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ORIGINAL RESEARCH

Impact of Dry Age-Related Macular Degeneration on Daily Activities and Quality of Life: Interview Findings From Patients and Caregivers Relative to a General Population

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Purpose: To investigate impacts of dry age-related macular degeneration (AMD) on patients and caregivers.

Patients and Methods: Semi-structured interviews were conducted with patients with dry AMD, caregivers, and controls (individuals without dry AMD, of similar age, sex, and comorbidity profile to patients) between March 2021 and June 2023. Patients aged ≥50 years, with a best corrected visual acuity (BCVA) score from the most recent eye exam after dry AMD diagnosis, were enrolled from the US and UK. Controls with mild visual impairment and unpaid adult caregivers of patients were also enrolled. Main outcomes were functional impairment impact on daily activities, quality of life (QoL), and mental health among patients relative to controls; dry AMD impact on patient daily activities from caregiver perspective; caregiver work productivity, QoL, and burden.

Results: Thirty patients, 20 controls, and 20 caregivers were interviewed. Patients had a mean age of 65.1 years; 63.3% were female, 83.3% were White, and 96.7% were from the US. Visual impairment based on BCVA score was mild in 70.0% and moderate to severe in 30.0% of patients. Most patients reported problems performing usual activities, whereas most controls experienced no or mild problems. More daily activities in the past month were affected by dry AMD in patients than by visual impairment in controls (mean 4.5 and 2.1), with reading, shopping, and hobbies being most commonly affected in patients. More patients than controls experienced emotional problems. Patients with moderate-to-severe visual impairment reported more impact on activities relative to those with mild visual impairment. Most caregivers were employed, with 46.2% reporting their work productivity was affected at least sometimes, and many experienced mental and emotional burdens and impacts on their daily lives.

Conclusion: Dry AMD impaired the functional ability of patients regardless of visual impairment level and posed significant burdens to caregivers.

Keywords: functional impairment, geographic atrophy, qualitative study, quality-of-life impact, visual impairment, work productivity

Introduction

Age-related macular degeneration (AMD), a severe and chronic eye disorder, is the leading cause of vision loss among adults over 55 years.[1] There were almost 8 million cases of AMD globally in 2019, and it is estimated that prevalence will keep increasing, with almost 290 million people expected to be affected by 2040.[2,3] Dry AMD, the more common form of AMD which is characterized as lacking blood or serum leakage, accounts for 85%–90% of AMD and currently cannot be cured.[1,4] However, novel therapies such as pegcetacoplan or avacincaptad pegol have received approval for treatments of the advanced geographic atrophy (GA) form of dry AMD.[5,6] Typically, symptoms of AMD result in a significant loss of independence, requiring the aid of a caregiver.[7] Consequently, as novel therapies for dry AMD continue to be developed, it is essential to

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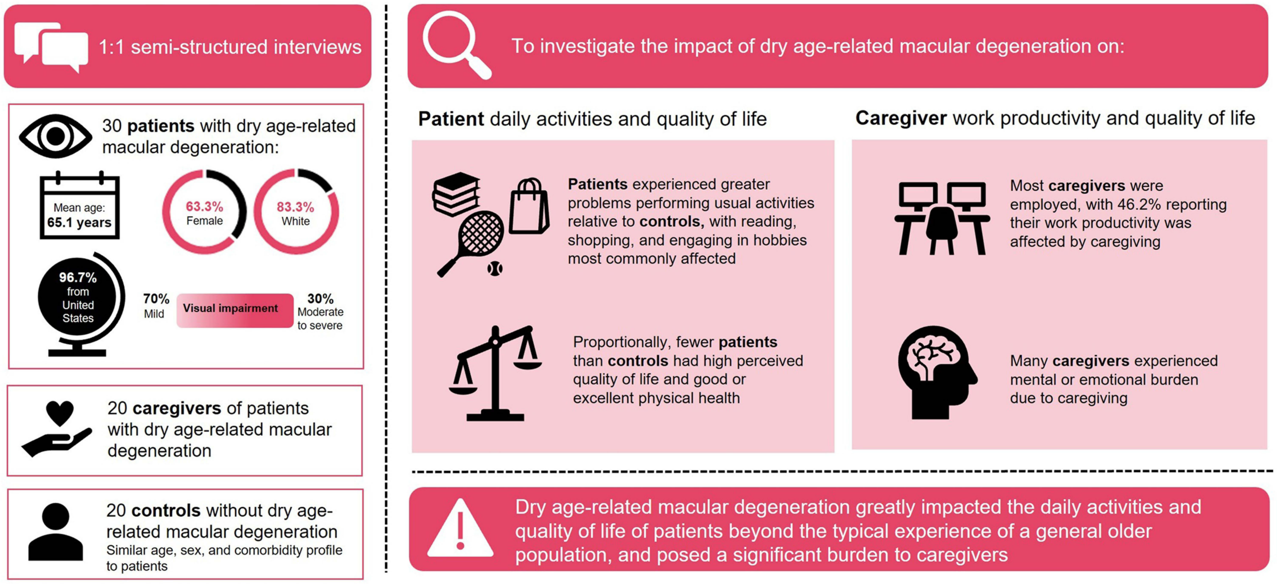
Graphical Abstract



1:1 semi-structured interviews

30 **patients** with dry age-related macular degeneration:

20 **caregivers** of patients with dry age-related macular degeneration

20 **controls** without dry age-related macular degeneration
Similar age, sex, and comorbidity profile to patients

To investigate the impact of dry age-related macular degeneration on:

Patient daily activities and quality of life

Patients experienced greater problems performing usual activities relative to **controls,** with reading, shopping, and engaging in hobbies most commonly affected

Proportionally, fewer **patients** than **controls** had high perceived quality of life and good or excellent physical health

Caregiver work productivity and quality of life

Most **caregivers** were employed, with 46.2% reporting their work productivity was affected by caregiving

Many **caregivers** experienced mental or emotional burden due to caregiving

Dry age-related macular degeneration greatly impacted the daily activities and quality of life of patients beyond the typical experience of a general older population, and posed a significant burden to caregivers

consider the United States (US) Food and Drug Administration recommendations for medical product development and regulatory decision-making, to capture and incorporate meaningful patient insights and caregiver input.[8]

