

## Educating Patients with Neovascular AMD about its Treatment and Low Vision Support Services Available to Them: An Evaluation from the Patient and Clinician Perspective

Jessica Boyle BHLthSc(Hons) BOrth&OphthSc<sup>1</sup>

Meri Vukicevic PhD<sup>1</sup>

Konstandina Koklanis PhD<sup>1, 2</sup>

Catherine Itsiopoulos PhD<sup>3</sup>

Gwyneth Rees PhD<sup>4, 5</sup>

<sup>1</sup>Department of Community & Clinical Allied Health, La Trobe University, Melbourne, Australia

<sup>2</sup>Department of Ophthalmology, Royal Children's Hospital, Melbourne, Australia

<sup>3</sup>Department of Rehabilitation, Nutrition & Sport, La Trobe University, Melbourne, Australia

<sup>4</sup>Centre for Eye Research, Royal Victorian Eye and Ear Hospital, East Melbourne, Australia

<sup>5</sup>Department of Surgery, Ophthalmology, University of Melbourne, Melbourne, Australia

### ABSTRACT

Anti-vascular endothelial growth factor (VEGF) treatment for neovascular age-related macular degeneration (AMD) is chronic and invasive. Patient education can play a key role in reducing treatment burden. The experiences of patients undergoing anti-VEGF injections for AMD with respect to patient education have not been widely investigated, with just a few small, single-centre investigations having been undertaken. Furthermore, no study has explored issues affecting patient referral to low vision services and patient support groups in this clinical population, from the perspective of ophthalmologists and orthoptists. This study aimed to: i) investigate the experiences of AMD patients undergoing anti-VEGF treatment in relation to patient education, and ii) identify issues surrounding patient referral to support services according to ophthalmologists and orthoptists.

Forty patients (16 males, 24 females) with neovascular AMD undergoing anti-VEGF treatment were recruited from a private ophthalmology practice and public hospital in Melbourne, Australia. Patients participated in semi-structured interviews regarding the information and patient education they received about their eye condition and its management. Interviews were audio recorded and thematic analysis performed. In addition, eighteen orthoptists and one ophthalmologist, recruited from the same locations, completed a self-administered questionnaire exploring the provision of patient education and referral of patients to support groups and low vision services.

Corresponding author: **Jessica Boyle**

Department of Community & Clinical Allied Health

School of Science, Health & Engineering

La Trobe University Melbourne VIC 3086 Australia

email: Jess.Boyle@latrobe.edu.au

Accepted for publication: 12th April 2019

Patient satisfaction with the quantity of educational information received was low, especially in public patients. Many patients reported receiving inadequate information about AMD and its treatment. Patient awareness and uptake of low vision services and support groups was poor. Factors influencing uptake (as per patients) included: timing of referral, financial outlay, perceived benefits and accessibility. Barriers to patient referral (as per orthoptists) included: practical and knowledge-based factors, patient factors and clinical protocols.

Many patients felt uninformed about their treatment and also reported limited knowledge of available support services. Improving the provision of patient education and more consistent referral to support services may lessen treatment-related anxiety and assist patients to better manage the challenges of AMD treatment.

**Keywords:** age-related macular degeneration, anti-VEGF treatment, patient education, patient support groups, low vision services

### INTRODUCTION

**A**ge-related macular degeneration (AMD) is the leading cause of legal blindness in Australia, responsible for 50% of all cases of blindness.<sup>1</sup> Globally, it is the third most common cause of vision impairment, affecting 30 to 50 million individuals worldwide.<sup>2</sup> The global prevalence of AMD is projected to increase to 288 million by 2040, owing to an increase in the average life expectancy of the population.<sup>3</sup> In turn, this will contribute to heightened service capacity pressures and economic burden in the future.

Of its two principal forms, neovascular AMD is less common than dry AMD, affecting only 10% of patients with AMD.<sup>4</sup> However, neovascular AMD accounts for most vision impairment, being attributable to 90% of all legal blindness associated with AMD worldwide.<sup>5</sup> Currently the most effective therapy for neovascular AMD involves repeated intravitreal anti-vascular endothelial growth factor (VEGF) injections with the aim of delaying disease progression and preserving eyesight.<sup>6-9</sup> Injections are typically continued indefinitely and regular ophthalmic review, often 4 to 8 weekly, is required.<sup>10,11</sup> Whilst treatment adherence is generally high in patients with neovascular AMD,<sup>12,13</sup> the ongoing and repetitive nature of the therapy protocol poses considerable burden on patients and their families.<sup>14,15</sup>

Central to the patient experience of ophthalmic treatment, and indeed any other medical or surgical intervention, is patient education.<sup>16,17</sup> Despite the chronic and invasive nature of AMD management, patients' perceptions regarding education have not been widely investigated in individuals undergoing anti-VEGF treatment for neovascular AMD.<sup>18,19</sup> Of the few studies to have explored this to date, all have been small, single-centre investigations with recruitment confined to only one practice location, hereby reducing external validity. Notwithstanding, these studies reported that patients receive inadequate information pertaining to the injection procedure and its outcomes.<sup>18,19</sup>

In a qualitative study of 10 patients undergoing anti-VEGF therapy for neovascular AMD, 90% of patients interviewed reported receiving insufficient information pre-treatment regarding: i) the procedure itself (eg use of a lid speculum, recumbent position), ii) the effect of the drug used (eg vision improvement, the need for recurrent injections), and iii) the natural history of the disease.<sup>18</sup> In addition, many patients reported having to actively seek information themselves from other sources such as the internet.<sup>18</sup> In a different qualitative study of 22 patients newly diagnosed with AMD, the majority of patients interviewed reported that they were informed that the treatment involved injections into the eye, but received little further information or opportunity to discuss the procedure in detail.<sup>19</sup> Inadequate information regarding clinical assessments and visual prognoses were also highlighted as key issues by patients. This lack of information was thought to not only have a detrimental impact on patients' experiences of treatment, but was also linked to heightened pre-treatment anxiety in patients.<sup>19</sup>

Pre-procedural anxiety has been reported in many patients undergoing intravitreal injections.<sup>15,18,19</sup> This anxiety is often centred on a fear of 'the unknown'.<sup>15,19</sup> Studies involving patients undergoing cataract surgery have found that patient education can decrease procedure-related anxiety, increase patient satisfaction with treatment and improve patients' understanding of expected treatment

outcomes.<sup>16,17</sup> The provision of structured preoperative information may also help minimise anxiety and improve patient satisfaction with treatment in patients undergoing intravitreal injections. It is, however, first necessary to gain a better understanding of the perceptions of patients undergoing treatment for neovascular AMD in relation to the provision of educational information. The primary aim of this study was to investigate the experiences of those undergoing intravitreal anti-VEGF injections for neovascular AMD in relation to patient education.

