E.8 Information

E.8.1 Barriers and facilitators to appointment attendance and update of treatment for people with age-related macular degeneration

RQ17: What are the barriers and facilitators to appointment attendance and uptake of treatment for people with AMD?

Bibliographic reference	Boulanger-Scemama E, Querques G, About F, Puche N, Srour M, Mane V, Massamba N, Canoui-Poitrine F, and Souied E H. 2015. "Ranibizumab for exudative age-related macular degeneration: A five year study of adherence to follow-up in a real-life setting". Journal Francais d Opthalmologie 38:620-7.
Country/ies where the study was carried out	Creteil University, France
Study type:	Retrospective review the charts of all consecutive patients with exudative AMD who underwent their first ranibizumab injection, and a 7-item multiple-choice questionnaire was to be completed by patients who had not attended a follow-up visit for more than 6 months
Aim of the study:	To analyse adherence to follow-up over 5 years in patients treated with intravitreal ranibizumab for exudative age-related macular degeneration (AMD) in a tertiary health care centre.
Study dates:	1st October 2006 and 31st March 2012
Source of funding	Not reported
Sample size	58
Inclusion criteria	Patients with exudative age-related macular degeneration who underwent their first ranibizumab.
Exclusion criteria	Patients with choroidal neovascularisation resulting from conditions other than AMD were excluded.
Participants chacteristics	Baseline characteristics: the following characteristics were recorded for each patient: gender, previous treatment, opposite eye involvement, best corrected visual acuity at baseline and follow-up visit, number of visits and number of ranibizumab injection over the follow-up and distance from home to hospital
Methods	All eligible patients were followed up and those who had not attended a follow-up visit for more than 6 months at the final observation were considered to be lost to follow-up. A phone surgery then was conducted to establish patients' actual follow-up status and reasons for discontinuation. Those who were contactable were asked to complete a 7- item multiple-choice questionnaire. The questionnaire was also sent by mail to each patient. When no response was obtained either by phone or by mail, follow-up status was considered as unknown.
	Questionnaire: which of the following reasons for dropping out of follow-up applies to you?
	Answer items:
	General comorbidities
	Social isolation

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Bibliographic reference	Boulanger-Scemama E, Querques G, About F, Puche N, Srour M, Mane V, Massamba N, Canoui-Poitrine F, and Souied E H. 2015. "Ranibizumab for exudative age-related macular degeneration: A five year study of adherence to follow-up in a real-life setting". Journal Francais d Opthalmologie 38:620-7.
	Financial burden
	Burden of periodic follow-up visit
	Subjective dissatisfaction with IVT benefit
	IVT intolerance
	Long distance from home to hospital
	"Yes" or "no" were possible for each item
Results: barriers to adherence appointment attendance and uptake of treatment	A total of 58 patients completed the 7-item questionnaire either by phone or by mail, and the mail reasons for follow-up discontinuation were:

Reasons for discontinuation	Percentage of patients reported
Long distance from home to hospital	51.7% (n=30)
Subjective dissatisfaction with IVT benefit	34.5% (n=20)
Burden of periodic follow-up visits	24.1% (n=14)
Financial burden	8.6%
Social isolation	5.2%
General comorbidities	1.7%
IVT intolerance	0.0%

Results: facilitators to adherence appointment attendance and uptake of treatment	None given

Bibliographic reference	Burton Amy E, Shaw Rachel, and Gibson Jonathan. 2013. "Experiences of patients with age-related macular degeneration receiving anti-vascular endothelial growth factor therapy: A qualitative study". British Journal of Visual Impairment 31:178-188.
Country/ies where the study was carried out	UK
Study type	Interpretative phenomenological study
Aim of the study:	To investigate the subjective experiences of patients with anti-VEGF injections.