Dry AMD has a considerable functional impact on patients, including their depth perception; mobility, including driving capability; ability to recognize faces; cognitive functioning; reading ability; and ability to participate in leisure activities.[9–12] Previous studies have evaluated the impact of dry AMD from the patient perspective, but none have contextualized this impact relative to visual impairment typical of an aging population without the condition or comprehensively examined the full spectrum and severity of functional impact by the level of visual impairment.[9,10,13] Moreover, dry AMD impacts patient quality of life (QoL) and particular psychosocial aspects, with studies indicating that patients experience frustration, stress, and anxiety as a result of their condition, with some unable to participate in their usual social activities.[9,14] However, real-world evidence of this impact is limited, and typically focuses on quantitative data, lacks comparator groups, is narrow in focus (ie exclusively late-stage dry AMD population), or is derived from small or localized populations.[9,14–17] Additionally, the impact of caring for patients with AMD on caregivers has been established previously in a small Australian dataset, with caregivers reporting substantial burden, fatigue, and depressive symptoms.[18] Furthermore, no studies have focused specifically on the impact of dry AMD on caregivers.

The present study sought to assess patient and caregiver perspectives on the extent to which dry AMD symptoms impact patient function, daily lives, and QoL, relative to the typical vision-related experience of older members of the general population without dry AMD. The study also aimed to assess the impact from a caregiver perspective and the burden of caring for patients with dry AMD on caregiver work productivity, daily life, and QoL.

Materials and Methods

This cross-sectional qualitative interview study was conducted from March 2021 to June 2023, and included patients with dry AMD, individuals without dry AMD (controls) of similar age, sex, and comorbidity profile as patients, and unpaid caregivers of patients with dry AMD, who spoke fluent English, primarily from the US as well as the United Kingdom (UK). Western Copernicus Group Institutional Review Board approval was obtained, and the study adhered to the tenets of the Declaration of Helsinki.

Study Design

Study design is summarized in Supplementary Figure 1. Patients were primarily recruited via clinician referral, patient panels, patient associations, and social media advertisements; controls were recruited using the same methodology as patients, where applicable. Paired caregivers were recruited after consent was provided by the corresponding patient; caregivers were also separately recruited via patient panels, associations, or social media advertisements. Participants were screened using a pre-approved screener via telephone to confirm their eligibility and obtain informed consent, including to the presentation of results in publications. Information including demographic data, comorbidities, most recent best corrected visual acuity (BCVA) score for their worse-seeing eye, and impact of vision in the last month on activities was collected during this or a second call. Age at dry AMD diagnosis and GA diagnosis status were collected from patients and caregivers, and documentation of diagnoses and BCVA score were obtained, if available.

Participants who met study inclusion criteria were invited to complete a one-hour, one-on-one double-blind interview with a moderator who was trained by Analysis Group, Inc. using semi-structured interview guides. Interviews were conducted via a teleconference service and consisted of open-ended questions, with follow-up probing questions, and close-ended questions to collect scalable data.

Interviews aimed to assess functional ability and impact on daily life (eg number, type, and extent of impaired functional activities in the past month) related to dry AMD for patients or related to visual impairment for controls. Functional ability was categorized in terms of capacity to read, drive, walk (or other forms of mobility; eg biking, public transport), perform daily activities (eg eating, cooking, paperwork), shop, engage in hobbies, socialize with friends and family, and perform self-care. Health status and QoL in the past month were also assessed for both groups.

Interviews also assessed the psychosocial impacts of dry AMD in the past month for patients. For caregivers, patient functional ability from the caregiver perspective was assessed, along with caregiver work productivity and impact on daily activities in the past week, and health status and QoL in the past month.

De-identified screening data and interview transcripts were reviewed and processed. Screener data were cleaned and summarized in the SAS Enterprise Guide (version 7.1). Interview transcripts were reviewed manually, and endpoints of interest summarized further in Excel. Interview results were pooled across both countries for each participant group (patients, controls, caregivers). For patients, findings were summarized for the overall patient group, and also by the level of visual impairment as defined by BCVA score (mild [>20/30–20/80]; moderate to severe [>20/80–20/320]). Outcomes for patients relative to controls were assessed descriptively and qualitatively, with no hypothesis testing.

Inclusion and Exclusion Criteria

Patients aged ≥50 years were included, with clinician-confirmed dry AMD diagnosis, when possible, although self-reported diagnosis was also accepted indicated during pre-approved screener in the absence of evidence of a clinician-confirmed diagnosis was also accepted in the context of the coronavirus pandemic restricting travel. A BCVA score from the most recent eye exam after diagnosis of dry AMD was required, and a documented score was requested, although self-reported was also accepted. Controls aged ≥50 years with absence of dry AMD diagnosis were selected to have similar characteristics to patients, in terms of age, sex, and comorbidity profiles. A BCVA score of 20/60 or better, indicating no or mild visual impairment, from the most recent eye exam within the past 8 years was required, and a documented score was requested, although a self-reported BCVA score provided during pre-approved screener in the absence of documentation was also accepted in the context of the coronavirus pandemic restricting travel.

Adult caregivers (aged ≥18 years) providing unpaid care (helping to complete activities that may be more difficult or not possible because of problems caused by dry AMD) for ≥3 months within the prior year for a patient aged ≥50 years with dry AMD were included.

For patients and controls, exclusion criteria included participation in an interventional clinical trial ≤3 months prior to recruitment, diagnosis of age-related eye conditions other than dry AMD that may lead to visual impairment (eg cataracts [unless the cataract was surgically treated in the previous ≥12 months prior to study recruitment], diabetic retinopathy, and glaucoma), and known diagnosis of wet AMD or receipt of regular injections into the eye (eg every 4–6 weeks), which is treatment indicative of wet AMD. All participants were excluded if they had been diagnosed with Alzheimer's disease, metastatic cancer, or other condition that may severely impair functioning. Caregivers whose patient met any of the exclusion criteria were also excluded.