Patient education not only relates to treatment knowledge but, in this study, also encompasses patient awareness of support services available to assist them in better managing their eye condition and its treatment, such as low vision rehabilitation organisations and AMD support groups. Despite the known benefits of low vision services such as improved independence and quality of life, in Australia fewer than one in five patients with low vision access such services.<sup>20</sup> Service uptake varies across the world from 3 to 15%.<sup>21</sup> One of the main contributors to low level service uptake is a lack of patient education leading to poor patient awareness of these services.<sup>22</sup> Other factors precluding uptake of vision rehabilitation services by patients include medical comorbidities, transport difficulties, language barriers and perceived lack of benefit from low vision rehabilitation.<sup>21,23</sup> With respect to referral, a lack of awareness of low vision services amongst eye care professionals and the need for more equal distribution of services across urban and rural areas have been identified as significant issues.<sup>23,24</sup> Whilst many studies have investigated the barriers and facilitators to the uptake of low vision services by patients with vision impairment, almost all of these studies have done so from the perspective of patients.<sup>21-23</sup> No study to date has investigated these issues from the perspective of ophthalmologists and orthoptists involved in the eye health care of patients. Moreover, no study has explored issues surrounding the provision of information pertaining to patient support groups. A secondary aim of this research was to identify issues surrounding patient education and the referral of patients to low vision services/patient support groups from the perspective of ophthalmologists and orthoptists.

## METHODS

This study conformed to the provisions of the 1995 Declaration of Helsinki (as revised in Edinburgh, 2000) and relevant ethical approval was obtained before commencement (La Trobe University FHEC 13/067 and RVEEH HREC 14/1163H). All participants provided written informed consent.

## Participants

### *Patients*

Patients were purposively recruited from a private ophthalmic practice and a public eye hospital in Melbourne, Australia. All were diagnosed with neovascular AMD by an ophthalmologist and were undergoing active anti-VEGF treatment at the time of the study or had undergone treatment within the last 12 months. Participants were excluded if they were non-English speaking, or if they had a history of neurological disorder or other diagnosis that could affect memory recall, as determined by their medical record.

### *Ophthalmologists and orthoptists*

Ophthalmologists and orthoptists working at the above clinics were invited to participate in this study. It was a prerequisite that participating ophthalmologists and orthoptists had a minimum of two years' experience working in vitreoretinal clinics and in managing patients with neovascular AMD.

## Procedure

### *In-depth interviews*

Patients took part in semi-structured, one-on-one interviews exploring their experiences in relation to anti-VEGF treatment. An interview topic guide was used, the development of which was based on data obtained from two patient focus groups conducted prior to the one-on-one interviews. The purpose of the focus groups was solely to inform the development of the interview schedule. The focus groups lasted for approximately one hour and were conducted with a total of five participants (2 males, 3 females) who met the same patient eligibility criteria. Topics that arose from the focus group data included: i) burden of therapy, ii) strategies used to manage burden of therapy, iii) satisfaction with treatment and service delivery, iv) treatment motivation, v) effect of patient education, and vi) the provision of information relating to patient support groups/low vision services and patient awareness of such services. The framework for the in-depth interviews covered all of the aforementioned topics, however, only the findings in relation to topics v and vi above are discussed in this paper. The findings with respect to the latter topics were extracted as a subset of the original data and are exclusive to this paper, with all other findings having been reported elsewhere.<sup>15</sup>

During the interviews, the specific wording and order of questions was flexible and adapted to each participant as needed. Given the semi-structured format, deviations from the main points of discussion were permitted and the researcher was able to explore these leads where appropriate or probe to elicit further responses.

All interviews were audio recorded and transcribed strict verbatim, with the exception of two where participant consent to be recorded was not provided, for which detailed written notes were made. The semi-structured interviews lasted between 1 and 2.5 hours and were undertaken at either the participant's home or a private meeting room at the treating clinic/hospital. All interviews were conducted by the first author (JB). The researcher was not directly involved in the care of participants at either treatment location.

The focus of this paper is on patient education and the provision of information relating to support services. As such, only those interview findings pertaining to this specific theme will be discussed herein. These findings are exclusive to this paper. Details of the other findings that emerged from the patient interviews have been reported elsewhere.<sup>15</sup>

## Electronic questionnaire

Eye health care professionals participating in the study were invited to undertake an electronic questionnaire designed by the study investigators using Google Forms. Questions were informed by the results of the patient interviews and related to issues surrounding patient education and the provision of information to patients about AMD support groups and low vision services, as well as barriers and facilitators to referring patients to these services. The questionnaire consisted of 36 compulsory closed-ended questions and 17 optional open-ended questions. To ensure participants remained anonymous, no information regarding participant demographics was collected during the survey with the exception of which health sector/s (public and/or private) participants worked in. The questionnaire was self-administered and took approximately 15 minutes to complete.

## Data analyses

Interview transcripts were coded by one researcher (JB) using NVivo 10 (QSR International, Doncaster, Australia). The data were coded by organising and categorising information into emergent themes using an iterative strategy and comparative method until all meaningful data had been coded. To enhance analytical rigour and auditability, a decision trail was used to document decisions made and rules developed for the assignment of the data into themes.<sup>25</sup> Thematic analysis of the coded data was undertaken. For each theme that emerged, the coded narratives of private patients were compared to those of public patients, and the similarities and differences identified. A content analysis approach was also used in that participant responses were numerically counted.

The Mann-Whitney U test was used to analyse differences

in patient age, gender and distance travelled to receive treatment between public and private patients. The assumption of normality was violated for all variables with the exception of age, and therefore non-parametric statistical tests were used. The level of significance was set at  $\alpha = 0.05$ . Descriptive statistics were used to summarise the data arising from the electronic survey.

## RESULTS

### Participant demographics

Forty patients (16 males, 24 females) participated in this study, not including the five focus group participants. The sample included all eligible participants who were approached with the exception of two patients who declined participation owing to reasons of chronic illness. Nineteen patients were recruited from a private ophthalmic practice and 21 from a public eye hospital. The mean age of patients was 81.95 years (range = 64 - 93). There was no significant difference in the mean age ( $p = 0.206$ ) nor gender ( $p = 0.799$ ) of private and public patients. Public patients travelled significantly further to the treating clinic (mean 38.9 km, range = 8.3 - 113.0) than private patients (mean 10.4 km, range = 1.8 - 34.8) ( $p < 0.001$ ). No patients withdrew from the study.

Eighteen orthoptists participated in this study. Thirteen worked in the private sector, four in the public sector, and one worked in both the private and public sectors but primarily public. Whilst 20 ophthalmologists were invited to participate in the electronic survey, only one response was received and as such this data was not included in the analyses. Multiple follow-up invitations were issued however the response rate of ophthalmologists remained poor.

### In-depth interviews

Several global themes emerged from the patients' narratives, one of which was patient education. The findings pertaining to this specific theme are exclusively provided in this paper. Details of the other findings have been reported elsewhere.<sup>15</sup> The theme of patient education encompassed: i) patient satisfaction regarding information provided to them about their eye condition and its treatment; ii) the use of optical coherence tomography (OCT) as a patient education tool and the value that patients placed on receiving this type of feedback as part of their treatment; and iii) patient awareness of AMD support groups and low vision services available, as well as factors influencing service uptake.

