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Patients' and health professionals' views on shared decision-making in age-related macular degeneration care: a qualitative study

Mariska Scheffer¹, Juliane Menting¹, Ruud Roodbeen², Sandra van Dulmen^{3,4,5}, Manon van Hecke⁶, Reinier Schlingemann^{7,8,9}, Ruth van Nispen¹⁰, Hennie Boeije¹

- ¹ Department of Care and Participation of People with Chronic Conditions, Netherlands Institute for Health Services Research (Nivel), Utrecht, The Netherlands
- ² Department of Research, Breuer&Intraval Research and Consultancy, Groningen, The Netherlands
- ³ Department of Communication in Healthcare, Netherlands Institute for Health Services Research (Nivel), Utrecht, The Netherlands
- ⁴ Department of Primary and Community Care, Radboud University Medical Center, Radboud Institute for Health Sciences, Nijmegen, The Netherlands
- ⁵ Faculty of Caring Science, University of Borås, Borås, Sweden
- ⁶ Department of Ophthalmology, Elisabeth-TweeSteden Ziekenhuis, Tilburg, The Netherlands
- ⁷ Department of Ophthalmology, Amsterdam UMC, University of Amsterdam, Amsterdam, The Netherlands
- ⁸ Bergman Clinics Ogen, Amsterdam, The Netherlands
- ⁹ Department of Ophthalmology, University of Lausanne, Jules-Gonin Eye Hospital, Fondation Asile des Aveugles, Lausanne, Switzerland
- ¹⁰ Department of Ophthalmology, Amsterdam UMC, Vrije Universiteit, Amsterdam Public Health Research Institute, Amsterdam, The Netherlands

Abstract

Background: Age-related macular degeneration (AMD) is one of the principal causes of irreversible visual impairment in the older adult population. Recent evidence indicates that there are signs of undertreatment and overtreatment, underdiagnosis and insufficient information provision in AMD care. Shared decision-making (SDM) can aid information sharing between patients and health professionals and enhances high-quality care. This research aimed to gain insight into patients' and professionals' views on SDM in AMD care.

Methods: Semi-structured interviews were conducted with 20 patients with AMD and 19 health professionals in June and July 2020. Participants were recruited through hospitals, professional and patient associations and (social) networks. Sample representativeness was ensured in terms of sociodemographic and disease characteristics for patients, and profession-related characteristics for health professionals. Interviews were analysed according to a predetermined coding framework.

Results: Although SDM is receiving attention in AMD care, health professionals and patients experienced barriers in making shared decisions. The most common barriers reported included limitations in treatment options, time constraints, strict treatment guidelines and patients' comorbidity. Furthermore, most patients indicated that they were not (fully) informed about all aspects of AMD trajectory, such as the possibility to discontinue therapy or the long-term and invasive character of treatment. Some patients expressed the need for a more empathic and person-centred communication style from their health professional.

Conclusion: The concerns raised by patients and health professionals suggest that there is room for improvement in delivery of SDM in AMD care. Findings from this study indicate that information provision and communication can be improved.

Introduction

Age-related macular degeneration (AMD), the leading cause of irreversible visual impairment, is a medical condition affecting 9% of older adults worldwide.^{1,2} Due to the ageing population, the number of people with AMD is expected to increase to around 288 million in 2040.² A distinction can be made between nonexudative, or 'dry' AMD and exudative, also called 'wet' AMD. The former is characterised by a gradual progression, whilst the latter can result in a sudden loss of vision due to bleeding and fluid leakage.^{3,4} Even though the cause of AMD is complex, various clinical, demographic and environmental risk factors, such as age and smoking, are associated with disease progression.⁵

No efficacious pharmaceutical interventions exist for the nonexudative form. People with nonexudative AMD are therefore recommended to make lifestyle modifications, such as avoidance of smoking, eating a nutritious diet and using nutritional supplements to slow progression.^{5,6} Visual acuity of people with exudative AMD can be effectively maintained by anti-vascular endothelial growth factor (VEGF) injections. This requires rapid diagnosis, timely initial treatment and ongoing and regular follow-up to stabilise and control disease activity and visual outcomes.^{7,8}

Various health professionals are involved in the diagnosis, treatment and process of vision rehabilitation of patients with AMD.⁹ In the Netherlands, people who experience visual problems can turn to their general practitioner, optometrist or optician. When suspected symptoms of AMD are recognised, the patient is referred to an ophthalmologist by the general medical practitioner or optometrist. Specialised institutions for rehabilitation support patients with vision loss, for instance when they experience challenges with normal daily activities such as reading, driving or watching television.¹⁰ The establishment of a suitable rehabilitation plan requires a team approach, which often includes vision rehabilitation therapists, occupational therapists, social workers, psychologists and orientation and mobility trainers. The goal of vision rehabilitation is to enhance an individual's functional potential, thereby increasing independence and quality of life.