Bibliographic reference	Burton Amy E, Shaw Rachel, and Gibson Jonathan. 2013. "Experiences of patients with age-related macular degeneration receiving anti-vascular endothelial growth factor therapy: A qualitative study". British Journal of Visual Impairment 31:178-188.
Study dates	Recruitment May and July 2010, and interviews were conducted over 18 months.
Source of funding	The Aston Research centre for healthy ageing, Aston University
Sample size	7
Inclusion criteria	Patients with wet age-related macular degeneration amenable to treatment
Exclusion criteria	Not reported
Participants chacteristics	Sample characteristics: Average age of participants was 82 years older, ranging from 75 to 89 years. 2 were male. 2 participants had wet AMD in both of their eyes; 3 participants had wet AMD in one eye and dry AMD in other eye; and the other 2 participants had wet AMD in one eye and no AMD in the other eye.
Methods	Face to face interviews which lasted between 1 and 2.5 hours, were completed at 3 time points over 18 months. The first interview was completed as soon after recruitment as possible, the second at 9 months post-recruitment, and the third at 18 months post recruitment.
	Initial interviews were based on a semi-structured schedule, which included questions about experience of diagnosis, impacts on daily activities, relationships with family and friends, and thoughts about the future. Later interviews began with the open question "how have things been since the last time we met" in order to expand upon previous accounts and ensure that interviews were led by participant experience.
	A thematic account of the participants' experience was produced using interpretive phenomenological analysis.
Thematic analysis: barriers to adherence appointment attendance and uptake of treatment	Imagination of treatment could be more distressing than the reality is an important issue that patients may decline treatment due to fear.
	Communication:
	1. Hospital appointments involving multiple tests and interactions with a variety of health-care professionals could be confusing;
	"I didn't see the reason why there were so many different people that I had to go and see individually, I mean the same nurse could have come and done, put...the injection in my arm, she could have come and took it out, you were going from one place to another, and you waited, another place to another, then you waited, another place to another you waited...when I asked, for someone to come and take this [needle] out at the end, one young lady came and she took my blood pressure. I'd finished the, and I said 'are you going to take this?' 'no you'll have to wait for a nurse'.
	2. Not having enough information to provide informed consent for treatment;
	"It seemed like they were photographing my eyes, there was a flash, I presume that was it. Because jokingly, I said what was that and I said well you could have said smile like you know and she looked at me as if I'm barmy...But then I went to, I think it was about 4 or 5 different places, which , well they know what they're doing. It's no use me arguing about it is it?"
	3. Problems with hospital appointment letters, which give little information about what each appointment was for and what the patients should expect;

Bibliographic reference	Burton Amy E, Shaw Rachel, and Gibson Jonathan. 2013. "Experiences of patients with age-related macular degeneration receiving anti-vascular endothelial growth factor therapy: A qualitative study". British Journal of Visual Impairment 31:178-188.
	"When I read all this (in the letters)…I thought they've sent me all these {appointments} all at once, having they slipped up? Which one am I supposed to have? Because I know they do slip up at hospitals because at the orthopaedic hospital, they sent me a, the follow up of what the scans going to be before I had and appointment for the scan!"

Participants were unsure about when their treatment cycle would end, and there were examples of patient attempting to make their own judgement about the need for treatment. |
| Thematic analysis:

facilitators to adherence appointment attendance and uptake of treatment | Prior knowledge and experience to ease anxiety, fear and uncertainty during treatment.

"On the last treatment…there was (an) older lady…there was her husband and she was… (nervous) like you know, obviously…they said, 'what's it like', and I said, 'your first one?'…I'd had two or three, and I said, 'no, there is no pain' I said, and 'I said there's no need to worry, no pain, definitely no pain'…she went in before me and when she come out her husband went, 'thanks', I said 'it's alright, it's no problem', and you know, I'm glad I could have put someone at ease,"

Relationship with service providers as a way to manage the distress treatment caused.

"It is scary going in to hospital, it is, so when you get to know all the staff and the staff know you, and it is, and they are all, I don't know how many people who's hand I've held, because they all do that, I might tell you, it is very very good, because when the initial thing goes, the needle is there, you do, and you grip you know? And so it mightn't sound much when the nurses do it but it is very important, very important, because you do grab the hand, I mean, it doesn't last for long but it's quite scary."