Notably, this study was conducted prior to the approval and widespread use of regular treatments for GA secondary to dry AMD.[5,6]

Sample Size

In qualitative research, sample size determinations are informed by the estimated number of participants needed to achieve saturation of concept.[19] As such, the planned sample size for recruitment (30 patients, 20 controls, and 20 caregivers) was deemed sufficient for collecting the necessary data to address the study endpoints.

Results

Participant Characteristics

Participant characteristics are summarized in Table 1. Seventy participants were interviewed, including 30 patients, 20 controls, and 20 caregivers; this met the planned sample size for recruitment. The mean (standard deviation [SD]) age of patients was 65.1 (7.8) years and 63.3% were female. Overall, 83.3% of patients were White and 96.7% were from the US. In total, 80% of patients lived with first-degree family, and 50% reported that they were assisted by a caregiver. Two (6.7%) patients also reported having a GA diagnosis, 21 (70.0%) had mild visual impairment, eight (26.7%) had moderate visual impairment, and one (3.3%) had severe visual impairment. In general, controls had similar characteristics to patients with dry AMD. Thirteen (65.0%) participants had a BCVA score >20/30–20/60 and the remainder (n=7; 35.0%) had a BCVA score ≤20/30 and were classified as having "no impairment" (Table 1).

Table 1 Participant Characteristics

A) Patients and Controls

Characteristic	**Patients With Dry AMD**			**Controls (N=20)**
	Total (N=30)	**Mild Visual Impairment (N=21)**	**Moderate to Severe Visual Impairment (N=9)**	
Age, years				
Mean (SD)	65.1 (7.8)	65.0 (9.1)	65.4 (3.8)	63.4 (8.0)
Min–max	51–87	51–87	59–71	50–79
Sex, n (%)				
Female	19 (63.3)	15 (71.4)	4 (44.4)	13 (65.0)
Male	10 (33.3)	6 (28.6)	4 (44.4)	7 (35.0)
Prefer not to answer	1 (3.3)	0	1 (11.1)	0
Country, n (%)				
US	29 (96.7)	20 (95.2)	9 (100.0)	19 (95.0)
UK	1 (3.3)	1 (4.8)	0	1 (5.0)
Caregiving, n (%)				
Assisted by a caregiver	15 (50.0)	10 (47.6)	5 (55.6)	–
Caregiver included in study	7 (23.3)	5 (23.8)	2 (22.2)	–
Race/Ethnicity, n (%)				

(*Continued*)

Table 1 (Continued).

A) Patients and Controls				
Characteristic	**Patients With Dry AMD**			**Controls (N=20)**
	Total (N=30)	**Mild Visual Impairment (N=21)**	**Moderate to Severe Visual Impairment (N=9)**	
White	25 (83.3)	19 (90.5)	6 (66.7)	14 (70.0)
Other[a]	5 (16.7)	2 (9.5)	3 (33.3)	6 (30.0)
Living situation, n (%)				
With first-degree family[b]	24 (80.0)	17 (81.0)	7 (77.8)	14 (70.0)
Alone	5 (16.7)	3 (14.3)	2 (22.2)	5 (25.0)
With second-degree or other relatives, or others[c]	1 (3.3)	1 (4.8)	0	1 (5.0)
Comorbidities, n (%)				
Arthritis	10 (33.3)	6 (28.6)	4 (44.4)	5 (25.0)
Cardiovascular disease[d]	8 (26.7)	4 (19.0)	4 (44.4)	2 (10.0)
Depression	8 (26.7)	4 (19.0)	4 (44.4)	3 (15.0)
Asthma/COPD	6 (20.0)	3 (14.3)	3 (33.3)	3 (15.0)
Diabetes	6 (20.0)	5 (23.8)	1 (11.1)	4 (20.0)
Chronic kidney disease	3 (10.0)	2 (9.5)	1 (11.1)	1 (5.0)
Stroke	1 (3.3)	1 (4.8)	0	1 (5.0)
Other	6 (20.0)	2 (9.5)	4 (44.4)	2 (10.0)
None of the above	10 (33.3)	9 (42.9)	1 (11.1)	7 (35.0)
Age at first dry AMD diagnosis, years				
Mean (SD)	61.7 (7.4)	61.5 (8.3)	62.2 (5.0)	–
Min–max	51–82	51–82	53–70	–
Years since dry AMD diagnosis				
Mean (SD)	3.4 (2.8)	3.4 (2.8)	3.3 (2.8)	–
Min–max	0.4–10.7	0.4–10.7	0.5–9.7	–
BCVA score at dry AMD diagnosis, n (%)				
Mild	9 (30.0)	8 (38.1)	1 (11.1)	–
Moderate to severe	2 (6.7)	0	2 (22.2)	–
Unknown/not reported	19 (63.3)	13 (61.9)	6 (66.7)	–
Most recent BCVA score,[e] n (%)				
Mild	21 (70.0)	21 (100.0)	0	13 (65.0)[f]
Moderate	8 (26.7)	0	8 (88.9)	0

(*Continued*)

Table 1 (Continued).

A) Patients and Controls				
Characteristic	**Patients With Dry AMD**			**Controls (N=20)**
	Total (N=30)	**Mild Visual Impairment (N=21)**	**Moderate to Severe Visual Impairment (N=9)**	
Severe	1 (3.3)	0	1 (11.1)	0
GA diagnosis, n (%)	2 (6.7)	2 (9.5)	0	–

B) Caregivers	
Characteristic	**Caregivers (N=20)**
Age, years	
Mean (SD)	49.0 (13.0)
Min–max	27–66
Sex, n (%)	
Female	8 (40.0)
Male	12 (60.0)
Country, n (%)	
US	18 (90.0)
UK	2 (10.0)
Race/Ethnicity, n (%)	
White	13 (65.0)
Black or African American	5 (25.0)
Latino or Hispanic	2 (10.0)
Relationship to the patient with dry AMD, n (%)	
Spouse/partner	7 (35.0)
Child	10 (50.0)
Other family member	2 (10.0)
Friend	1 (5.0)
Years spent caring for the patient with dry AMD	
Mean (SD)	2.8 (2.4)
Min–max	0.5–10.0
Patient age at first dry AMD diagnosis, years	
Mean (SD)	65.0 (8.9)
Min–max	(47–80)
Years since patient's diagnosis of dry AMD	
Mean (SD)	2.4 ± 1.7

(*Continued*)

Table 1 (Continued).