The patient experience with respect to patient education was found to differ according to whether individuals were

treated in the public or private setting. Table 1 shows examples of participants' narratives from both public and private patients pertaining to this global theme, as well as the number of references made in relation to each of its organisational sub-themes.

#### *Effect of clinical setting on provision of information*

Patients' experiences in relation to the level of information provided to them differed between individuals and varied depending upon whether they were treated in the public or private setting. Patient satisfaction with the quantity of educational information provided was high in private patients but low in public patients. Public patients often reported feeling ill-informed about AMD and the purpose of treatment. In one instance, one public patient who had received multiple injections reported that she was not aware as to why she was undergoing treatment until being recruited into the study. Several public patients reported that they undertook 'information prompting', whereby they probed specialists for information and asked questions pertaining to their eye condition and treatment. These patients expressed that they felt the need to do so, otherwise limited information would be provided to them.

#### *Effect of visual aids (OCT scans) on patient understanding of disease and treatment*

Patients are sometimes shown their OCT scan during treatment visits as a means of feedback on their eye condition and how their treatment is progressing. This was perceived by most patients to be a useful adjunct to the verbal explanation provided by their specialist as it facilitated their understanding of their eye condition and their response to anti-VEGF treatment. Differences were however reported amongst patients as to how often they were shown their OCT scan. Most private patients reported being shown their OCT scan by their specialist on a regular basis when presenting for treatment. In comparison, few public patients reported having been shown their OCT scan in the past despite being interested in this. Consequently, this contributed to these patients feeling relatively uninformed about treatment.

Some patients also expressed that being shown their OCT scan created an opportunity for them to communicate with their specialist and ask questions. It allowed them to feel included in the treatment decision-making process. Whilst the decision whether and how often to treat is largely at the discretion of the ophthalmologist, patients valued being informed about the underlying reasons governing the need for and frequency of treatment. Many public patients who were not shown their OCT scan expressed that they felt largely excluded from the treatment decision-making process.

**Table 1. Illustrative examples of participant narratives from public and private patients relating to each sub-theme under the global theme 'Patient education'.** The number of public and private patients who made at least one comment and number of comments made are also shown for each sub-theme

GLOBAL THEME: PATIENT EDUCATION	Organisational theme: General provision of information			
		Public patient responses		Private patient responses
	Satisfaction with quantity of educational information provided	7 participants 26 responses	<p>"No, no, no I haven't had... No clue whatsoever of what goes on, I don't... No" (ALB003, male, age 87)</p> <p>"I got no explanation. There was no information provided... Just told "You're getting an injection", well I sort of thought, "What the hell for?" I didn't know it was for macular... I didn't know until you told me." (AND005, female, age 79)</p> <p>"[I'd like] to know a little bit more. You're sort of kept in the dark a bit." (BOY006, female, age 79)</p>	6 participants 14 responses
Information prompting	6 participants 9 responses	<p>"I had a verbal explanation as well, because I am a person who always asks things. Yes, I always ask. I ask if this is good for me or not. Yes, I do ask. Even one of the doctors told me to - there is no other treatment, there is no laser, nothing else, but eat erm, yellow veggies... Things like that, that probably another person doesn't know because they don't ask. But this is not every time, because if I don't ask they don't tell me anything." (BEN015, female, age 76)</p> <p>"If I ask a question, then I get answers." (BIR021, female, age 87)</p>	N/A	
Organisational theme: Effect of visual aids (OCT feedback) on patient understanding of disease and treatment				
		Public patient responses		Private patient responses
OCT feedback is a useful adjunct to verbal information	14 participants 29 responses	"I would like to see what's going on. Like here, this eye had a bleed and they said 'Oh you know, there was a scar there from the bleeding.' I would like to see that scar." (BOY006, female, age 79)	12 participants 26 responses	"I do love to see the visual image, exactly what's happening. And then I can see the improvements. I can see the peaks like this, you know. They're coming down all the time. It's very good to see that." (FYF005, female, age 87)
Desire to be shown OCT scan	17 participants 29 responses	<p>"They're (specialists) looking at it and I'm looking over their shoulder and thinking, what the hell's going on here?" (AND005, female, age 79)</p> <p>"Like the other day... The doctor... He said eight weeks before I went back in and then he said, 'No, six weeks'. I would like to have known why. I should've asked him but I didn't." (AND005, female, age 79)</p>	15 participants 32 responses	<p>"When he explains it to me, I understand what is going on and why I am having the treatment. I see the images on the screen... You know that's the reason why you need it." (DAW012, male, age 87)</p> <p>"... Tis a month and in the month it's got back to what it was last time usually. So I see, I see a 'sameness' but she (doctor) sees a difference. And then she'll show me the two pictures side by side and then you can see the difference. Erm, so that's what I mean, I'm, I'm in the loop, I'm, I'm being informed all the time of what's going on, which is great." (SHA007, female, age 78)</p>
Usefulness of OCT feedback dependent upon specialist's interpretation and other factors	9 participants 12 responses	<p>"I couldn't understand it at all. Too technical." (GAV011, female, age 87)</p> <p>"I, I think for me anyway, just a pencil drawing... Um, you know, because you look at the scan and it's got lines everywhere and little dots and things... But just even a pencil drawing of, saying this is your eye, this is the back of it and this is what's happening, you know? Maybe even that simple..." (MAS008, male, age 89)</p> <p>"When they show it to you, you've got drops in your eyes and it's all blurry and it's, it's really... I can't see it that well." (MAL010, female, age 79)</p>	12 participants 13 responses	<p>"Well it's hard to understand for somebody who is not in that field. I can remember him showing me on the computer and I thought well it doesn't really mean much to me. I have to rely on what he says." (DEL009, female, age 88)</p> <p>"Even though I may not truly understand it, in my mind it helps to clarify what he's talking about if he can say 'Well there are signs of so and so there' and point it out. He might use a clinical term... And there's a little bump at the bottom and I understand that's what he's talking about." (LOW016, male, age 93)</p>

Patients acknowledged that the degree of benefit from being shown their OCT scan was largely dependent on their specialist's explanation of the scan. Consequently, some patients indicated that more simplified information, such as a schematic drawing, might be of greater use to them. Other

factors influencing the usefulness of OCT feedback included the patient's level of vision impairment and whether they had had topical mydriatic agents instilled.

*Patient support groups and low vision services*

Almost all patients were unaware of available AMD patient support groups, such as Bayer’s Smart Sight Program or Novartis’ Via Opta, with only one patient interviewed during the study being aware of, and currently enrolled in, such a group. This patient was a private female patient. Patient awareness of general low vision services provided by support organisations, such as Vision Australia and Guide Dogs Australia, was greater than awareness of patient support groups. This was observed in both public and private patients.