Patients preferred appointment that exemplified balanced relationship, mutual respect, and professional friendship and that left them feeling empowered about decision they could make regarding treatment management of their condition. |

Bibliographic reference	Burton A E, Shaw R L, and Gibson J M. 2013. "'I'd like to know what causes it, you know, anything I've done?' Are we meeting the information and support needs of patients with macular degeneration? A qualitative study". BMJ Open 3:e003306.
Country/ies where the study was carried out	UK NHS
Study type:	Interpretative phenomenological study
Aim of the study:	To examine patients' experience of information and support for age-related macular degeneration.
Study dates	2010
Source of funding:	The Aston Research centre for healthy ageing, Aston University
Sample size	13
Inclusion criteria:	patients with age-related macular degeneration and were capable of taking part in in-depth interviews

Bibliographic reference	Burton A E, Shaw R L, and Gibson J M. 2013. "'I'd like to know what causes it, you know, anything I've done?' Are we meeting the information and support needs of patients with macular degeneration? A qualitative study". BMJ Open 3:e003306.
Exclusion criteria:	Not reported
Participants characteristics	Sample characteristics: participant ages ranged from 75 to 89 with a mean age of 81.5. Best eye visual acuity ranged from 6/6 to 6/30 while worse eye visual acuity ranged from 6/9.5 to hand movement only. Seven of the participants were eligible for treatment and six were unable to be treated (two due to having dry AMD and three had wet AMD which was too advanced for treatment).
Methods	In-depth semi-structured interviews were used to explore issues which were important to participants in their own words.
	The interview schedule included questions focusing on experience of diagnosis and other eye care consultations, the impact of AMD and related vision impairment on daily activities, relationships with and/or support needs from family and friends, and thoughts about the future.
	Perceptions and experience can change over time and interviews were therefore carried out with each participant on up to three occasions over 18 months to explore perceptions of on-going encounters with healthcare professionals during this time.
	Analysis was conducted guided by the thematic analyses.
Thematic analysis: barriers to adherence appointment attendance and uptake of treatment	Source of information: For those being treated for AMD the number of appointment, letters sent were overwhelming and confusing. In addition, the wait for information through letters could be frustrating time for patients.
	"I've got to go next month. So, whether they'll [treat] the one eye today and then do the other one next month, I don't know."
	Some leaflets given by the hospital were unread and forgotten about;
	A wide variety of information deficits following diagnosis was evident in the accounts: the cause of AMD, reasons for medical process and procedures, vitamins, registering as partially sighted, impact of smoking, foods for eye health and activities they should or should not pursue.
	A lack of knowledge about the purpose of medical process and procedures. For example, letters were often unclear about the purpose of appointments. In addition during long3-4hour appointment patients were not made aware of the purpose of scan and other procedures.
	Few participants were aware of the support services available to them.
Thematic analysis: facilitators to adherence appointment attendance and uptake of treatment	Half of participants expressed a desire for regular monitoring by healthcare professionals (a sense of security knowing that they were under the care of the hospital)
	Self-advocacy: 8 participants highlighted the need to self-advocacy (they were expected to identify advancing vision loss and seek the appropriate support as and when it was necessary. Most did not feel they were adequately informed to identify any 'big changes' in vision that warranted a return to the hospital.

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Bibliographic reference	Droege K M, Muether P S, Hermann M M, Caramoy A, Viebahn U, Kirchhof B, and Fauser S. 2013. "Adherence to ranibizumab treatment for neovascular age-related macular degeneration in real life". Graefes Archive for Clinical & Experimental Ophthalmology 251:1281-4.
Country/ies where the study was carried out	Cologne University hospital, German
Study type	A survey of patients' adherence to ranibizumab treatment
Aim of the study	To identify factors and problems influencing treatment adherence in patients undergoing anti-VEGF therapy for neovascular age-related macular degeneration (AMD) under real-life conditions.
Study dates	Published 2013
Source of funding	Not specified
Sample size	95
Inclusion criteria	patients treated with rainbizumab for exudative age-related macular degeneration with full cover of health insurance for ranibizumab treatment
Exclusion criteria	Not reported

Participants characteristics

Baseline characteristics: 42 men and 53 women were included in the study.

