions of the causes of age-related macular degeneration. <i>Visual Impairment Research</i>, 9: 39-43.</b>
Country/ies where the study was carried out	UK
Study type	Interpretative phenomenological study
Aim of the study	To determine what reasons people with AMD give for their vision loss
Study dates	Not stated
Source of funding	Not stated
Sample size	15
Inclusion criteria	Patients diagnosed with bilateral age-related macular degeneration with a visual acuity of 6/12 or worse in their better eye. Patients that had attended the Moorfields Medical Retina clinic once and were going for their first ever low-vision clinic appointment later that day. Patients were selected based on having equal exposure to ophthalmological interventions within that episode of vision loss.
Exclusion criteria	other eye conditions in addition to AMD
Sample characteristics	Participant ages ranged from 73 to 91 years and just under half were male. Patients lived in London or Essex. Visual acuity ranged from 6/12 to 6/120. AMD subtype was not described. Patients were at an early stage of contact with clinics
Methods	A semi-structured interview was carried out in a non-clinical room by a research psychologist wearing informal clothing. This research was carried out as part of a larger interview investigating patients' expectations of the low vision clinic. All participants were asked "Can you describe your eyesight at the moment?" "Why do you think this has happened?" Follow-up questions were along the lines of "Can you tell me more about this?" "What exactly do you mean by that?" The interviews were recorded, transcribed and independently assessed by two senior optometrists to identify key themes. Any discrepancies were resolved by discussion.
Thematic analysis	Themes for reason of vision loss identified by participants: Old age– identified by the majority of study participants " ..... doesn't matter if you go to your dentist, doctor, optician- it's your age" [Male, 85 years]  Reading/close work/ "using eyes" – the idea that you can "use your vision up" came up several times.

Bibliographic reference	Crossland MD, Helman CG, Feely MP, Gould ES, Rubin GS. 2007. Why did I lose vision? A qualitative study of patient perceptions of the causes of age-related macular degeneration. <i>Visual Impairment Research</i> , 9: 39-43.
	<p>Smoking- mentioned as a potential cause by 2 participants, but not necessarily believed.          “They say that smoking does it- I’ve been smoking now since 1941, 42. ....I’ve got arthritis in both knees, they say that’s due to smoking, high blood pressure, that’s due to smoking.... [I] Just think they’re all wrong, I don’t know what to say. [Male, 76 years]</p> <p>Medical/surgical intervention          Chance- “apparently these things just happen” [Male, 76 years]          No idea/refused to speculate          Trauma to eye          Stress          Diet</p>
Authors’ comments	<p>The authors were surprised that relatively few people thought of old age as the cause of AMD and that no-one raised genetic susceptibility as a potential cause.</p> <p>Of concern that some participants attributed vision loss to other medical treatments (e.g. cataract surgery) and misunderstood the use of photodynamic therapy and laser photocoagulation, expecting an improvement in symptoms rather than a reduced risk of disease progression.</p> <p>Despite counselling, patients may continue to hold incorrect beliefs about the causes of their vision loss.</p> <p>Of particular concern was the idea of “using their vision up” as this may have implications for peoples’ quality of life if they avoid certain activities as a result. It was thought to be important to tell people more than once that they would not make things worse by using their eyes.</p> <p>To note- patients were at an early stage of contact with medical services for their AMD.</p> <p>Conclusion: patients attribute their vision loss to many, often incorrect, causes. Patients need access to more accurate education regarding AMD.</p>
Quality Assessment	<p>Was there a clear statement of the aims of the research? Yes</p> <p>Is a qualitative methodology appropriate? Yes</p> <p>Was the research design appropriate to address the aims of the research? Yes</p> <p>Was the recruitment strategy appropriate to the aims of the research? Yes</p> <p>Was the data collected in a way that addressed the research issue? Yes</p> <p>Has the relationship between researcher and participants been adequately considered? Unclear</p> <p>Have ethical issues been taken into consideration? Yes</p> <p>Was the data analysis sufficiently rigorous? Unclear</p> <p>Is there a clear statement of findings? Yes</p>

<b>Bibliographic reference</b>	<b>Crossland MD, Helman CG, Feely MP, Gould ES, Rubin GS. 2007. Why did I lose vision? A qualitative study of patient perceptions of the causes of age-related macular degeneration. Visual Impairment Research, 9: 39-43.</b>
	How valuable is the research? High value Overall quality: Moderate