Several patients reported that they were aware of low vision services available to them, however only a few of these had utilised such services. These patients were typically private patients and female. In most instances, patient knowledge of low vision services was first acquired through a relative or visiting district nurse. Few patients were referred by their treating ophthalmologist or orthoptist. Of those who had utilised a low vision service, satisfaction varied in relation to the quality of service received.

Several key factors were identified by patients when considering whether or not they would utilise a patient support group or low vision service. The timing of referral to a patient support group or low vision service was thought to be an important consideration. Most patients expressed that a support group would be most beneficial if offered at

the time of diagnosis, owing to being unfamiliar with the treatment procedure and treatment-related apprehension typically being higher. With respect to low vision services, any financial outlay associated with the uptake of the service or product was an important consideration. Patients indicated that they were prepared to make sacrifices to afford a low vision product or service if it was perceived to be of benefit, however many patients did not perceive such products and services to be of personal benefit to them. The majority were of the belief that a patient needed to be significantly vision impaired in order to benefit from the service and as such, did not consider their own vision to be sufficiently reduced to warrant service uptake. This was often despite the patient describing difficulty in managing their day-to-day affairs, including undertaking household chores, and reading and managing bills. The location and accessibility of the patient support group or low vision service was of importance. Many expressed that transport to clinic-based low vision organisations can be difficult owing to being: unable to drive, reluctant to use public transport, and/or reliant on relatives or carers to provide transport and acquire leave from work. Many reasons were identified by patients both in support of and against the uptake of patient support groups and low vision services. These reasons have been outlined in Tables 2 and 3 with supporting patient narratives.

Table 2. Reasons for the uptake of patient support groups or low vision services as provided by patients	
Reason	Example of supporting statement
Patient support group presents an opportunity to make new friends and support one another	<i>“We can find friends there... having the same problem”</i> (BEN015, female, age 76, public patient)
Help to relieve feelings of loneliness, anxiety and frustration	<i>“I would like to know what other people think as well as myself. I feel lonely, thinking about it. And if I had someone to talk to, it would help”</i> (AND005, female, age 79, public patient)
Opportunity to receive additional information and means of keeping informed	<i>“You know, I’ve kept involved. I’ve seen paperwork from the Macular Degeneration people and joined them, you know. I don’t know, I think I joined their membership or something. In fact I think they sent me an information sheet the other day. Dispensing useful information, you know. Well, interesting information anyway”</i> (SMI008, male, age 92, private patient)
Might not need all products/services on offer but at least it provides options	<i>“I mean, when you go into that room, all of the things that you can have. I felt so much better when I came out of there because, you know, there were things you don’t even think about, you know, like filling your cup up with - you know, to make a cup of tea. Well, you’re probably pouring water all over the place. But, I mean, there’s something there to tell you that’s how far you go up the cup. How good is that!? And um - oh, absolutely blew me away, that place”</i> (SWA013, female, age 93, private patient)  <i>“I said to her, there’s a lot of this I don’t really need right now, and I didn’t then. Um but there might come a time and I want to know what’s available to me”</i> (SWA013, female, age 93, private patient)
Positive attitude towards seeking help	<i>“That’s my attitude, that if there’s anything that can help you... Vision Australia, anywhere, I will try it. And that’s what all these things are for... To help you. So you do have to take it - I mean, you’re very foolish if you don’t take advantage of all these things that are there to help you”</i> (SWA013, female, age 93, private patient)
Notion of: “I like to be ahead of the disease”. Prefer to learn to use a product or service now whilst still a sighted-patient.	<i>“I did ring them because I wanted to go down. I like to be sort of ahead if I can... I wanted to go down and see what was available. Um and ah - and it was quite interesting really... I mean, it’s amazing the things they have there”</i> (SWA013, female, age 93, private patient)
Patient support group would be useful to discuss the impact of AMD and coping with low vision, more so than the treatment itself	<i>“Um... Not, not as far as the injections go... Um, but as far as general vision is concerned, I would like that”</i> (SEL006, female, age 81, private patient)

Table 3. Reasons against the uptake of patient support groups or low vision services as provided by patients