	Adherent	Dropout (loss of motivation)	Dropout (other reasons)
Number of patients (%)	77 (81.1)	7 (7.3)	11 (11.6)
Number of male	37	1	4
Mean age (SD), years	77.8 (7.4)	83.7 (10.0)	82.6 (8.6)
Follow-up time (days) (SD)	753 (128)	263 (83)	392 (287)
Number of ranibizumab injections (SD)	11.4 (5.1)	5.0 (1.4)	7.0 (4.6)
Number of visits (SD)	21.4 (4.1)	7.6 (2.1)	11.1 (7.3)
BCVA change at last visit, letter (SD)	-5.1 (17.6)	-12.1 (21.2)	-6.6 (19.0)

Methods	Patients treated with rainbizumab for exudative age-related macular degeneration were followed up and asked to respond to a 16-item questionnaire regarding anxiety, benefit and administrative factors of treatment. The questionnaire was pretested in 5 AMD patients for internal validation. The questionnaire was administrated by 2 study nurses.

Results: barriers to adherence appointment attendance and uptake of treatment

18 patients stopped visits for the following reasons

Reasons for discontinuation	Details	No. of patients
Loss motivation	Withdrew from further treatment due to subjective dissatisfaction	7
Other reasons	Serious general disease	3

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	Droege K M, Muether P S, Hermann M M, Caramoy A, Viebahn U, Kirchhof B, and Fauser S. 2013. "Adherence to ranibizumab treatment for neovascular age-related macular degeneration in real life". Graefes Archive for Clinical & Experimental Ophthalmology 251:1281-4.	
Bibliographic reference		
	Chosen treatment option closer to home	5
	No further anti-VEGF due to fibrosis	2
	Death	2
Results: facilitators to adherence appointment attendance and uptake of treatment	None given	
Problems associated with treatment	Most patients were anxious about examination results regarding disease activities (62.1%), whereas only 19.0% of patients were afraid of IVIs	

Anxiety and pain	% of participants reported
I was afraid of the first intravitreal injection	32.6% mostly true
I was afraid of subsequent intravitreal injection	63.2% definitely false
My fear of intravitreal injection decreased in the further course of treatment	41.1% definitely true
I was afraid of examination results regarding disease activity	34.7% mostly true
I experienced intravitreal injection as painful	48.4% definitely false
Benefit	
I have benefit from treatment	53.7% definitely true
My visual acuity would probably be worse without treatment today	70.5% definitely true
My expectations regarding treatment have generally been met	43.2% mostly true
I would undergo treatment again if I had to choose again	93.7% mostly true
Insurance	
Cost of treatment was reimbursed by health insurance	74.7% definitely true
Advance payment for treatment was a financial burden	52.6% definitely false
I have general problem with my health insurance regarding treatment approval and refunds	85.3% definitely false
Other factors	
The frequency of monthly visit was arduous	64.2% definitely false
Examinations and treatment were impeded by my general health	69.5% definitely false

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Bibliographic reference	Droege K M, Muether P S, Hermann M M, Caramoy A, Viebahn U, Kirchhof B, and Fauser S. 2013. "Adherence to ranibizumab treatment for neovascular age-related macular degeneration in real life". Graefes Archive for Clinical & Experimental Ophthalmology 251:1281-4.	
	Travel to/from the hospital was generally a problem	43.2% definitely false
	I required an accompanying person for travel to/from the clinic	61.5% mostly true

Bibliographic reference	McCloud C, Khadka J, Gilhotra J S, and Pesudovs K. 2014. "Divergence in the lived experience of people with macular degeneration". Optometry & Vision Science 91:966-74.
Country/ies where the study was carried out	Australia
Study type	Interpretative phenomenological study
Aim of the study	To explore and understand the lived experiences of people diagnosed with aged-related macular degeneration including people whose treatment was successful and those whose treatment had failed to maintain vision.
Study dates:	July 2012-May 2013
Source of funding	National Health and Medical Research Council
Sample size	34
Inclusion criteria	Patients with a diagnosis of age-related macular degeneration.
Exclusion criteria	Not reported
Sample characteristics	Median age of participants was 81 years (range: 56-102). 56% were female. The majority of participants (n-28) had exudative macular degeneration and were undergoing (n=24) intravitreal injection of anti-VEGF treatment.
Methods	Participants were recruited into either a focus group (60-90 minutes) of 3 to 5 participants or to single in-depth interviews. A semi-structured interview guide was developed based on evidence from the literature and expert knowledge. Data collection ceased when conceptual saturation was achieved. Consistent with an editing analysis style of qualitative data analysis and to enable development of a sense of the whole data set, data analysis began when data collection was complete and all transcriptions were read and re-read. After this initial immersion within the data, line-by-line coding occurred with subsequent conceptual coding and theme development through an iterative movement from coding to theme using the NVivo.
Thematic analysis: barriers to adherence appointment attendance and uptake of treatment	Much of the anxiety participants felt could be attributed to the relative newness of the treatment and experience of participants where disease progressed. Participants worried about the cost of treatment relative to the improvement achieved and wondered whether they may be a criteria for withdrawal.