<b>Bibliographic reference</b>	<b>Dahlin Ivanoff S, Sjöstrand J, Klepp KI, Axelsson L, Lundgren Lindqvist B. 1996. Planning a health education programme for the elderly visually impaired person- a focus group study. Disability and rehabilitation, 18: 515-522.</b>
Country/ies where the study was carried out	Sweden.
Study type	Interpretative phenomenological study
Aim of the study	To determine how people with a diagnosis of AMD perceived and described their disease and how it affected their activities of daily living in order to design a health education programme.
Study dates	Not stated
Source of funding	Not stated
Sample size	25
Inclusion criteria	Patients with a diagnosis of AMD referred by an ophthalmologist and attending the low-vision clinic for the first time during the study period. ≥ 65 years with AMD as the primary diagnosis and a visual acuity of the better eye with correction of no less than 0.1. Still living in their own homes and able to take part in a focus group discussion.
Exclusion criteria	Not stated
Sample characteristics	10 men and 15 women of 80.5 years on average. 12 people lived with a spouse. Visual acuity ranged from 0.1 to 0.6 (median 0.3) for the better eye.
Methods	A focus group methodology was employed whereby a group of participants meet to discuss different aspects of a topic. A moderator was used to facilitate the discussion and encourage everyone to contribute. The number of groups depends on the amount of information available and data collection continues until nothing new emerges, usually after 3-4 groups. This study consisted of 5 focus groups of 3-6 participants. The groups had the same moderator and assistant moderator. Each session began by clarifying the purpose of the focus group and then asking patients in turn to describe how their problems started. The moderator was not allowed to answer questions from the participants during the discussion and could only ask for statements to be explained further. Each group met twice, a week apart, and all sessions were recorded and transcribed verbatim. Themes were identified within each of the 4 research questions. These included one regarding the information required by people with AMD and how they wanted to receive it.

<b>Bibliographic reference</b>	<b>Dahlin Ivanoff S, Sjöstrand J, Kleep KI, Axelsson L, Lundgren Lindqvist B. 1996. Planning a health education programme for the elderly visually impaired person- a focus group study. Disability and rehabilitation, 18: 515-522.</b>
Thematic analysis	<p>Limited to data pertaining to patients' informational needs.</p> <p>Perceptions of the disease:</p> <p>Uncertainty regarding the names of other eye diseases and whether they are alternative names for AMD.</p> <p>AMD as part of the normal ageing process and that, as a result, nothing can be done.</p> <p>Problems related to the lack of public awareness of the disease.</p> <p>There is the perception that no research is being carried out and that the disease cannot be as common as they have been told as they were unaware of it before diagnosis. They believe that there is no fund-raising to help prevent the disease.</p> <p>Potential causes discussed include: work that could cause eye strain (for example working with computers); other diseases and medication; chemicals; violent sports; reading and watching TV a lot; looking at eclipses.</p> <p>Questions concerning treatment alternatives covered laser surgery; vitamin supplements; transplantation of the eye, cornea or lens.</p> <p>A lack of understanding exists as to why spectacles seldom improve the vision of AMD sufferers.</p> <p>Information required:</p> <p>More information is desired about the disease and its consequences, with an emphasis on disease prognosis and the expected speed of decline in their vision.</p> <p>They discussed a wish to have all available information to allow them to prepare for the future and to have straight answers about the disease.</p> <p>Patients discussed a need for more time to be allocated to giving them information and the problems of being intimidated/ feeling ignorant/ feeling like time wasters at the doctors that meant that it was hard for them to ask questions and fully process the information provided.</p> <p>Patients were worried that they might go blind.</p>
Author's comments	Conclusion: That these patients need a health education programme based on their own perceptions.
Quality Assessment	<p>Was there a clear statement of the aims of the research? Yes</p> <p>Is a qualitative methodology appropriate? Yes</p> <p>Was the research design appropriate to address the aims of the research? Yes</p> <p>Was the recruitment strategy appropriate to the aims of the research? Yes</p> <p>Was the data collected in a way that addressed the research issue? Yes</p> <p>Has the relationship between researcher and participants been adequately considered? Unclear</p> <p>Have ethical issues been taken into consideration? Unclear</p> <p>Was the data analysis sufficiently rigorous? Yes</p>



<b>Bibliographic reference</b>	<b>Dahlin Ivanoff S, Sjöstrand J, Kleep KI, Axelsson L, Lundgren Lindqvist B. 1996. Planning a health education programme for the elderly visually impaired person- a focus group study. Disability and rehabilitation, 18: 515-522.</b>
	Is there a clear statement of findings? Yes How valuable is the research? High value Overall quality: Moderate