Reason	Example of supporting statement
Existing patient knowledge of AMD and its treatment is adequate and therefore it is felt that uptake of service is not warranted	<i>"I really haven't felt the need. No, I think it was all - everything was all explained well enough and I knew enough about it then that it, no didn't need it"</i> (FYF005, female, age 87, private patient)
Perception that product/service won't be of benefit to the individual patient, but may help others (eg non-English speaking patients, anxious patients)	<i>"Probably not. Only because uh, you know I'm aware of what has to be done, and the - and the consequences if you don't have it done. Whereas I just imagine somebody like an ethnic person who had not - no idea whatsoever, and got all stressed out about it all would need something like that"</i> (BRO017, female, age 76, public patient)  <i>"I don't think it's going to make any difference to my eye, whether I talk to anybody or not. It's there and you know... Yeah, the only thing it would be - it could be a calming nature if people are agitated about it I guess. That - that - that's the benefit to that I guess"</i> (BRO017, female, age 76, public patient)  <i>"Mm [pause], I suppose some people would like to do that. It's never occurred to me that I would like to do that. Um, [pause] um, no it hasn't. It - it hasn't occurred to me... But I guess some people would like to do that. I think I go all right..."</i> (SMA014, female, age 74, public patient)
Perception that appropriateness/usefulness of the service is age-dependent; more appropriate for a patient who is younger and more active in community	<i>"No, I don't think so. Don't think so, not at my age... and, you know, sort of thing. Because, see, see, it does happen to people much younger too and they're more active, you know, sort of thing... Although it has - that is one effect that it's had on me, I'm far - I'm not as active as I was... because, I mean, I'm, I'm old but, you know... I didn't, I didn't, um, didn't feel old until I got this. And now, I, I feel old because I'm very, ah... And I'm frightened of missing a step or, you know, that type of thing"</i> (GAV011, female, age 87, public patient)
Perception that patient's current level of vision does not warrant uptake of patient support group or service	<i>"No. No, not as yet because I don't think I'm, I don't think it's necessary yet"</i> (MAL010, female, age 79, public patient)
Reluctant to seek help from others	<i>"Well, I hadn't been told anything about that, I wouldn't even be interested. I've battled and struggled and we've managed all our lives, Betty and me. Fought our own battles..."</i> (ALB003, male, age 87, public patient)
Feel well supported and adequately cared for by existing family and friendship networks	<i>"We had a nurse come in here the other day. And something came up about the fact that I had macular degeneration. Oh, she said you've got - you can get support. But I really don't, I don't really need it. I get support from family and friends who want to know how it's going. That's alright, so - you know so it's not too bad"</i> (BAN002, male, age 86, private patient)  <i>"... I was lucky, my daughter in law, she's a nurse and close and she's just marvellous, you know. She got on the phone to Dr X. She was as concerned as me, you know. And she came and sat and watched the first. But no, I've had her all along so I really don't think a support group would help"</i> (MUR010, female, age 90, private patient)  <i>"I've got a cousin who's got dry actually, and she's worse than I am. But we sort of get together and... So we sort of support each other and..."</i> (TEL003, female, age 80, private patient)
Opportunities to talk to others who are diagnosed with AMD already exist (relatives, friends, other patients in waiting room)	<i>"I don't think that's necessary for me. I want to stay in the norm. You know, I... Yeah. I just want to stay in the norm. I, I've become friends with quite a few people in there and we can tell stories. We tell stories about stupid things we do. Ah, so I, you can, you do form a rapport anyway... So I don't want to go down that road"</i> (MAL010, female, age 79, public patient)
A preference for one-on-one discussion between friends over group discussion with strangers	<i>"I don't know. A couple of people have rung me. Friends who know that I've got it. To say that they've just been diagnosed and what's it like. What the injection's like they've really wanted to know [laughs]. And I tell them - fine. I think what's happened with people that I know, who have rung me. Well, they've been friend to friend. I think if you just had someone you could ring up. Who could just tell you it doesn't hurt"</i> (SEA015, female, age 73, private patient)
Can't be bothered or not interested	<i>"But I always feel um [pause]... You know, I [pause]... didn't want to call on them, ah. I am aware that there is even a society for people like that. But I don't think I can be bothered with that"</i> (BOW017, female, age 89, private patient)
Lack of time owing to other medical appointments and social commitments	<i>"Well, it wouldn't benefit me, I don't think because I really haven't got time. By the time you do your medical things, and you know, you go and have a couple of lunches with, you know... Or see the family um the week's gone. Then I get so tired, you know..."</i> (SWA013, female, age 93, private patient)
Acceptance of condition or treatment situation for what it is. Don't wish to discuss it with others.	<i>"I don't think so. I don't think I'd go. Well, see with my fibromyalgia as well, they have group thing-os and that. I don't go to those. Because I think well I've got it, they've got it. What are we going to do - sit there and compare notes about how much pain we're in? No."</i> (JAN012, female, age 79, public patient)  <i>"I accept what it is. I don't dwell on it too much"</i> (TER001, male, age 79, public patient)  <i>"No. No, no, I just prefer not to... I'm the same with my, erm, breast cancer. I don't go to groups. I suppose it could help others maybe, but I just want to put it behind me. And this is just part of my life now, you know. I don't have to share it with anybody..."</i> (SHA007, female, age 78, private patient)
Perception that you must be a certain type to join groups	<i>"I have not had anything to do with support groups. I don't think I am that sort of type really, you know"</i> (FLO004, male, age 64, private patient)
Negative stigma associated with uptake of service or use of product; desire to "stay in the norm" and perception that use of service constitutes falling out of the norm	<i>"I don't think that's necessary for me. I want to stay in the norm. You know, I... Yeah. I just want to stay in the norm. I, I've become friends with quite a few people in there and we can tell stories. We tell stories about stupid things we do. Ah, so I, you can, you do form a rapport anyway... So I don't want to go down that road"</i> (MAL010, female, age 79, public patient)
Travel/accessibility	<i>"I don't know. I don't know, I think it's bad enough ... [long pause]... I suppose, I don't know ... [long pause]... Not sure that I'd want to go. All be miserable together [hysterical laughter]. And you have to get there and ah, you see I wouldn't drive a long way. I wouldn't go far. Because I would only drive around here"</i> (BOW017, female, age 89, private patient)  <i>"I wouldn't be interested now. Maybe early on but then I've always had a problem with the transport because I don't drive and I've had the problems with the taxi before I started. And the family, I guess they used to drive me around and my husband did prior to that. You know before he passed away, he drove. So, it wouldn't be any good to me now but I s'pose as long as you had transport and you were able to get out... I could"</i> (SIN011, female, age 88, private patient)

**Questionnaires**

*Referral of patients to patient support groups*

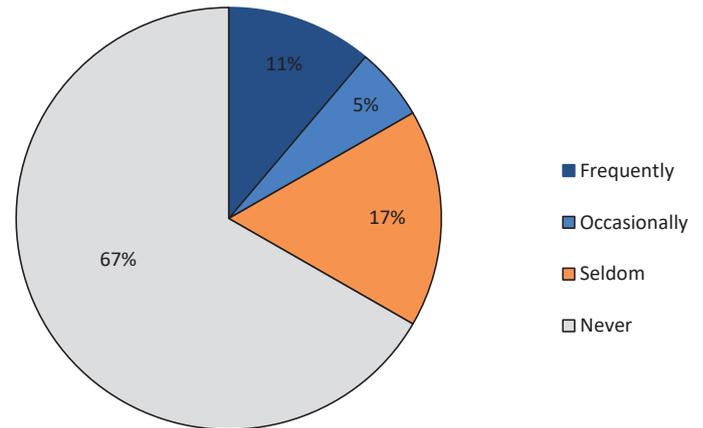
Figure 1 shows the frequency with which orthoptists surveyed refer patients with neovascular AMD to patient support groups. Of those orthoptists surveyed, 67% (n = 12) indicated that they never refer patients to patient support groups, and a further 17% (n = 3) indicated that they seldom refer patients. Ophthalmologists, followed by orthoptists and then nursing staff, were most frequently identified by survey respondents as the health care professionals within their workplace who were primarily responsible for the referral of patients to patient support groups and low vision services.

Of those orthoptists who indicated that they refer patients to support groups (n = 6), 67% felt that less than half of those patients that they refer actually enrol in the support group. The remaining 33% indicated that they felt half of those patients whom they refer actually enrol in the patient support group. Of those orthoptists who had previously provided patients with information pertaining to patient support groups, this information was most commonly provided to patients via both written and verbal means.

*Barriers and facilitators to the referral of patients to patient support groups*

Table 4 lists the barriers, as reported by orthoptists, to referring patients to patient support groups and Table 5 shows suggestions provided by orthoptists as to how these barriers might be improved or resolved. Some of the most

commonly reported barriers included time constraints in clinic which prohibited orthoptists from providing patients with information, and lack of clinician awareness around patient support groups. To address these barriers, a streamlined and more efficient electronic referral process was recommended, as well as the provision of greater workplace training.