B) Caregivers	
Characteristic	**Caregivers (N=20)**
Min–max	(0.5–8.0)
Patient's most recent BCVA score,[e] n (%)	
Mild	14 (70.0)
Moderate	2 (10.0)
Severe	0
Unknown/not reported	4 (20.0)
Patient with GA diagnosis, n (%)	3 (15.0)
Patient included in study, n (%)	7 (35.0)
Caregiver comorbidities, n (%)	
Arthritis	1 (5.0)
Asthma/COPD	2 (10.0)
Cardiovascular disease[d]	1 (5.0)
Diabetes	2 (10.0)
None of the above	15 (75.0)
Patient comorbidities, n (%)	
Arthritis	3 (15.0)
Asthma/COPD	4 (20.0)
Cardiovascular disease[d]	3 (15.0)
Chronic kidney disease	1 (5.0)
Depression	2 (10.0)
Diabetes	2 (10.0)
Stroke	1 (5.0)
Other	1 (5.0)
None of the above	15 (75.0)

Notes: Mild visual impairment was defined as a BCVA score >20/30–20/60. Moderate to severe visual impairment was defined as a BCVA score >20/80–20/320. Race and ethnicity are cultural constructs with biological contribution through genetic heritage, but do not have well defined nor clear scientific meaning. [a]Includes Black or Native American, Latino, Hispanic, or Asian. [b]e.g. spouse/partner, children, or parents. [c]Includes with roommate. [d]e.g. Myocardial infarction, congestive heart failure, and peripheral vascular disease. [e]Most recent was defined as ≤8 years for controls, no time limit for patients. [f]All controls in the mild BCVA subgroup had a BCVA score >20/30–20/60, according to inclusion criteria; thus, no controls had a BCVA score >20/60. Seven (35.0%) controls had a BCVA score ≤20/30 and thus were classified as having "no impairment". – denotes result is not available.

Abbreviations: AMD, age-related macular degeneration; BCVA, best corrected visual acuity; COPD, chronic obstructive pulmonary disorder; GA, geographic atrophy; max, maximum; min, minimum; SD, standard deviation.

Caregivers had a mean (SD) age of 49.0 (13.0) years, with 40.0% female, 65.0% White, and 90.0% from the US. Seven caregivers were recruited from patients participating in this study. Overall, caregivers reported that the patients receiving their care had a mean (SD) age of 67.3 (8.9) years; three (15%) patients had a GA diagnosis, 14 (70.0%) had mild visual impairment, two (10.0%) had moderate-to-severe visual impairment, and four (20.0%) had unknown/not reported visual impairment.

Outcomes

Results from key outcomes are described below. Example quotes captured during the interviews with participants are summarized in Supplementary Table 1.

Functional Ability and Impact on Daily Activities

The mean (SD) number of daily activities affected by dry AMD in the last month was 4.5 (2.0) as reported by patients and 5.9 (1.3) as reported by caregivers, relative to 2.1 (2.4) activities affected by visual impairment for the controls. Within the dry AMD group, patients with mild visual impairment reported a numerically lower mean (SD) number of activities affected by their condition (4.2 [1.5]) relative to those with moderate-to-severe visual impairment (5.2 [1.5]), although the difference was small. Patients reported broad functional impacts of dry AMD:

> I just can't do the things that I used to because of my eyesight, it's also affected me where I'm teetering around very carefully, worrying about tripping, just always super conscious if I'm going to slip and fall.— Patient, moderate to severe visual impairment

Among 29 (96.7%) patients who responded to the question about impact of dry AMD on daily activities, 58.6% experienced at least moderate problems with performing common daily activities (Figure 1). Relative to controls, patients were more likely to experience moderate or severe problems with their usual activities, including reading, driving, shopping, and engaging with hobbies. Overall, and for most activities, a greater proportion of patients with moderate-to-severe visual impairment reported higher degrees of problems due to dry AMD (88.9%) relative to those with mild visual impairment (45.0%). Notably, eight (26.7%) patients reported that they did not drive so did not rate how their ability to drive was affected, and seven of these patients noted they did not drive due to symptoms of dry AMD. All patients with moderate-to-severe visual impairment reported that their usual activities were affected by dry AMD, and the majority of patients with mild visual impairment (70.0%) reported their usual activities were affected to some degree. In general, most controls (63.2%) reported no problems with conducting their usual activities in the last month. Most controls were also unaffected by their vision for each individual activity, except for driving where 50.0% reported it to be unaffected by their vision, with a further 38.9% and 11.1%, respectively, reporting it to be mildly and moderately affected by their vision. When questioned about their dependence on others to complete usual activities in the past month, 33.3% of all patients with dry AMD reported that they "did not seek help", and 20.0% reported that they "rarely sought help" from others to complete usual activities.

From the perspective of caregivers, the majority (84.2%) of patients experienced at least moderate problems performing usual activities due to dry AMD, including reading, driving, shopping, and engaging in hobbies. In general, caregivers more frequently reported that patients had problems performing usual activities than the patients in our study did, both overall and for each individual activity.

Reading (30.0%) and driving (10.0%) were regarded by patients with dry AMD as the most important activities to be able to perform without difficulty, with 53.3% and 36.7% reporting these respective activities to be the most difficult or inconvenient to perform because of their symptoms (Supplementary Table 2):

> …When I'm reading I have to really intensely focus in on it and after a while I get really tired and it puts a strain on my eyes and it kind of scares me and makes me feel like I need more rest to tackle it. — Patient, mild visual impairment

> Driving is the biggest part of it. […] The doctor said, "Are you driving? Because if you're driving, I'm calling you in". […] God forbid I do need to get in the car or drive to the market for an emergency, I don't want anything on my record. So, I stopped driving. — Patient, mild visual impairment

QoL and Impact on Daily Life for Patients and Controls

Less than half of the patients reported experiencing "pretty good" (30.0%) or "very good" (10.0%) general QoL; conversely, 75.0% of controls experienced at least "pretty good" general QoL (Figure 2). Just over one-third (36.7%) of patients reported "very good" or "excellent" physical health, while half (50.0%) of controls did so. A small proportion of patients (6.7%) reported that they experienced "poor" physical health, while none of the controls did so. Proportionally, slightly more patients than controls also experienced some degree of emotional problems (73.3% and 65.0%, respectively), although these problems were described as "extreme" by a greater proportion of controls (15.0%) than patients (3.3%).