<b>Bibliographic reference</b>	<b>McCloud C, Lake L. 2015. Understanding the patient's lived experience of neovascular age-related macular degeneration: a qualitative study.. Eye, 29: 1561-1569.</b>
Country/ies where the study was carried out	Australia
Study type	Interpretative phenomenological study
Aim of the study	To understand the experiences of neovascular AMD patients, including ongoing treatment with anti-vascular endothelial growth factor (VEGF) with the intention of informing clinical practice.
Study dates	Not stated
Source of funding	Flinders University Faculty start up grant 2013-14
Sample size	25
Inclusion criteria	Patients with a diagnosis of neovascular AMD and receiving treatment with anti-VEGF in at least one eye on a regular basis. Patients did not make co-payments for their treatment and were identified from the clinical records of a South Australian Tertiary Public Hospital.
Exclusion criteria	Not stated
Sample characteristics	12 male participants; ages ranging from 67-90 years. Visual acuity was varied from 6/6 to 6/120 and count fingers. Treatment with anti-VEGF ranged from 9 months to >10 years.
Methods	Data was collected using the recording of individual participant experiences using in-depth, unstructured interviews. Patients were interviewed individually. Interviews started with the statement "tell me of your experience of AMD and the treatment you are receiving" and ended when the participant had nothing else to say. Data was recorded and sorted into themes, Data was also collected from medical records and a focus group session with nursing staff carrying out the anti-VEGF injections.
Thematic analysis	The research identified two major themes: 'A life negotiated by neovascular AMD' and 'uncertainty'. The information presented in this summary relates only to AMD patient or carer/family member informational needs.

Bibliographic reference	McCloud C, Lake L. 2015. Understanding the patient’s lived experience of neovascular age-related macular degeneration: a qualitative study.. Eye, 29: 1561-1569.
	<p>Theme 1: A life negotiated by neovascular AMD</p> <p>Following diagnosis and information about treatment options patients expressed relief that the condition was treatable. Patient familiarity with the process of injections and treatment in general helped with anxiety, but anxiety remained and was increased when treatment was given by an unfamiliar doctor.</p> <p>“I tootle along, and I know exactly what’s going to happen and it doesn’t bother me at all.”</p> <p>“I feel a bit uptight because someone is going to stick a needle in my eye and you don’t get the same doctor each time.”</p> <p>Small unexpected or larger planned changes in the procedure or staff involved were linked to recovery difficulties, but if the reasons for the changes were communicated well, once they were used to the changes, participants felt that the new methods improved the experience.</p> <p>‘there’s been some improvements here, that they’ve made’</p> <p>Once patients were aware of the visual disturbances and discomfort following treatment they developed coping strategies while they waited for vision to return.</p> <p>“If I go there, I know I’m going to get an anaesthetic in the eye, and I’m going to get the injection, and..... and I’m going to be unable to see clearly for a number of hours. I can come back home, I can put ....just relax and when it comes back, then I’m back to normal. “</p> <p>Patients did not usually seek help or advice when unfamiliar symptoms occurred after injection.</p> <p>Patients acceptance of invasive treatment was associated with an underlying fear of blindness</p> <p>“I’d just want to lay down and die if that happened to me.”</p> <p>Theme 2: Uncertainty</p> <p>Many patients felt that vision problems were a part of the aging process.</p> <p>“And I thought it was age, everybody’s eyesight deteriorates with age..”</p> <p>Patients lived with a sense of uncertainty and fear for their future linked to the continued effectiveness of the anti-VEGF treatment. They knew that anti-VEGF was a way of managing AMD, not a cure.</p> <p>Patient experiences were more positive if they received reassurance, support and caring communication from medical staff.</p>
Author’s comments	Conclusion: Anxieties and uncertainties about the future emerged, coupled with thankfulness for treatment, along with the importance of familiar processes and guarded optimism. The information provided by this study could be used to help provide better patient-centred care.
Quality Assessment	<p>Was there a clear statement of the aims of the research? Yes</p> <p>Is a qualitative methodology appropriate? Yes</p> <p>Was the research design appropriate to address the aims of the research? Yes</p> <p>Was the recruitment strategy appropriate to the aims of the research? Yes</p>

<b>Bibliographic reference</b>	<b>McCloud C, Lake L. 2015. Understanding the patient's lived experience of neovascular age-related macular degeneration: a qualitative study.. Eye, 29: 1561-1569.</b>
	<p>Was the data collected in a way that addressed the research issue? Yes</p> <p>Has the relationship between researcher and participants been adequately considered? Unclear</p> <p>Have ethical issues been taken into consideration? Yes</p> <p>Was the data analysis sufficiently rigorous? Yes</p> <p>Is there a clear statement of findings? Yes</p> <p>How valuable is the research? High value</p> <p>Overall quality: High</p>