**Figure 1.** Frequency of referral of patients with nvAMD to patient support groups by orthoptists.

Table 4. Barriers to the referral of patients to patient support groups		
Type of barrier	Examples	Number of survey respondents who identified this as a perceived barrier
Practical	Time constraints in clinic	3
	Lack of ease of referral	1
Knowledge based	Lack of clinician awareness that patient support groups exist	4
	Limited knowledge regarding the types of services and/or benefits offered to patients upon enrolling in a patient support group	1
	Limited information available in relation to patient support groups that can be relayed to patients	2
	Having the knowledge to be able to identify patients in need of these support services	1
Patient factors	Location of service not convenient for patient	1
	Perception that patient support group will not benefit the patient for a variety of reasons (eg patient has trialled it before)	1
	Clinician met by the reluctance of patients to uptake the support group as the patient can't be bothered or they feel that they do not require help	2
Clinical protocol	Practice protocol	1
	Not considered routine clinical practice to recommend such support groups to patients	1
	Perception that it is the responsibility of the ophthalmologist to refer patients to support groups if necessary	2
Other	Commercial bias of support groups	1
	Support services are often internet-based and therefore deemed accessible to the patient without the need for clinician referral	1

Table 5. Recommendations for how barriers to the referral of patients to patient support groups might be improved or resolved

Type of barrier	Recommendation/s
Practical	Referral process to be made easier by the use of referral pads or an internet referral system whereby referrals can be made quickly and sent in the presence of the patient
Knowledge based	Offer greater tertiary based training and workplace training in these services
	Increase awareness and educate eye health care professionals about the types of services that exist for patients
	Educate eye health care professionals on the types of clues or criteria that identify patients who are eligible for/might benefit from referral to such services
	Make information more readily accessible – most patients are elderly and don't have or use internet
	Employ a consultant who has increased knowledge of patient support groups to contact patients
Patient factors	Increase home visits to rural and remote areas
Clinical protocol	Ophthalmologist to make the referral of patients to patient support groups by orthoptists part of their clinical protocol
	Change to current clinical protocol whereby orthoptists enlisted with responsibility of referring patients and a system is introduced whereby patients are referred before/after their initial injection as standard procedure

### Referral of patients to low vision services

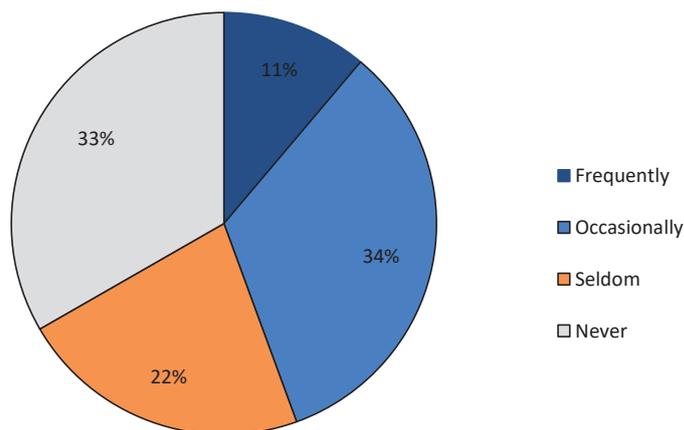
Figure 2 shows the frequency with which those orthoptists surveyed refer patients with neovascular AMD to low vision services. Only 11% (n = 2) of orthoptists surveyed indicated that they frequently refer patients to such services. Thirty-three percent (n = 6) of orthoptists surveyed indicated that they never refer patients to low vision services. This was not dependent on where the respondents worked. However, by their own report, the referral of patients to low vision services by orthoptists was higher than the referral of patients to patient support groups.

Of those orthoptists who indicated that they refer patients to low vision services (n = 12), 58% thought that only half of those patients that they refer actually utilised the service, 33% thought that most of those patients that they refer utilised the service, and 9% thought that all of those patients that they refer utilised the service. Of those orthoptists who had previously provided patients with information pertaining to low vision services, this was most commonly done via verbal discussion only.

### Barriers and facilitators to the referral of patients to low vision services

Table 6 lists the barriers, as reported by orthoptists, to referring patients to low vision services and Table 7 shows suggestions provided by orthoptists as to how these barriers might be improved or resolved. The most common barriers to referral were clinic time constraints and clinicians' lack of knowledge about low vision services available to patients. A change in clinician workload, the addition of more clinical staff, an easier referral process, and low vision up-skill workshops were offered as recommendations to lessen these barriers.

Orthoptists were also asked to indicate their level of agreement/disagreement with respect to whether certain factors influenced whether or not they refer patients with neovascular AMD to patient support groups and low vision services. Figure 3 shows the percentage of orthoptists and corresponding level of agreement for each factor. Sixty-one percent of orthoptists surveyed (n = 11) indicated that the location where a patient lives did not influence whether or not they referred patients to patient support groups and low vision services. However, 80% of orthoptists surveyed (n = 15) reported that the perceived ability of a patient to comprehend information provided to them influenced whether or not they referred patients.



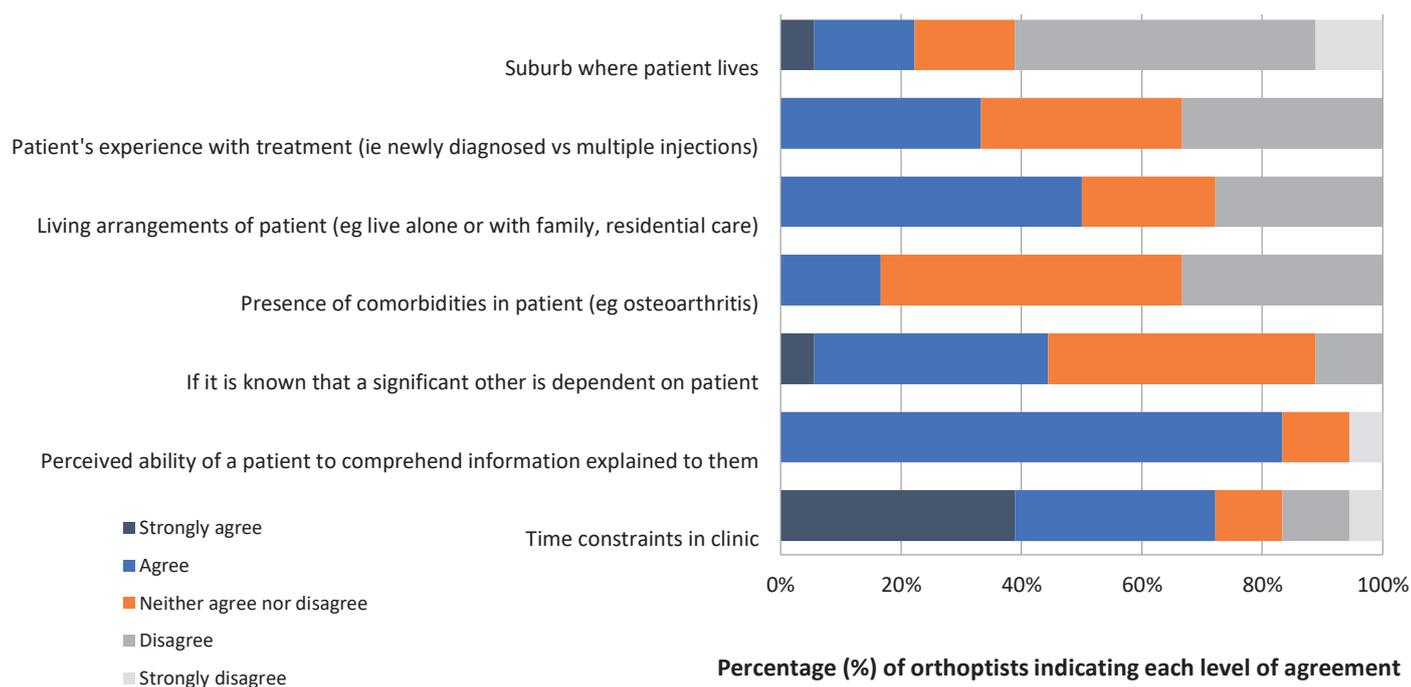
**Figure 2.** Frequency of referral of patients with nvAMD to low vision services by orthoptists.