Figure 1 Impact of dry AMD symptoms experienced by patients or observed by caregivers, or impact of visual impairment experienced by controls, on ability to perform usual activities (**A**), including reading (**B**), driving (**C**), shopping (**D**), and engaging in hobbies (**E**), in the last month.

Notes: Percentages were calculated based on the total populations of participants that provided a response. Mild visual impairment was defined as a BCVA score >20/30–20/80. Moderate-to-severe BCVA was defined as a score >20/80–20/320. Eight patients reported that they did not drive, of which seven reported this was due to dry AMD.

Abbreviations: AMD, age-related macular degeneration; BCVA, best corrected visual acuity.

When asked about the psychosocial impacts of dry AMD visual impairment, patients reported at least "sometimes" feeling frustration (76.7%), loneliness (36.7%), or hopelessness (36.7%). Most patients also felt at least some difficulty coping with the demands of life (90.0%) or were worried about worsening vision (96.7%). Furthermore, those patients with moderate-to-severe visual impairment were more likely than those with mild impairment to experience increased negative feelings related to their vision (Table 2):

> Mostly there are things that I'm afraid are in my future. The thing that has bothered me about all of this is the fact that there's no treatment. We feel like there's nothing we can do. — Patient, mild visual impairment

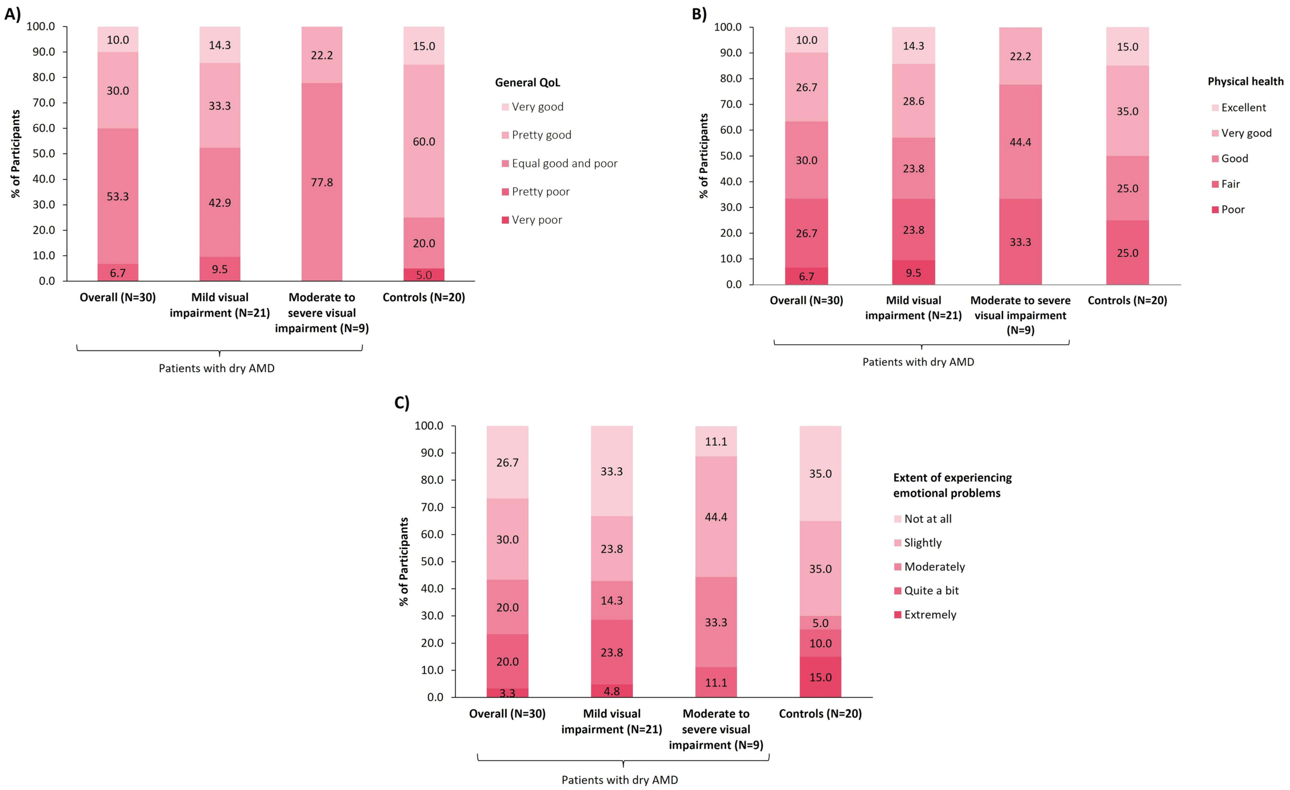


Figure 2 Patient and control general QoL (**A**), physical health (**B**), and emotional problems (**C**).
Notes: Mild visual impairment was defined as a BCVA score >20/30–20/80. Moderate-to-severe visual impairment was defined as a BCVA score >20/80–20/320.
Abbreviations: AMD, age-related macular degeneration; BCVA, best corrected visual acuity; QoL, quality of life.