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Bibliographic reference	McCloud C, Khadka J, Gilhotra J S, and Pesudovs K. 2014. "Divergence in the lived experience of people with macular degeneration". Optometry & Vision Science 91:966-74.
	The invasiveness of the treatment and often painful recovery were significant issue.
	"Even though I've getting injection for three years now you still get very apprehensive when you go there for you next injection. It's not the actual fear, it's just you're apprehensive because you know what's coming".
	"I had the two injections and they were extremely painful… quite frankly I was a bit traumatised. I was in shock"
	"Two days with a lot of rubbish in your eye. Must be a shovel full of gravel in my eye I think for two days afterwards"
	The physical difficulties participants experienced with frequent and on-going treatment were often compounded by psychological issues of anxiety and fear.
	When treatment failed or was not an option as occurred with participants diagnosed with exudative AMD that progressed to geographic AMD, the stopping of treatment or inability to treat was felt as a major loss.
	"I kept going back and having these injection and now they've given up on them…I think I'd rather die [than go blind]".
	"With the dry[AMD], they can't do nothing for me, and that is what I'm upset that with wet they give you help, with dry, nothing".
Thematic analysis: facilitators to adherence appointment attendance and uptake of treatment	Optimism: a level of optimism that was felt when treatment was effective and can be further seen in the participants who responded well to treatment, and participants whose vision had not improved with treatment but had remained stable also expressed a degree of optimism.
	"It isn't treating it, it's slowing it down, it's slowing the deterioration down…"
	Despite the visual and psychological difficulties, participants expressed a clear willingness to endure the injections if they continued to gain or maintain their vision.
	"If I didn't have treatment I'd go blind, clinically blind, therefore the only thing to do was to have the injections".

Bibliographic reference	Mitchell J, Bradley P, Anderson S J, Ffytche T, and Bradley C. 2002. "Perceived quality of health care in macular disease: a survey of members of the Macular Disease Society". British Journal of Ophthalmology 86:777-81.
Country/ies where the study was carried out:	UK NHS
Study type	a survey of experience of people with macular disease
Aim of the study	To investigate the experiences of people with macular disease within the British healthcare system
Study dates	1999
Source of funding	Macular disease society and Alcon laboratories
Sample size	1421 completed questionnaires
Inclusion criteria	18 year old or over, diagnosed with macular disease for at least 6 months, and resident in the UK
Exclusion criteria	Not reported

Bibliographic reference	Mitchell J, Bradley P, Anderson S J, Ffytche T, and Bradley C. 2002. "Perceived quality of health care in macular disease: a survey of members of the Macular Disease Society". British Journal of Ophthalmology 86:777-81.
Baseline characteristics	Not specified
Methods	A questionnaire was randomly sent to 2,000 Macular Disease Society members.
Results: barriers to adherence appointment attendance and uptake of treatment	Experience at the diagnostic consultation Reasons for dissatisfaction with diagnostic consultation as below:

Reasons for dissatisfaction	Number of patients (%)
Specialist's attitude (dismissive, patronising, brusque, unfeeling, uninterested in patient/condition, use of jargon, talking to colleagues while ignoring patients, making patients fee of no consequence because of their age)	263 (43.5)
Lack of information or advice (about condition, prognosis, adjustment, low vision aids, self-help groups, counselling), lack of written information	262 (43.4)
Told nothing could be done	80 (13.1)
Problems with management (delay in getting appointment, paperwork, correspondence lost, seeing different doctors)	71 (11.7)
Shocked by what they were told	47 (7.1)
Lack of time with consultant	41 (6.9)
Discharged after consultation	34 (5.6)
Condition not named	32 (5.4)
No opportunity for questions	21 (3.5)
Wanted second opinion	11 (1.8)

Experience with general practitioners (GPs) around the time of diagnosis*

	Participants' response
To what extent was your general practitioner will informed about macular disease	185 reported that their GP was very well informed; 379 reported their GP was not at all well informed;
To what extent has your GP been helpful and supportive	About equal number reported their GP was either very supportive (383) or not at all supportive (379)

*a high proportion of non-responders to these 2 questions.