Evidence-based Dutch AMD guidelines provide recommendations for health professionals and outline best practice activities for managing the care of patients with, or suspected of having, AMD.¹¹ Despite the existence of these guidelines, recent evidence indicated that there is room for improvement within different domains of AMD care. Among others, there are signs for undertreatment and overtreatment, underdiagnosis and insufficient information provision.¹² Shared

decision-making (SDM), an approach where health professionals and patients share information when faced with the task of making decisions, can aid information sharing and enhance high-quality care.¹³ Nevertheless, it is unknown whether patients are sufficiently involved in the care process and to what extent are informed about the AMD trajectory. To the best of our knowledge, no studies have previously investigated SDM, including information provision and patient-provider communication, in the context of AMD. This indicates a need to gain insight into the perceived components of SDM in AMD care from the perspective of those involved.

Key points

- The research highlighted important challenges for shared decision-making in age-related macular degeneration care, including the limited time between diagnosis and initial treatment.
- More effort is needed to monitor whether the information provided about disease, treatment and prognosis has been adequately understood by patients with age-related macular degeneration.
- To improve patient education and overcome time constraints, it is recommended that nurse practitioners are deployed in macular degeneration care for providing additional information and answering questions.

Methods

Study design

Data were collected using individual interviews with health professionals and patients with AMD. This allows for a deeper exploration of lived experiences with SDM in routine clinical practice from stakeholders' perspectives. A semi-structured interview guide was used to ensure a similar structure across interviews (File S1). The Medical Ethics Review Committee of Amsterdam University Medical Centers (VU University Medical Center, FWA00017598) determined that this study (reference 2020.234) is not subject to the Medical Research Involving Human Subjects Act (Dutch law).

Study population and recruitment

A purposeful sample of patients with AMD and health professionals was utilised to establish representativeness of participants involved in all stages across the care trajectory. Participants underwent baseline screening to ensure eligibility for participation. Health professionals were recruited, taking into account differences in sex, age, type of health professional (e.g., ophthalmologists and optometrists), number of years of work experience and work location. Representativeness among patients was ensured in terms of sex, age, level of education, diagnosis (wet vs. dry AMD), duration of illness, severity of vision loss and type of healthcare facility (hospital vs. independent treatment centre). Health professionals were recruited through four professional associations (Netherlands Ophthalmological Society [NOG], Dutch Optometric Association [OVN], Dutch Association of Physician Assistants [NAPA] and Dutch Association for Rehabilitation for Visually Impaired [VRS]) and (social) networks of the involved research institute, healthcare institute and advisory committee. Patients were recruited via medical records of two treatment locations (Amsterdam University Medical Centers and Bergman Clinics), two patient associations (Macular Association and MaculaVereniging), Eye Association Netherlands (Oogvereniging) and (social) networks of the related institutes. All participants received a voucher as compensation for their time.

Data collection

Participants received an information letter and signed informed consent prior to participation. Due to the constraints posed by the COVID-19 pandemic, most interviews were completed by telephone. Three interviews were performed face-to-face. Each interview lasted between 40 and 90 min. The interviews were carried out independently by three researchers [MS, JM and RR] between June and July 2020, until data saturation was reached. A break was suggested to avoid interviewee and interviewer fatigue. The interviews were audio-recorded and transcribed verbatim. Participant information was anonymised and identified with a unique number to protect confidentiality.

Data analysis

Interview transcripts were analysed using MAXQDA11 software (maxqda.com).¹⁴ A predetermined coding framework was applied, as defined by the study aims. The main themes included the following: (1) information provision, (2) shared decision-making moments, (3) personal attitudes towards shared decision-making and (4) experiences with shared decision-making. Guided by the overarching themes, initial coding was performed independently by the three researchers. Subthemes were derived from the data and refined by discussion during team meetings. A list of main themes and subthemes can be found in Figure 1.

Results

Sample characteristics

A total of 20 patients and 19 health professionals with different backgrounds participated in this study. Participants' demographical and clinical characteristics are shown in Table 1. Vision rehabilitation specialists were represented by three different types of health professionals.