> Well, I do a lot less, that's all I do is a lot less and it's kinda saddening because I don't like that. It interferes, and so like I said, I don't go out at night, I don't drive as much. I don't do very many activities anymore. I can't read a book, unless I have a magnifying glass but and not only that, my eyes get irritated fast. So, if I start looking at something too long, they get irritated. — Patient, moderate to severe visual impairment

Table 2 Impact of Dry AMD Symptoms on Daily Life, as Reported by Patients

Aspect of Daily Life	Patients With Dry AMD		
	Overall (N=30)	**Mild visual Impairment (N=21)**	**Moderate/ Severe Visual Impairment (N=9)**
Difficulty coping with demands of life, n (%)			
No effect	3 (10.0)	3 (14.3)	0
A little difficult	13 (43.3)	10 (47.6)	3 (33.3)
Moderate difficulty	11 (36.7)	6 (28.6)	5 (55.6)
Very difficult	2 (6.7)	2 (9.5)	0
Unable to cope at all	1 (3.3)	0	1 (11.1)

(*Continued*)

Table 2 (Continued).

Aspect of Daily Life	Patients With Dry AMD		
	Overall (N=30)	**Mild visual Impairment (N=21)**	**Moderate/ Severe Visual Impairment (N=9)**
Vision impacts relationship with family or friends, n (%)			
No impact	13 (43.3)	11 (52.4)	2 (22.2)
Minor impact	11 (36.7)	7 (33.3)	4 (44.4)
Moderate impact	4 (13.3)	2 (9.5)	2 (22.2)
Big impact	2 (6.7)	1 (4.8)	1 (11.1)
Very big impact	0	0	0
Feeling frustrated or annoyed, n (%)			
Never	2 (6.7)	2 (9.5)	0
Rarely	5 (16.7)	4 (19.0)	1 (11.1)
Sometimes	15 (50.0)	10 (47.6)	5 (55.6)
Often	6 (20.0)	3 (14.3)	3 (33.3)
Always	2 (6.7)	2 (9.5)	0
Feeling lonely or isolated, n (%)			
Never	14 (46.7)	11 (52.4)	3 (33.3)
Rarely	5 (16.7)	2 (9.5)	3 (33.3)
Sometimes	8 (26.7)	5 (23.8)	3 (33.3)
Often	3 (10.0)	3 (14.3)	0
Always	0	0	0
Feeling hopeless or helpless, n (%)			
Never	12 (40.0)	11 (52.4)	1 (11.1)
Rarely	7 (23.3)	5 (23.8)	2 (22.2)
Sometimes	9 (30.0)	4 (19.0)	5 (55.6)
Often	2 (6.7)	1 (4.8)	1 (11.1)
Always	0	0	0
Feeling embarrassed, n (%)			
Never	12 (40.0)	11 (52.4)	1 (11.1)
Rarely	8 (26.7)	5 (23.8)	3 (33.3)
Sometimes	6 (20.0)	1 (4.8)	5 (55.6)
Often	2 (6.7)	2 (9.5)	0
Always	2 (6.7)	2 (9.5)	0

(*Continued*)

Table 2 (Continued).

Aspect of Daily Life	**Patients With Dry AMD**		
	Overall (N=30)	**Mild visual Impairment (N=21)**	**Moderate/ Severe Visual Impairment (N=9)**
Loss of confidence, n (%)			
Never	7 (23.3)	6 (28.6)	1 (11.1)
Rarely	10 (33.3)	8 (38.1)	2 (22.2)
Sometimes	9 (30.0)	3 (14.3)	6 (66.7)
Often	3 (10.0)	3 (14.3)	0
Always	1 (3.3)	1 (4.8)	0
Worried about eyesight worsening, n (%)			
Never	1 (3.3)	1 (4.8)	0
Rarely	5 (16.7)	5 (23.8)	0
Sometimes	9 (30.0)	6 (28.6)	3 (33.3)
Often	9 (30.0)	6 (28.6)	3 (33.3)
Always	6 (20.0)	3 (14.3)	3 (33.3)
Feeling scared, n (%)			
Never	9 (30.0)	8 (38.1)	1 (11.1)
Rarely	3 (10.0)	3 (14.3)	0
Sometimes	12 (40.0)	5 (23.8)	7 (77.8)
Often	3 (10.0)	2 (9.5)	1 (11.1)
Always	3 (10.0)	3 (14.3)	0
Feeling like a nuisance or burden, n (%)			
Never	11 (36.7)	11 (52.4)	0
Rarely	8 (26.7)	5 (23.8)	3 (33.3)
Sometimes	9 (30.0)	5 (23.8)	4 (44.4)
Often	2 (6.7)	0	2 (22.2)
Always	0	0	0

Notes: Mild visual impairment was defined as a BCVA score >20/30–20/80. Moderate to severe visual impairment was defined as a BCVA score >20/80–20/320.
Abbreviations: AMD, age-related macular degeneration; BCVA, best corrected visual acuity.

Caregiver Work Productivity

Overall, 75.0% of caregivers were employed while providing care, with a mean (SD) working time of 30.9 (11.7) hours per week and missed 2.8 (4.2) hours of work in the last week due to providing care (Table 3). Additionally, caregivers reported spending a mean (SD) of 6.5 (8.2) hours per day and 6.1 (1.9) days per week providing care. In total, 46.2% of caregivers reported that their work productivity was at least "sometimes" affected by caregiving:

Table 3 Impact of Caring for Patients With Dry AMD on Caregivers' Work Productivity

Aspect of Work Productivity	Caregivers (N=20)
Caregiver was employed while providing care, n (%)	15 (75.0)
Hours worked per week,[a] mean ± SD	30.9 ± 11.7
Hours of work missed due to providing care per week,[a] mean ± SD	2.8 ± 4.2
Hours providing care per day,[a] mean ± SD	6.5 ± 8.2
Impact of caregiving on work productivity, n (%)	
Never affected	4 (30.8)
Rarely affected	3 (23.1)
Sometimes affected	4 (30.8)
Often affected	2 (15.4)
Always affected	0

Notes: [a]In the last week in which the caregiver provided care.
Abbreviations: AMD, age-related macular degeneration; SD, standard deviation.