Bibliographic reference	Mitchell J, Bradley P, Anderson S J, Ffytche T, and Bradley C. 2002. "Perceived quality of health care in macular disease: a survey of members of the Macular Disease Society". British Journal of Ophthalmology 86:777-81.
Results: facilitators to adherence appointment attendance and uptake of treatment	None given

Bibliographic reference	Nunes R P, Nobrega M J, De Novelli , F J, Coral S A, Berti T B, Missen M M, and Correa M C. 2010. Causes of interruption of bevacizumab therapy in age-related macular degeneration. Arquivos Brasileiros de Oftalmologia 73:146-9.
Country/ies where the study was carried out:	Brazi
Study type	Retrospective case series
Aim of the study	To evaluate the rate and the causes of interruption of bevacizumab intravitreal therapy in patients with exudative age-related macular degeneration (AMD).
Study dates	Published 2010
Source of funding	Not specified
Sample size	19 answered to telephone questionnaire
Inclusion criteria	Patients with exudative age-related macular degeneration who were treated with one or more bevacizumab intravitreal injection.
Exclusion criteria	Not reported
Baseline characteristics	Not specified amongst participants
Methods	The causes of cessation of therapy were obtained through telephone interview. The criteria of interruption of treatment was the absence of patient follow-up after a minimum of 3 months from the last ophthalmic examination.
Results: barriers to adherence appointment attendance and uptake of treatment	82 patients were treated, and 19 answered to telephone questionnaire {{TABLE}}

Table inside last cell:

Reasons for discontinuity	Number of patients reported (%)
Unexpected poor visual results	8 (42.1)
Lack of information about follow-up visits	5 (26.3)
Comorbidities	3 (15.8)
Difficulties in booking new appointment	2 (10.5)

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Bibliographic reference	Nunes R P, Nobrega M J, De Novelli , F J, Coral S A, Berti T B, Missen M M, and Correa M C. 2010. Causes of interruption of bevacizumab therapy in age-related macular degeneration. Arquivos Brasileiros de Oftalmologia 73:146-9.
	Travelling problem	1 (5.3)
Results: facilitators to adherence appointment attendance and uptake of treatment	None given

Bibliographic reference	Thompson A C, Thompson M O, Young D L, Lin R C, Sanislo S R, Moshfeghi D M, and Singh K. 2015. "Barriers to Follow-Up and Strategies to Improve Adherence to Appointments for Care of Chronic Eye Diseases". Investigative Ophthalmology & Visual Science 56:4324-31.
Country/ies where the study was carried out	USA
Study type	A cross sectional of survey of individuals attending follow-up ophthalmology appointments
Aim of the study	To understand factors associated with poor attendance of follow-up appointments for care of glaucoma (GL), age-related macular degeneration (AMD), and diabetic retinopathy (DR) in a tertiary referral centre, and to identify strategies to improve adherence.
Study dates	2009
Source of funding	The Stanford Medical Scholars Programme
Sample size	240 participants (84 were with age-related macular degeneration)
Inclusion criteria	Individuals aged 18 years or over and a medical record that documented treatment for a diagnosis of GL, AMD or DR at least 12 months.
Exclusion criteria	Individuals were excluded if they were a new referral or had more than one of the aforementioned diseases

Participants characteristics

	Follow-up, n(%)		Un adjusted odd ratios (95%CI) for poor follow-up
	Poor 102 (42.5)	Good 138 (57.5)	
AMD	29 (28.4)	57 (41.3)	1.17 (0.50, 2.87)
DR	10 (9.8)	23 (16.7)	1 (reference)
Duration of eye disease, median year (range)	6 (1-50)	6 (1-55)	
Mean age (SD)	70.5 (14.3)	72.2 (14.7)	