Information provision

Health professionals experienced that information provision at the diagnosis phase is often related to the type and severity of AMD. In general, the focus of information provision among patients with nonexudative AMD is regarding prevention and self-monitoring, whereas patients with exudative AMD receive more information on existing treatment options. Additionally, findings showed that health professionals repeat information more frequently to patients with exudative AMD, as patients with nonexudative AMD are often not monitored regularly after diagnosis.

[Figure 1] [Table 1]

Most patients with nonexudative AMD reported that they were informed about the value of self-monitoring from the start of the care trajectory. They received an Amsler grid from their health professional to detect vision problems caused by changes in the retina. Nevertheless, not all patients wanted to use the Amsler grid, as they found themselves confronted with their condition. Some felt that the tool is unnecessary in later phases of the care trajectory. Even though most patients with nonexudative AMD were informed about the importance of self-monitoring, for most of them, it was unclear that the nonexudative form can progress to the exudative form.

I have such a grid pattern [...] but since I have a scan and a regular check-up in the hospital every three months, I have the feeling that it is monitored sufficiently. [63 years old, exudative and nonexudative AMD]

Most professionals reported that they regularly communicated to patients about measures to prevent progression of the condition, such as eating a nutrient-dense diet and giving up smoking.

Half of the patients indicated that they were informed about these two preventative measures. Some health professionals also reported that they provide information regarding the need for sufficient exercise, healthy blood pressure, limited alcohol intake and the use of sunglasses against UV radiation.

I often argue with patients [about smoking] and tell them: quitting smoking is the best thing you can do. Then a discussion starts. [optometrist, 36 years work experience]

Regarding treatment, most patients were informed by their health professional about treatment methods and the length of intervals between anti-VEGF injections. However, fewer patients reported being informed by their health professional about treatment duration, potential side effects and adjustments in injection frequency. A small number of health professionals informed patients about the possibility to discontinue treatment.

Overall, most patients with AMD reported that they often had to take the initiative themselves, primarily with regard to information retrieval on vision aids and rehabilitation. Many patients reported that they did not receive (timely) information regarding this subject. This experience is echoed by all three health professionals working in vision rehabilitation.

I often talk to people who are already severely visually impaired and have never heard that they can go to low vision organizations. I find this worrying. [vision rehabilitation specialist, 28 years work experience]

Shared decision-making moments in age-related macular degeneration (AMD) care

According to ophthalmologists, four principal decision-making moments can be identified across the AMD care pathway, mostly relevant for patients with exudative AMD. SDM can aid in choices regarding whether or not to: (1) initiate the AMD care trajectory after diagnosis; (2) start anti-VEGF therapy; (3) change treatment or regime and (4) discontinue treatment during follow-up. During diagnosis, health professionals provide information about the condition and progression of AMD, signal signs, the importance of self-monitoring and the possibilities for treatment. In almost all cases, treatment for exudative AMD is initiated. If patients have a poor response to treatment, there is a possibility to switch to another anti-VEGF medication. Furthermore, based on the effectiveness of the anti-VEGF medicine, the injection treatment regimen can be adapted.

Even though the choice to initiate treatment seems self-evident, health professionals reported different reasons to discontinue anti-VEGF therapy. The main grounds included insufficient effect of anti-VEGF therapy or a high treatment burden, which is often influenced by other medical conditions that interfere with AMD treatment. In these complex situations, the advantages and disadvantages of therapy are discussed. Patients' life expectancy and quality of life were important factors driving the decision whether to start anti-VEGF therapy, or discontinue treatment at a later stage.

Others are indeed those patients who are very old and already see quite poorly, or those who see reasonably well but are in a wheelchair and really struggle to go to the consultation. [ophthalmologist, 5 years work experience]

All of a sudden, there were many things going on in my life. I thought, I can't do this right now. [56 years old, exudative AMD]

Especially for people with more severe vision loss, referral to vision rehabilitation is an important decision-making moment. As described earlier, many patients reported that they were not involved

in decision-making around this subject. However, most patients would prefer timely information regarding potential rehabilitation options.

At the time, I decided that I didn't need it yet [vision rehabilitation], because I could still see with my left eye. But I think it was very useful to have this information for future reference. [75 years old, exudative AMD]

Personal attitudes towards shared decision-making (SDM)

Most health professionals believed that SDM adds value to the care of patients. They believed that involving patients in decision-making can positively contribute to treatment motivation and adherence. However, the majority of health professionals also felt that SDM has little benefit within this specific care trajectory, due to a limited number of treatment options for AMD.