> When I'm home I'll interrupt what I'm doing to help her, and so it does impact efficiency because if you're working on a task, say, at the computer and you get called away to something, and it might only be five minutes where you come back to that same task, it takes you another five minutes to get your brain and your mental state back to where it was. — Caregiver

QoL and Daily Life for Caregivers

Forty-five percent of caregivers reported their QoL as "pretty good" and a further 45.0% reported it as "equal good and poor" (Figure 3). Fifty-five percent reported "good", 15.0% "very good", and 10.0% reported "excellent" physical health. However, 80.0% of caregivers still experienced some degree of emotional problems, with 75.0% reporting that they felt stressed balancing caregiving and work or families at least "sometimes":

> It's a little bit emotional always helping, it's just tiring sometimes. It's tiring, it's stressful sometimes being the caregiver, but that's just part of the game. It's part of everything, it's part of life. — Caregiver

Many caregivers also reported that caregiving impacted their ability to do regular activities "sometimes" (42.1%) or "quite frequently" (26.3%). Furthermore, over half (55.0%) of caregivers interviewed felt strained at least some of the time when around the patient they cared for, with 85.0% reporting a change in their relationship with the patient. Overall, 70.0% of caregivers also felt that caregiving prevented them from having time to themselves at least "sometimes" (Supplementary Table 3). Additionally, 65.0% felt that their health had suffered to some degree due to involvement with the person they cared for (Supplementary Table 3). The activities that caregivers reported to be most impacted by caring for patients were time spent with family and friends (35.0%) and shopping (20.0%):

> …It just takes away time from my… things that I enjoy doing like watching sports and going out for a meal with my friends, talking to my friends. It's emotionally [consuming] and time consuming and it just seems like there's more pressure on me to do what my wife wants and… it feels like… it's a job. — Caregiver

Almost all caregivers (95.0%) reported that their patients at least "sometimes" needed help with their usual activities. Caregivers also reported that the activities that patients receiving their care were most dependent on them for were driving (55.0%), running errands (20.0%), and housekeeping (20.0%).

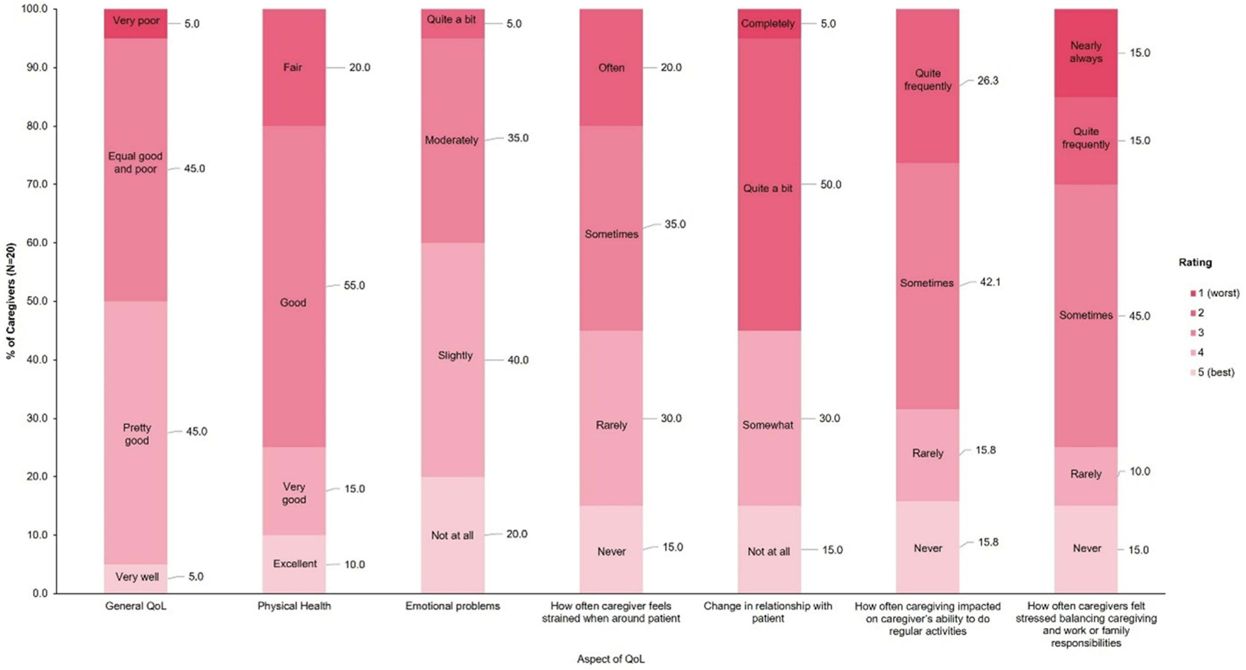


Figure 3 Caregiver QoL and burden.

Notes: Percentages for "How often caregiving impacted on caregivers' ability to do regular activities" were calculated based on the total populations of participants that provided a response (N=19).

Abbreviations: QoL, quality of life.

Discussion

This cross-sectional qualitative interview study evaluated the experiences of patients with dry AMD relative to the experience of normal ageing, as well as the day-to-day burden and QoL impacts for caregivers. Regardless of visual impairment level, patients with dry AMD experienced considerable functional impacts, with most reporting moderate or severe problems performing usual activities, whereas most controls without dry AMD of similar age, sex, and comorbidity profiles experienced no or mild problems. Beyond physical consequences and impact to daily activities, dry AMD also had a considerable emotional burden on patients, with the majority experiencing some problems, including frustration, loneliness, and hopelessness. Proportionally, more patients with dry AMD than controls experienced emotional problems.

There were some differences in the level of impact reported by patients in relation to those observed by caregivers. Overall, caregivers reported slightly worse findings for the patients receiving their care than patients in the study reported for themselves. This was the case for the number of daily activities affected and the frequency at which patients needed help with their usual activities. This may reflect a "disability paradox", whereby patients are more likely to report lesser impacts than their caregivers, as seen for other chronic conditions.[20] Furthermore, in relation to driving, caregivers were more likely than the patients themselves to report that patients were severely affected, supported by the 55% of caregivers reporting that patients were dependent upon them for driving, relative to the 36.7% of patients reporting that driving was the most inconvenient activity to perform because of their symptoms. However, this imbalance may reflect the additional 26.7% of patients who did not respond to queries related to driving, as they reported they were no longer driving, oftentimes due to dry AMD.

