Barriers to Adherence to Neovascular Age-Related Macular Degeneration and Diabetic Macular Oedema Management Plans: A Multi-national Qualitative Study

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Purpose

This study aimed to understand the current treatment experiences, satisfaction levels and drivers and barriers to adherence in neovascular age-related macular degeneration (nAMD) and diabetic macular oedema (DMO) from patients', caregivers' and retina specialists' (RSs) perspectives

Introduction

- nAMD and DMO can cause vision loss and lead to blindness if left untreated, which is associated with reduced functional status and quality of life[1,2]
- Anti–vascular endothelial growth factor (VEGF) therapies can help patients with nAMD or DMO to improve or maintain vision, but require frequent monitoring and injections
- Patients with nAMD and DMO in the real world receive fewer injections and experience worse vision outcomes than patients in clinical trials[3,4]
  - Poorer real-world outcomes are attributed in part to the difficulty of adhering to nAMD/DMO treatment management plans,[3,4] **but the critical factors for adherence remain unknown**

Methods

- One-time, 1:1, semi-structured concept elicitation interviews were conducted via telephone with:
  - Patients living with nAMD or DMO
    - Treatment initiated ≥ 12 months before screening; most recent injection was ≤ 6 months before screening
  - Caregivers of patients living with nAMD or DMO
  - Ophthalmologists with ≥ 5 years of experience, treating ≥ 30 patients with nAMD or DMO with anti-VEGF therapy over the past 12 months (RSs)
- 94 patients; 79 caregivers, including 48 patient-caregiver dyads; and 62 RSs were interviewed across the United States, Canada, France, Germany, Italy and Spain
  - Interviews were conducted by trained and experienced interviewers
  - Interviews were audio recorded, transcribed verbatim, translated into English when needed and de-identified
- Analysed using a thematic approach without a priori hypotheses to categorise emergent themes and concepts
  - MAXQDA 2020 software used; concepts that met ≥ 10% threshold are included in this presentation

Conclusions

- The **doctor-patient relationship** was the most frequently reported driver by patients; **treatment education** was reported by RSs and patients, but not caregivers; and **overall treatment effectiveness** was reported by patients, caregivers and RSs as a key driver of following the treatment management plan
- Side effects, injection fear/anxiety and frequency of visits were the key barriers for patients and caregivers
- RSs reported the top barriers to be travel logistics, comorbidities, treatment effectiveness and injection fear/anxiety
- New therapies offering improved or longer-acting effectiveness, along with enhanced patient treatment education, may improve nAMD/DMO patient adherence, increase vision outcomes and support the doctor-patient relationship/communication
- **Limitations:** (1) Non-adherent patients may be underrepresented (less likely to participate in the study); (2) Adherence was derived from patient self-report; interviews were conducted during the COVID-19 pandemic and impact of the pandemic was not captured

1. Patient, Caregiver and RSs Characteristics

A. Patient and Caregiver Sociodemographic Characteristics

Characteristic	Patients[a]		Caregivers[a]	
	nAMD (n = 49)	DMO (n = 46)	nAMD (n = 47)	DMO (n = 33)
Female, n (%)	37 (76%)	18 (39%)	32 (68%)	21 (64%)
Age, n (%)				
< 60 years	5 (10%)	22 (48%)	18 (38%)	15 (45%)
60–69 years	10 (20%)	18 (39%)	17 (36%)	15 (45%)
70–79 years	24 (49%)	5 (11%)	8 (17%)	3 (9%)
≥ 80 years	10 (20%)	1 (2%)	4 (9%)	0
Working status, n (%)				
Retired	40 (82%)	15 (33%)	21 (45%)	11 (33%)
Working full or part time	3 (6%)	15 (33%)	18 (38%)	16 (48%)
Looking after home/family	1 (2%)	2 (4%)	2 (4%)	0
Disabled	1 (2%)	8 (17%)	–	–
Unemployed/seeking work	1 (2%)	3 (7%)	2 (4%)	4 (12%)
Other	2 (4%)	1 (2%)	3 (6%)	2 (6%)
Not captured	1 (2%)	2 (4%)	1 (2%)	0
Relationship to patient, n (%)				
Partner/spouse	–	–	18 (38%)	15 (45%)
Child	–	–	17 (36%)	3 (9%)
Parent	–	–	2 (4%)	8 (24%)
Friend	–	–	4 (9%)	2 (6%)
Other	–	–	6 (13%)	5 (15%)
Living status, n (%)				
Lives with patient	–	–	24 (51%)	21 (64%)
Does not live with patient	–	–	23 (49%)	9 (27%)
Not captured	–	–	0	3 (9%)

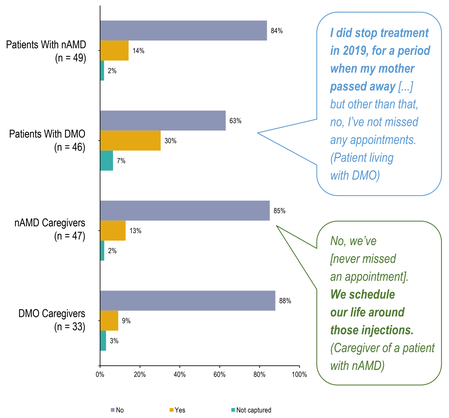
Column percentages may not add up to 100% due to rounding error.
[a] A Canadian patient was diagnosed with both nAMD and DMO and was thus counted twice, once in the nAMD group and once in the DMO group. The same was done for the patient's caregiver.
[b] Not all physicians answered all questions; inclusion criteria for ≥ 5 years of experience refers to years of practice in ophthalmology overall. [c] Physicians may have a mixed practice.
[d] Normalised per month frequency (1 month = 4 weeks = 20 days, weekends not included).
DMO, diabetic macular oedema; IVT, intravitreal; nAMD, neovascular age-related macular degeneration; RS, retina specialist; VEGF, vascular endothelial growth factor.