Bibliographic reference	Thompson A C, Thompson M O, Young D L, Lin R C, Sanislo S R, Moshfeghi D M, and Singh K. 2015. "Barriers to Follow-Up and Strategies to Improve Adherence to Appointments for Care of Chronic Eye Diseases". Investigative Ophthalmology & Visual Science 56:4324-31.		
	Male	47 (46.1)	63 (45.7)	
	Education level			
	High school or less	24 (23.3)	32 (23.2)	1.02 (0.55, 1.86)
	College/graduate degree	78 (76.5)	106 (76.8)	1 (reference)
	Employment			
	Working	18 (17.65)	33 (23.9)	0.68 (0.35, 1.28)
	Not working	84 (82.25)	105(76.1)	1 (reference)

Methods	A cross sectional study of 240 individual's follow-up ophthalmology appointment. Upon arrival for their eye appointment, eligible subjects were invited for a private oral interview by one or two trained study investigator.
	Participants were categorised as cases of poor follow-up if at any time in the 12 months proceeding their oral interview, they had failed to reschedule a missed or patient-cancelled appointment within 1 month of the desired follow-up.
	Data were collected form patients interviews and chart review using a validated questionnaire on barriers to follow-up, strategies to improve follow-up, disease knowledge, and perceptions that may impact follow-up patterns.

Results: barriers to adherence appointment attendance and uptake of treatment		Follow-up, n (%)		Unadjusted Odd ratios for poor follow-up(95%CI)
	Self-reported barriers to follow-up	Poor 102 (42.5)	Good 138 (57.5)	
	Long wait time			
	Yes	53 (52.0)	51 (37.0)	1.85 (1.1, 3.1)
	No	49 (48.0)	87 (63.0)	1 (reference)
	Difficulty rescheduling			
	Yes	38 (37.3)	37 (26.8)	1.62 (0.93, 2.81)
	No	64 (62.8)	101 (73.2)	1 (reference)
	Financial barriers			
	Yes	26 (25.5)	21 (15.2)	1.91 (1.00, 3.66)
	No	76 (74.5)	117 (84.8)	1 (reference)
	Work responsibilities			
	Yes	12 (11.8)	9 (6.5)	1.91 (0.78, 4.9)

Bibliographic reference	Thompson A C, Thompson M O, Young D L, Lin R C, Sanislo S R, Moshfeghi D M, and Singh K. 2015. "Barriers to Follow-Up and Strategies to Improve Adherence to Appointments for Care of Chronic Eye Diseases". Investigative Ophthalmology & Visual Science 56:4324-31.		
	No	90 (88.2)	129 (93.4)	1 (reference)
	Other medical/physical illness			
	Yes	24 (23.5)	25 (19.6)	1.39 (0.74, 2.6)
	No	78 (76.5)	113 (81.9)	1 (reference)
	Lack of an escort			
	Yes	22 (21.6)	27 (19.6)	1.13 (0.60, 2.12)
	No	80 (78.4)	111 (80.4)	1 (reference)

Results: facilitators to adherence appointment attendance and uptake of treatment	Patient reported potential strategies to improve attendance of follow-up appointments	
		N (%), 240 (100)
	Pre-appointment reminder (by phone, text, email)	196 (81.7)
	Parking vouchers	115 (47.9)
	Transportation service to and from the clinic	107 (44.6)
	Mobile eye care van	77 (32.1)
	Networking with other patients with the same eye disease	99 (41.3)
	More education on one's eye disease	98 (40.8)
	More education on the importance of follow-up	72 (30.0)

Bibliographic reference	Varano Monica, Eter Nicole, Winyard Steve, Wittrup-Jensen Kim U, Navarro Rafael, and Heraghty Julie. 2015. Current barriers to treatment for wet age-related macular degeneration (wAMD): findings from the wAMD patient and caregiver survey. Clinical Ophthalmology 9:2243-50.
Country/ies where the study was carried out	9 countries (Australia, Brazil, Canada, France, Germany, Italy, Japan, Spain, and UK)
Study type	Cross-sectional survey
Aim of the study	To evaluate the current management of wet age-related macular degeneration (wAMD) and to identify barriers to treatment from a patient/caregiver perspective.
Study dates	June 2012 and September 2012