We always provide the information that injections are an option. The other option, because there is not much of an alternative, is to not give injections. A lot of patients say, but then I don't actually have a lot of choice. [physician assistant/optometrist, 7 years work experience]

When patients were asked about SDM, contrasting attitudes were apparent. Some patients did not feel the need to be involved in the decision-making process, as they were confident that the health professional would make the right decisions for them. In contrast, others reported that participation in SDM makes them feel more comfortable and that it is vital for patient autonomy. Preferences for involvement in decision-making among patients could be related to patient needs regarding information provision.

These are my eyes, it is my body. I want to get informed. But this does not mean that I must follow-up on everything, I can decide for myself. [61 years old, nonexudative AMD]

Barriers and facilitators in shared decision-making (SDM)

The limited number of treatment options was often mentioned by health professionals as a barrier to SDM. As the consequences of untreated exudative AMD are significant, health professionals indicated they put a lot of effort in making sure patients adhere to the agreed upon treatment. Moreover, several health professionals described strict treatment guidelines as a common barrier to SDM. In the Netherlands, the off-label intravitreal bevacizumab (Avastin®) is the first choice anti-VEGF treatment for AMD. The majority of health professionals adhere to this option but are also reluctant to provide information about other anti-VEGF medications. Some professionals explained that they want to prevent giving the impression that patients can choose between different types of medication, as the sequence of medicine options are standardised in the Dutch guidelines. Accordingly, this raised questions among patients when reading about other medication options, for example in patient folders. Two patients reported doubting the effectiveness of injections, as they felt they were not well informed by their ophthalmologist. For this reason, one of them did not consider initiation of treatment with anti-VEGF medication.

Other barriers frequently mentioned by both health professionals and patients were the short length of the consultation and the limited amount of time between diagnosis and initial treatment. The sudden onset of AMD, and the need for rapid treatment, often puts pressure on the decision-making process.

You do not have the space and office hours to talk to someone four times about something that should happen preferably next week. [ophthalmologist, 36 years of work experience]

Moreover, the substantial amount of information that is conveyed to patients at different points of care, particularly at the stage of diagnosis, prevents patients from asking questions and makes it challenging for health professionals to verify whether the provided information has been understood. Health professionals argued that the presence of family members or significant others during the consultation can help in processing the abundance of information. Furthermore, health professionals also mentioned dosing of information, referral to other professions and provision of clear information folders or websites as helpful solutions in processing this information. In complex situations, family and carers also aid in the decision-making process itself.

Children are often present at the consultation. Older patients sometimes ask them to make the decision for them, as they find the situation too difficult. [ophthalmologist, 5 years work experience]

Almost all patients argued that good communication skills are an important facilitator in the AMD care trajectory. A common view among patients was that calm communication behaviour is highly valued, especially at the moment of diagnosis. A business-like communication style was, however, described as unpleasant and impersonal.

I do remember that man who gave me the injection, and it was just the way he said and did things. And since I was nervous, I felt treated like a child. [56 years old, exudative AMD]

Others reported that they felt their health professional gave them the feeling of a poor and distant relationship. In these cases, patients felt that they were not being taken seriously.

He measured my eyes but we did not have any conversation at all. The man was very introverted. He shook my hand and he started the measurements. [89 years old, non-exudative AMD]

According to patients, showing empathy as health professionals is particularly important. It can strengthen their relationship with patients and can improve patients' satisfaction with the care given. Half of the patients in this study experienced negative emotions, such as shock and sadness at the diagnosis stage, and psychological stress and anxiety during injections with anti-VEGF medication. This group of patients in particular reported that they highly value empathy and reassurance from their health professional.

He grabbed my hands, and he said, I feel really sorry for you. I have to bring you bad news. [67 years old, exudative AMD]

Discussion

The findings of this study reveal a discordance between the substantial amount of information that is given to patients and the rapid referral and treatment that is often required. Without information and understanding potential options, prognosis and treatment, patients cannot effectively participate in SDM. Moreover, the study highlights discrepancies between the views and decision-making preferences of patients and health professionals. Additionally, several barriers to SDM were identified, including the limited number of treatment options, strict treatment guidelines, the short length of the consultation, the limited amount of time between diagnosis and initial treatment and the large quantities of information. In contrast, empathic communication was often mentioned by patients as an important facilitator of SDM.