**Table 6. Barriers to the referral of patients to low vision services**

Type of barrier	Examples	Number of survey respondents who identified this as a perceived barrier
Practical	Time constraints in clinic	5
	Possibility of interruption to clinic flow	1
	Some referral pads supplied are designed for ophthalmologist or optometrist referral	1
	Lack of referral pads or brochures in clinic	1
Knowledge based	Lack of knowledge about low vision organisations available to patients	2
	Lack of knowledge around the types of services that different low vision organisations offer to patients	1
	Lack of guidelines around how to identify patients who could benefit from such services	1
Patient factors	Accessibility/location issues	2
	Consideration for burden placed on relatives or carers to provide transport or accompaniment	1
	Patient has already trialled service and it did not benefit them	1
	Patient managing okay without the need for low vision aid	1
	Perception that more appointments would not be welcomed by patient	1
Clinical protocol	Not current practice protocol	1
	Perception that it is the responsibility of the ophthalmologist to refer patients to low vision services if necessary	1
Other	Patient must first indicate to clinician that they are experiencing difficulty in undertaking activities of daily living before referral is initiated	1
	Perception that it is the preference of the patient to speak with their ophthalmologist about such services, over other eye care providers	1

**Table 7. Recommendations for how barriers to the referral of patients to low vision services might be improved or resolved**

Type of barrier	Recommendation/s
Practical	Change in workload/more staff
	Easier referral process
Knowledge based	Establish guidelines that clinicians can use to identify patients who could benefit from service
	Educate clinicians as to low vision services available (eg low vision up-skill for orthoptists and ophthalmologists)
	Clinicians to undertake self-directed research into the organisations and services available to patients in order to be able to better inform patients
Patient factors	At-home low vision assessment
Clinical protocol	Greater liaison with ophthalmologists – if doctor allows orthoptist to suggest referrals then this needs to be communicated. If the doctor would like the decision of referral to rest with them, but would like the orthoptist to talk to the patient/provide information then there needs to be a method of communicating this in the patient notes.



**Figure 3.**

Level of agreement as to whether certain factors influence orthoptists when considering referring a patient to a patient support group or low vision service.

## DISCUSSION

This study investigated the experiences of patients undergoing repeated intravitreal injections for neovascular AMD in relation to patient education. It also explored issues surrounding the provision of information to patients regarding low vision services and AMD support groups from the perspective of orthoptists.

To date, only a few studies have investigated the perceptions of patients undergoing treatment for neovascular AMD with respect to the provision of educational information.<sup>18,19</sup> These studies have reported that patients lack information relating to the treatment procedure, expected visual outcomes, ocular assessment and the natural history of AMD.<sup>18,19</sup> The generalisability of these findings was limited however, owing to small sample size and almost all participants being treatment-naïve at enrolment. Furthermore, participants were recruited from only one practice location in each of these studies. As such, some of the issues surrounding patient education may have been specific to the clinic where participants were recruited from. Our study has added to the scarce research in this area and extended the applicability of previous findings in that it incorporated a larger number of participants who were recruited from both a public and private clinic.

Overall, this study found that patient satisfaction in relation to the provision of educational information varied. Many

patients felt inadequately informed about AMD and its treatment. This finding was congruent with the results of previous studies.<sup>18,19</sup> A trend was observed in our study whereby satisfaction was higher in private patients than public patients. Public patients also reported that they felt the need to probe specialists for information and ask questions, or else limited information would be provided. This has not been explored in previous research owing to a lack of sub-groups.

Visual information in the form of OCT feedback was perceived by most patients to be a useful adjunct to any verbal information conveyed by their specialist and facilitated their understanding of their treatment. However, discrepancies were found to exist with respect to the frequency with which patients were shown their OCT scan. Most private patients reported being shown their OCT scan regularly. In comparison, few public patients reported having been shown their OCT scan. This was thought to contribute to public patients' feelings of relative exclusion from the treatment decision-making process. The usefulness of OCT feedback provided was dependent upon adequate explanation of the scan by the treating physician, the patient's level of vision and whether or not topical mydriatics had been instilled. Previous studies have not reported on the impact of receiving OCT feedback on patients' understanding of treatment in this clinical population.

This study also revealed a significant lack of patient

awareness regarding low vision services and support groups, irrespective of whether patients were treated in the public or private setting. A minority of patients had utilised a low vision service in the past and only one patient had previously enrolled in a patient support group. Amongst these patients, knowledge of the service was typically first gained through a family member or district nurse and not their treating eye specialist. Factors influencing the uptake of low vision rehabilitation services and patient support groups, as identified by patients included: timing of referral, financial outlay, perceived benefit/s, and accessibility. Whilst no study to date has explored the barriers preventing the uptake of patient support groups in this clinical population, these findings were consistent with previous studies investigating factors influencing the uptake of low vision rehabilitation services by patients.<sup>21,24</sup>

This study was the first to investigate issues surrounding the provision of information to patients regarding low vision services and support groups according to orthoptists. Referral rates were low. Of those orthoptists surveyed, 67% indicated that they never refer patients to patient support groups and 33% indicated that they never refer patients to low vision services. Barriers to the referral of patients to low vision services and patient support groups, as identified by orthoptists included: practical factors (eg clinic time constraints), knowledge-based factors (eg lack of clinician awareness), patient factors (eg perception that the service will not be of benefit to patient) and clinical protocol. Suggestions to improve these barriers included: a more simplified referral process, greater education and training for orthoptists, and a change to existing clinical protocol which would see orthoptists enlisted with greater responsibility in terms of referring patients.

A limitation of this study was that the response rate amongst ophthalmologists was poor ( $n = 1$ ) and consequently, this precluded data analysis. The low response rate of ophthalmologists was thought to be owing to these individuals being time-poor and therefore less inclined to participate. Also, only a small number of orthoptists participated in this research. The researchers chose to evaluate the perceptions of eye health care professionals by way of electronic survey as it was thought that this would yield a higher response rate than a more in-depth approach, such as one-on-one interviewing, especially given that these professionals are typically time-poor.