Most caregivers were employed, with almost half reporting that their work productivity was affected by caregiving. Although most caregivers reported their general QoL and physical health to be good, the majority experienced some degree of emotional problems, and relationships with patients were often affected, with feelings of strain commonly experienced when around the patient.

The findings presented here are largely consistent with previously published interview studies evaluating the experience of patients with dry AMD, while providing additional nuance and different perspectives.[9,10,21] In Taylor et al, reading and driving were identified as important everyday tasks affected by dry AMD,[10] with patients in the present study also reporting these to be the most inconvenient activities to perform because of their symptoms. Moreover, in Schultz et al, 95% (N=19) of patients with dry AMD identified difficulty driving and reading as immediate impacts of their condition,[9] relative to the 93.1% of patients in the present study who reported problems with reading, and 65.4% who reported problems with driving. It should also be noted that 26.7% of patients in the current study did not drive and so did not respond to related queries; however, as most of those patients stated that their lack of driving was due to dry AMD, the experience of dry AMD-related problems with driving may be understated in this study. While the controls in the present study were of a similar age to the patients with dry AMD, they were not age-matched, and it should be noted that difficulties with reading and driving go hand-in-hand with age-related visual impairment,[22,23] and are not unique to dry AMD. Schultz et al also reported that 90% of patients had difficulty completing activities of daily living as an impact of their condition.[9] This is consistent with the present study, where 90% of patients reported some difficulty coping with the demands of life. Reading and driving were also identified as being impacted in patients with the GA form of dry AMD,[21] although a GA diagnosis was only reported in a small proportion of the patients (two self-reported, three reported by a caregiver) in the current study. Additionally, Taylor et al, identified frequent mention of emotional problems experienced by patients with dry AMD,[10] which concurs with the findings in the present study that the majority of patients experienced some degree of emotional problems. In patients with GA, similar emotional problems have been identified to those reported in the present study, including frustration, lack of confidence, and worry.[21] Our study is the first to assess functional impairment as well as broader QoL impacts specific to dry AMD and relative to a control group with visual impairment typical of an aging population. Importantly, our study also addresses gaps in the literature on the broader impact to those close to patients with dry AMD by offering novel insights about the burden that caregiving imposes on caregivers' lives, including their work productivity, QoL, and relationships, furthering our understanding of the pervasive impact of dry AMD. Moreover, interviews were conducted using a novel semi-structured interview guide, which enabled us to cover a range of topics and tailor the questions to best understand participant experiences related to dry AMD.

Dry AMD is a progressive disease, and the patients interviewed in this study represent a range of disease severities and stages based on BCVA scores and GA diagnoses. As with any qualitative interview study, the participants' responses were voluntary and were subject to recall bias. Where possible, questions were restricted to a specific recent time frame (eg within the past month) to mitigate this bias. Moreover, these results are limited to participants who met the inclusion and exclusion criteria and who lived in the US or the UK, and therefore may not be generalizable to other populations. There was a particular predominance of patients from the US, meaning the impact of potential country-specific differences in daily activities and caregiver burden could not be established. However, this predominance was not due to a lack of recruitment efforts of patients/caregivers; instead, it was because most individuals from the UK did not have a BCVA score, a requirement for study participation to contextualize the participant responses, as it is not routinely used in the UK. In terms of clinical characteristics, fewer patients with more severe visual impairment were included than those with mild impairment, despite attempts to recruit patients via multiple channels. In terms of participant selection, patient inclusion was not restricted by BCVA score, and although all patients had at least mild visual impairment as per most recent BCVA score, the score could have been reported at any time after diagnosis of dry AMD. As with any observational study, there is no guarantee that the observed impacts of dry AMD on patients were due solely to dry AMD rather than the general effects of ageing on vision. However, this study used a control arm of participants with a similar age distribution to the patients with dry AMD and excluded patients and controls with a diagnosis of age-related eye conditions (other than dry AMD for patients) that could lead to visual impairment, including untreated cataracts, diabetic retinopathy, and glaucoma. This study design assumed that both groups would have similar underlying age-related visual impairment, thereby focusing on differences in impairment, burden, and QoL between patients with dry AMD rather than vision problems associated with aging. Similarly, controls were aged ≥50 years and had a BCVA score indicating no or mild visual impairment from the most recent eye exam within the past 8 years. It is possible that these participants may have experienced some visual deterioration as a result of normal aging in the period between eye exam and study initiation, which is not captured in our study. Additionally, inaccuracy may have been introduced by self-identification of GA or dry AMD and self-reporting of BCVA scores, although this was mitigated by the preference of confirmed diagnosis or BCVA scores when possible. Lastly, interviews took place during the coronavirus pandemic, meaning that daily activities could have been influenced by pandemic restrictions in addition to dry AMD.

Conclusion

Dry AMD greatly impacts the functional ability and daily activities of patients beyond the typical experience of a general older population. This disease poses many burdens on the lives of patients of various visual impairment levels and their caregivers. Regardless of level of visual impairment, patients with dry AMD often experienced difficulty with the activities that were most important for them to maintain. As such, there is a need for more awareness and novel treatments that could address the progression of the disease and the functional, QoL, and societal burdens associated with dry AMD.

Abbreviations

AMD, age-related macular degeneration; BCVA, best corrected visual acuity; GA, geographic atrophy; QoL, quality of life; SD, standard deviation; UK, United Kingdom; US, United States.

Data Sharing Statement

Details for how researchers may request access to anonymized participant level data, trial level data and protocols from Astellas sponsored clinical trials can be found at https://www.clinicaltrials.astellas.com/transparency/.

Ethics

The study was approved by the WCG IRB (No: 20210104).

Acknowledgments

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

AM is an employee of Astellas Pharma Europe Ltd. JS and AI are employees of Astellas Pharma, Inc. CXC was an employee of Astellas Pharma, Inc. at the time of the study. YS, MLE, AA, and DC are employees of Analysis Group, Inc., contracted by Astellas to carry out this study. KS was an employee of Analysis Group, Inc. at the time of the study. The authors report no other conflicts of interest in this work.

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