The limited number of potential treatment options within the AMD care trajectory was frequently mentioned by health professionals as one of the foremost influencing factors of SDM. For patients with exudative AMD, continuous anti-VEGF treatment is the first and only choice to stabilise vision or prevent rapid deterioration.¹⁵ This might explain why most health professionals in this study mentioned problems with taking decisions together with patients, for example, in talking with them about the option to refrain from treatment. These results match those from earlier research in China, which found that most professionals in AMD care inform patients about only one treatment option without sharing other available choices or the consequences of not accepting treatment.¹⁶ While not many patients refuse treatment, anti-VEGF therapy can be particularly challenging for older patients with comorbidity. For these patients especially, SDM can assist in conflicting treatment priorities.¹⁷

Managing patient expectations of health care is essential for therapy adherence and achieving positive patient experiences.¹⁸ Our findings show that most patients were informed about the importance of regular check-ups. Nevertheless, the majority of patients reported that they were unaware that the use of anti-VEGF medication is often long-term and invasive, or were not informed about adjustments in injection types and schedules. Additionally, most patients felt they did not receive (timely) information on the existence of visual aids and rehabilitation, such as mobility training and psychosocial support. Among others, these problems can be assigned to identified time constraints, which broadly supports the work of other studies in this area.¹⁹ Moreover, the organisation of AMD care with rapid medical treatments¹⁵ can limit time for (repeated) information provision by health professionals, and restricts room for questions. Nonetheless, sufficient time is crucial to assimilate and become aware of received information.²⁰ Additionally, stress and anxiety from diagnosis and treatment, which are common emotions among patients with AMD,^{21,22} can impact information retrieval even more.

The reported time constraints also seem to be related to the communication style of health professionals. Most patients experienced assembly-line style consultations, which can be attributed to the efficient organisation of the AMD care trajectory and an increase in the AMD population. This development seems to result in a decreased focus on the human dimensions of AMD care and neglects the generally acknowledged assets of person-centred care.²³ An environment in which health professionals are able to listen to patients and respect their concerns is where patients feel comfortable participating in shared decision-making.²⁴

In general, findings from the perspective of patients and health professionals indicate that there is room for improvement in SDM in the AMD care trajectory. The concerns raised by health professionals and patients have several key implications for clinical practice. When time constraints occur during consultations, nurse practitioners could be deployed to provide information and answer questions. Nurse practitioners already have an important role in improving patient education and communication in other care pathways, such as diabetes and chronic obstructive pulmonary disease.^{25,26} Moreover, most patients in our study expressed the desire to get informed about the current expected duration of treatment and prognosis. It is understandable that hesitancy exists among health professionals to share this knowledge at the beginning of the care trajectory, as AMD treatment and prognosis is highly patient-specific. Nevertheless, a short-term treatment plan to prevent acute visual impairment could be considered first. From there, a long-term treatment plan could be discussed. This type of management is often applied to patients suffering from conditions that can cause a sudden onset of symptoms, for example diabetic ketoacidosis.²⁷ Moreover, the presence of significant others during consultation or of patient associations can be of value to provide emotional support and assist in information recall.²⁸ Lastly, as AMD and related treatment often lead to stress and anxiety among patients²⁹, it seems important to check whether the provided information has been adequately understood and whether anti-VEGF injections are still tolerable for patients.

Although this study has highlighted important challenges for SDM in AMD care, there are some methodological considerations. The number of respondents is moderate, so it cannot be assumed

that the findings are representative of the broad group of stakeholders involved in AMD care. However, the aim of this qualitative study was not to generate representative data, but to gain insight into the experiences of those involved. In addition, a varied group of health professionals and patients were sampled and the sample size was adequate to achieve thematic saturation.³⁰ Nevertheless, qualitative research may be subject to interviewer bias. Even though researcher bias probably cannot be completely eliminated, we used a predetermined coding framework and conducted analysis with multiple researchers to mitigate this type of bias. Additionally, another limitation could be the possibility of recall bias among participants. When asking about past events, it could have been possible that participants did not remember previous events accurately or omitted details. Lastly, this study did not examine the SDM process during everyday healthcare encounters, so the extent in which SDM has actually been achieved remains unknown.

To conclude, this study has provided a deeper insight into the views of patients and health professionals on shared decision-making in AMD care. The raised concerns indicate that greater effort is needed to overcome existing barriers to SDM. Further researches should be undertaken to confirm the present findings quantitatively and to explore how SDM between patients with AMD and their health professionals can be improved.