Whilst the development of the electronic survey was informed by the patient interview data, the survey used was not psychometrically validated. At present, there is a lack of validated tools available to assess the perceptions of eye health care professionals with respect to patient education and issues affecting the referral of patients to support services. Finally, this study did not include patients who were non-English speaking. All patients needed to be English speaking in order to participate in the in-depth

interviews conducted as part of this research. However, non-English speaking patients are often subject to significant barriers with respect to patient education and language barrier can prohibit the uptake of low vision services. This is an important consideration for future research.

## CONCLUSION

Intravitreal anti-VEGF therapy represents the current treatment method of choice for neovascular AMD. Despite treatment adherence typically being high in this clinical population,<sup>13</sup> many patients report receiving inadequate information in relation to their treatment, especially those in the public setting. This contributes to them feeling uninformed and not included in the treatment decision-making process. Effective patient education has been shown to reduce procedural anxiety in patients undergoing other ophthalmic procedures, such as cataract surgery.<sup>14,15</sup> Pre-treatment anxiety is common in patients receiving anti-VEGF treatment<sup>15,18,19</sup> and strategies to improve patient education may help lessen this, especially given that the main reasons contributing to anxiety in these patients are a fear of the unknown and unfamiliarity with the treatment procedure.<sup>15,19</sup> Improving patient education by increasing the quality and quantity of information provided and upskilling clinicians in their knowledge of patient services may help to increase patient awareness of ancillary services available, such as low vision rehabilitation and patient support groups. This, in turn, may assist patients to better manage their eye condition and its treatment. Despite being largely under-utilised, such services may be of benefit to patients with AMD in coping with anti-VEGF therapy and the ongoing, burdensome treatment protocol.

## ACKNOWLEDGEMENTS

This work was supported by an investigator-initiated research grant from Bayer Australia Ltd, an Orthoptics Australia (Victorian Branch) Small Project Research Grant and a La Trobe University Postgraduate Support Grant. This research was carried out whilst the first author was the recipient holder of a La Trobe University Postgraduate Research Scholarship. The authors do not have any financial interest in the material presented.

The authors would like to acknowledge Eye Surgery Associates and The Royal Victorian Eye and Ear Hospital, Melbourne for allowing us to recruit participants, as well as the Centre for Eye Research Australia. Thank you to the patients and eye care professionals who participated in this study and gave of their time to share their experiences and perceptions for the benefit of others.

## REFERENCES

1. Macular Disease Foundation Australia. About Macular Degeneration; 2018 [cited 2019 17th Mar] Available from: <https://www.mdfoundation.com.au/content/what-is-macular-degeneration>.
2. World Health Organization. Blindness and vision impairment prevention: Priority eye diseases; 2019 [cited 2019 12th April] Available from: <http://www.who.int/blindness/causes/priority/en/index7.html>.
3. Jonas JB. Global prevalence of age-related macular degeneration. *Lancet Glob Health* 2014;2(2):65-66.
4. Kanski JJ, Bowling B. *Clinical Ophthalmology: a systematic approach*. 7th Ed. Edinburgh: Elsevier; 2011.
5. Bright Focus Foundation. Age-related macular degeneration: facts and figures; 2016 [cited 2018 12th Dec] Available from: <http://www.brightfocus.org/macular/article/age-related-macular-facts-figures>.
6. Busbee BG, Ho AC, Brown DM, et al. Twelve-month efficacy and safety of 0.5 mg or 2.0 mg ranibizumab in patients with subfoveal neovascular age-related macular degeneration. *Ophthalmology* 2013;120(5):1046-1056.
7. Brown DM, Kaiser PK, Michels M, et al. Ranibizumab versus verteporfin for neovascular age-related macular degeneration. *N Eng J Med* 2006;355(14):1432-1444.
8. Rosenfeld PJ, Brown DM, Heier JS, et al. Ranibizumab for neovascular age-related macular degeneration. *N Eng J Med* 2006;355(14):1419-1431.
9. Chakravarthy U, Harding SP, Rogers CA, et al. Ranibizumab versus bevacizumab to treat neovascular age-related macular degeneration: one-year findings from the IVAN randomized trial. *Ophthalmology* 2012;119(7):1399-1411.
10. Regillo CD. Anti-VEGF maintenance therapy for neovascular AMD. *Ret Today* 2014;9(4):63-67.
11. Royal College of Ophthalmologists. *Age-related macular degeneration: guidelines for management*. London: The Royal College of Ophthalmologists; 2013.
12. Polat O, Inan S, Ozcan S, et al. Factors affecting compliance to intravitreal anti-vascular endothelial growth factor therapy in patients with age-related macular degeneration. *Turk J Ophthalmol* 2017;47(4):205-210.
13. Droege KM, Muether PS, Hermann MM, et al. Adherence to ranibizumab treatment for neovascular age-related macular degeneration in real life. *Graefes Arch Clin Exp Ophthalmol* 2013;251(5):1281-1284.
14. Boyle J, Vukicevic M, Koklanis K, Itsiopoulos C. Experiences of patients undergoing anti-VEGF treatment for neovascular age-related macular degeneration: A systematic review. *Psychol Health Med* 2015;20(3):296-310.
15. Boyle J, Vukicevic M, Koklanis K, et al. Experiences of patients undergoing repeated intravitreal anti-VEGF injections for neovascular AMD. *Psychol Health Med* 2018;23(2):127-140.
16. Morrell G. Effect of structured pre-operative teaching on anxiety levels of patients scheduled for cataract surgery. *Insight* 2001;26(1):4-9.
17. Pager CK. Randomised controlled trial of preoperative information to improve satisfaction with cataract surgery. *Br J Ophthalmol* 2005;89(1):10-13.
18. Henriksen K, Adhami S. Patient experience of intravitreal injections in AMD. *Int J Ophthalmic Practice* 2010;1(2):68-72.
19. Thetford C, Hodge S, Harding S, et al. Living with age-related macular degeneration treatment: patient experiences of being treated with ranibizumab (Lucentis) intravitreal injections. *Br J Vis Impair* 2013;31(2):89-101.
20. Pollard TL, Simpson JA, Lamoureux EL, Keeffe JE. Barriers to accessing low vision services. *Ophthalmic Physiol Opt* 2003;23(4):321-327.
21. Matti AI, Pesudovs K, Daly A, et al. Access to low vision rehabilitation services: barriers and enablers. *Clin Exp Optom* 2011;94(2):181-186.
22. Walter C, Althouse R, Humble H, et al. West Virginia survey of visual health: low vision and barriers to access. *Vis Impair Res* 2004;6(1):53-71.
23. Southall K, Wittich W. Barriers to low vision rehabilitation: a qualitative approach. *J Vis Impair Blind* 2012;106(5):261-274.
24. Lim HY, O'Connor PM, Keeffe JE. Low vision services provided by optometrists in Victoria, Australia. *Clin Exp Ophthalmol* 2008;91(2):177-182.
25. Charmaz K. *Constructing grounded theory*. 2nd Ed. London: SAGE Publications Ltd; 2014.