Bibliographic reference	Varano Monica, Eter Nicole, Winyard Steve, Wittrup-Jensen Kim U, Navarro Rafael, and Heraghty Julie. 2015. Current barriers to treatment for wet age-related macular degeneration (wAMD): findings from the wAMD patient and caregiver survey. Clinical Ophthalmology 9:2243-50.
Source of funding	Bayer HealthCare Pharmaceuticals
Sample size	910 patients with AMD completed survey
Inclusion criteria	patients with wet age-related macular degeneration
Exclusion criteria	Not reported
Participant characteristics	Not specified
Methods	The survey was performed using a questionnaire. The self-administered 15-minute questionnaire was conducted online. The survey link was soft-launched, allowing a small number of responders to complete the questionnaire so that the data could be checked to ensure accurate capture. The questionnaire was divided into patient and caregiver section. Patients and caregivers were asked to provide yes/no/not sure answers based on a number of variable option or to rate question using impact scale, dependency scale or convenience scale.
Results: barriers to adherence appointment attendance and uptake of treatment	Most patients (65.4%, n=585) and caregivers (77.0%, n=685) reported a number of obstacles in managing wAMD, including: Treatment itself: having injection, frequency of injection, possible injection related side effects Treatment cost Finding the right treatment option: anti-VEGF (type, laser and related to information on choosing the best option Missing appointment: caregivers was unable to take them to the appointment; fear about receiving injection; patient illness. Other obstacles included: tired of treatment regimen; lack of understanding about disease; given inadequate disease information; getting access to/affording technology; other priorities. Obstacles to difficulty attending every appointment were reported by patients: Caregivers unable to take me to appointment Unwell or in hospital Scared about receiving an injection Sometimes forget the appointment Cannot afford to attend every appointment Appointments are too frequent/inconvenient
Results: facilitators to adherence appointment attendance and uptake of treatment	None given

Bibliographic reference	Vaze A, Fraser-Bell S, and Gillies M. 2014. Reasons for discontinuation of intravitreal vascular endothelial growth factor inhibitors in neovascular age-related macular degeneration. Retina 34:1774-1778.
Country/ies where the study was carried out	Sydney, Australia
Study type	Retrospective case series
Aim of the study	To identify the reasons for discontinuing intravitreal anti-vascular endothelial growth factor therapy in neovascular age-related macular degeneration.
Study dates	Published 2014
Source of funding	RANZCO eye foundation, Sydney and the National Health and Medical Research Council
Sample size	105 had discontinued treatment
Inclusion criteria	Patients with neovascular age-related macular degeneration began anti-VEGF treatment over the 6 years from March 2006 to June 2012
Exclusion criteria	Not reported
Participants characteristics:	Not specified
Methods	The Fight Retinal Blindness project data tracking system was used to identify accurately all patients who discontinued treatment. The reasons for discontinuation of the intravitreal anti-VEGF treatment for neovascular AMD during the study period were ascertained. The Fight Retinal Blindness data fields for treatment discontinuation include the following possibilities: Treatment being successful Further treatment being futile Patient goes to another doctor Patient declines Medically contraindicated Deceased
Results: barriers to adherence appointment attendance and uptake of treatment	A total of 105 patients discontinued treatment <table><tr><td>Reasons for discontinuity</td><td>Number of patients reported</td></tr><tr><td>Treatment stopped by the doctor because of inactive lesion</td><td>9</td></tr><tr><td>Treatment stopped by the doctor as further treatment futile</td><td>27</td></tr><tr><td>Treatment declined by the patient:</td><td>26</td></tr></table>

Bibliographic reference	Vaze A, Fraser-Bell S, and Gillies M. 2014. Reasons for discontinuation of intravitreal vascular endothelial growth factor inhibitors in neovascular age-related macular degeneration. Retina 34:1774-1778.	
		Pain/discomfort (3)
		Too frequent visits (2)
		Difficulty in attending the practice (2)
		Treatment not being perceived to be beneficial (6)
		Treatment perceived to be too expensive (2)
		Other medical condition that were more severe (11)
	Other reasons	40
		Patients were referred to another doctor locally or on-going management (27)
		Death (11)
		Complication about treatment (2)
	Missing (patients lost to follow-up)	3
Results: facilitators to adherence appointment attendance and uptake of treatment	None given	

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