AUTHOR CONTRIBUTIONS

Mariska M.J. Scheffer: Conceptualization (equal); data curation (equal); formal analysis (equal); investigation (equal); methodology (equal); software (equal); validation (equal); visualization (equal); writing –original draft (lead); writing –review and editing (lead). **Juliane Menting:** Conceptualization (equal); data curation (equal); formal analysis (equal); funding acquisition (equal); investigation (equal); methodology (equal); project administration (equal); resources (equal); software (equal); supervision (lead); validation (equal); visualization (equal); writing –original draft (equal); writing –review and editing (equal). **Ruud T.J. Roodbeen:** Data curation (equal); formal analysis (equal); investigation (equal); methodology (equal); software (equal); validation (equal); writing –review and editing (equal). **Sandra M. van Dulmen:** Conceptualization (equal); methodology (equal); supervision (equal); writing –original draft (equal); writing –review and editing (equal). **Manon V. van Hecke:** Resources (equal); writing –review and editing (equal). **Reinier O. Schlingemann:** Resources (equal); writing –review and editing (equal). **Ruth M.A. van Nispen:** Conceptualization (equal); methodology (equal); resources (equal); supervision (equal); writing –original draft (equal); writing –review and editing (equal). **Hennie R. Boeije:** Conceptualization (equal); funding acquisition (equal); methodology (equal); project administration (equal); supervision (equal); writing –review and editing (equal).

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CONFLICT OF INTEREST

None declared

DATA AVAILABILITY STATEMENT

The data used during the current study are available from the corresponding author on reasonable request.

ORCID

Mariska Scheffer <https://orcid.org/0000-0003-0117-9471>
Ruud Roodbeen <https://orcid.org/0000-0001-7315-4367>
Manon van Hecke <https://orcid.org/0000-0002-3389-5221>
Hennie Boeijs <https://orcid.org/0000-0002-7540-2114>
Sandra van Dulmen <https://orcid.org/0000-0002-1651-7544>
Reinier Schlingemann <https://orcid.org/0000-0002-2300-8289>

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Tables and figures

Figure 1 List of (sub) themes

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| <p>Shared decision-making (SDM) in Age-related Macular Degeneration (AMD) care</p> <ul style="list-style-type: none">- Information provision<ul style="list-style-type: none">o Content of informationo Timing of information provisiono Informed consent- SDM moments<ul style="list-style-type: none">o Aspects of SDMo Decisions on treatmento Reasons for non-treatmento Influence of patient characteristics- Personal attitudes towards SDM<ul style="list-style-type: none">o Health professional expertiseo Patient involvemento Added value of SDM- Experiences with SDM<ul style="list-style-type: none">o Barriers to SDMo Facilitators of SDM |
|---|

Table 1 Patients' and health professionals' characteristics (n = 39)

Characteristic		
Patients (n = 20)		
Sex (%)	Female	12 (60)
	Male	8 (40)
Age (range)		74 (48–93)
Education level (%)	Low	5 (25)
	Middle	9 (45)
	High	6 (30)
Type of diagnosis (%)	Nonexudative AMD	4 (20)
	Exudative AMD	10 (50)
	Nonexudative and exudative AMD	6 (30)
Time since diagnosis (%)	<12 months	3 (15)
	1–2 years	2 (10)
	2–5 years	6 (30)
	>5 years	9 (45)
Visual acuity score (%) ^a	Low	3 (15)
	Moderate	6 (30)
	High	3 (15)
	Unknown	8 (40)
Self-perceived eyesight (%)	Good	5 (25)
	Fair	8 (40)
	Poor	5 (25)
	Very poor	2 (10)
Reading disability (%)	Yes	8 (40)
	No	12 (60)

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Table 1 continued

Health professionals (n = 19)		
Sex (%)	Female	9 (47)
	Male	10 (53)
Age (range)		52 (36–64)
Type of health professional (%)	Ophthalmologist	6 (32)
	Optometrist	3 (16)
	General medical practitioner	2 (11)
	Vision rehabilitation specialist	3 (16)
	Physician assistant/optometrist	3 (16)
	Technical ophthalmic assistant	1 (5)
	Physician assistant	1 (5)
Type of care facility (%)	Independent treatment clinic	12 (63)
	General hospital	5 (26)
	Academic hospital	2 (11)

Abbreviation: AMD, Age-related macular degeneration.

^aVisual acuity scores (decimal equivalent): low <0.3 (severe vision loss); moderate 0.3–0.8 (moderate vision loss); high >0.8 (normal vision).