B. Clinical Background of RSs

Characteristic	Physicians (n = 62)	
Years practicing retinal ophthalmology specialty (or subspecialty), n (%)[b]		
< 5 years	9 (15%)	
5–10 years	12 (19%)	
11–15 years	15 (24%)	
> 15 years	25 (40%)	
Type of practice, n (%)[c]		
Hospital/public practice	38 (61%)	
Private practice	29 (47%)	
Number of patients seen monthly, n (%)[b]	**nAMD**	**DMO**
< 100	20 (32%)	40 (65%)
≥ 100	34 (55%)	13 (21%)
Anti-VEGF IVT injections per month, n (%)[b,d]		
< 100	25 (40%)	34 (55%)
≥ 100	37 (60%)	15 (24%)

2. Adherence to Treatment Management Plan

Have You/the Patient You Care for Ever Missed an Anti-VEGF Injection?



I did stop treatment in 2019, for a period when my mother passed away […] but other than that, no, I've not missed any appointments. (Patient living with DMO)

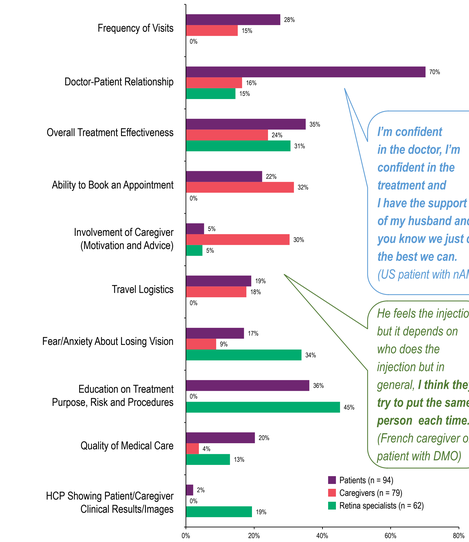
*No, we've [never missed an appointment]. **We schedule our life around those injections.*** (Caregiver of a patient with nAMD)

- 42% of RSs did not categorise the adherence of patients. Where this information was available, RSs estimated non-adherence to be between 0% and 20% for both patients with nAMD and DMO[a]
- Treatment-associated burdens were reported
  - 79% of patients and caregivers reported disruptions to their routine on the day before, the day of and/or day after the injection
  - 26% of caregivers of patients with nAMD and 39% of caregivers of patients with DMO reported the patient's treatment had a negative impact on their work attendance or required them to take time off work

[a] RSs may have considered follow-up visits or injection visits when estimating the proportion of their patients who are non-adherent; patients and caregivers were asked explicitly to consider only injection visits.
DMO, diabetic macular oedema; nAMD, neovascular age-related macular degeneration; RS, retina specialist; VEGF, vascular endothelial growth factor.

3. Drivers of Following Treatment Management Plan

- For the patients, the doctor-patient relationship was by far the most frequently reported driver (70%)
- Education on treatment was identified as a driver by 36% of patients
- For the caregivers, the ability to book appointments (32%) and involvement of caregivers (30%) were important factors
- Appointment frequency was reported as a driver by 28% of patients and 15% of caregivers
- For RSs, drivers were mostly related to patient treatment education (45%) and fear/anxiety about losing vision (34%)
- Overall treatment effectiveness was mentioned by 35% of patients, 24% of caregivers and 31% of RSs



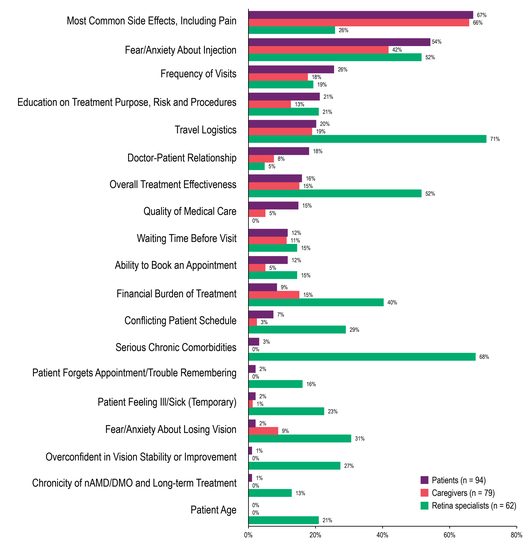
I'm confident in the doctor, I'm confident in the treatment and I have the support of my husband and you know we just do the best we can. (US patient with nAMD)

*He feels the injection, but it depends on who does the injection but in general, **I think they try to put the same person each time.*** (French caregiver of patient with DMO)

Drivers were reported if mentioned by ≥ 10% of patients/caregivers or RS.
DMO, diabetic macular oedema; HCP, healthcare provider; nAMD, neovascular age-related macular degeneration; RS, retina specialist.

4. Barriers to Following Treatment Management Plan

- Diverse barriers were identified, which could be grouped into 3 main categories:
  - **Tolerability** (pain/discomfort/irritation linked to the injection, bloodshot/red eye/bleeding, floaters/black spots, sensitivity to light)
  - **Logistical parameters** (financial burden, ability to book appointment, travel logistics, frequency of appointments)
  - **Human factors** (relationship with RS, patient education, perception of effectiveness, fear of injection)
- Reported barriers were more similar between patients and caregivers than either with RSs
- RSs mentioned other aspects, including travel logistics, comorbidities and overall treatment effectiveness



DMO, diabetic macular oedema; nAMD, neovascular age-related macular degeneration; RS, retina specialist.

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