<b>Bibliographic reference</b>	<b>Vukicevic M, Heraghty J, Cummins R, Gopinath B, Mitchell P. 2016. Caregiver perceptions about the impact of caring for patients with wet age-related macular degeneration. Eye, 30: 413-421.</b>
Country/ies where the study was carried out	Australia
Study type	Survey study (with open questions)
Aim of the study	To explore the perceptions of caregivers of person with neovascular AMD in relation to the most important aspects of caring.
Study dates	Not stated
Source of funding	Bayer Australia, Macular Disease Foundation Australia and Orthoptics Australia.
Sample size	643
Inclusion criteria	Caregivers of people with neovascular AMD, which included the spouse or partner, family members, friends and paid care workers.
Exclusion criteria	Not stated
Sample characteristics	Caregivers ranged from 35-39 years to >85 years and were predominantly female, as were the AMD patients they cared for
Methods	<p>A cross-sectional, self-administered survey with 27 closed responses (not detailed in this paper) and 2 open ended questions:</p> <ol style="list-style-type: none"> <li>1. Do you have any other comments about caring for someone with wet AMD that you believe are important for other people to know and understand?</li> <li>2. What are the three most important aspects of caring for someone with AMD for you?</li> </ol> <p>Extended responses were coded using NVivo, analysed using an inductive approach and sorted into thematic networks.</p>
Thematic analysis	<p>Three overarching themes arose: The Impact of Caring; Injections and Information; and Activities of Daily Living.</p> <p>The information presented in this summary relates only to AMD patient or carer/family member informational needs.</p>

<b>Bibliographic reference</b>	<b>Vukicevic M, Heraghty J, Cummins R, Gopinath B, Mitchell P. 2016. Caregiver perceptions about the impact of caring for patients with wet age-related macular degeneration. Eye, 30: 413-421.</b>
	<p>Theme 1: The Impact of caring To care for someone with wet AMD well they need to understand the condition and the physical/emotional effects on the person's wellbeing. This is considered important to help them be compassionate and empathetic in their dealings with the AMD sufferer. Caregiver's needs are not focused on by the respondents, but they do mention the importance of respite care.</p> <p>Theme 2: Injections and information Caregivers raised the point that since AMD has a genetic component it is important that all family members of AMD sufferers are aware of their increased risk and have regular eye tests. "Important to be monitored and diagnosed early to access treatment to stop if possible progress of disease. Important to be educated and be aware of risk and contributing factors." Information is seen to be lacking about wet AMD and how carers can help the patient manage their condition. There is also a shortage of information for carers about support services. There is the perception that other people (including the public and notably medical staff in eye clinics) did not understand the impact that AMD has on a person's life and were insensitive to patients' needs. "There is little understanding by health professionals, especially ophthalmologists of difficulties faced by patients." "It is surprising that staff, including administration, have very little idea on many simple things that make mobility difficult e.g. small occasional tables placed in the centre of a room below vision level and in the way of where he walks etc." Note: there is mention of the difficulty of paying for the costs of treatment in Australia and this is not relevant for patients in the UK.</p>
Author's comments	Conclusion: Most caregivers were family members who experienced distress due to their additional responsibilities and the subjugation of their own needs. This can have a negative impact on their relationship with the AMD sufferer and is compounded by the limited numbers seeking or being able to use respite care.
Quality Assessment	<p>Was there a clear statement of the aims of the research? Yes</p> <p>Is a qualitative methodology appropriate? Yes</p> <p>Was the research design appropriate to address the aims of the research? Yes</p> <p>Was the recruitment strategy appropriate to the aims of the research? Yes</p> <p>Was the data collected in a way that addressed the research issue? Yes</p> <p>Has the relationship between researcher and participants been adequately considered? Unclear</p> <p>Have ethical issues been taken into consideration? Yes</p> <p>Was the data analysis sufficiently rigorous? Yes</p> <p>Is there a clear statement of findings? Yes</p>

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<b>Bibliographic reference</b>	<b>Vukicevic M, Heraghty J, Cummins R, Gopinath B, Mitchell P. 2016. Caregiver perceptions about the impact of caring for patients with wet age-related macular degeneration. Eye, 30: 413-421.</b>
	How valuable is the research? High value Overall quality: High