

# The caregiver perspective on dry age-related macular degeneration: a qualitative interview study

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## INTRODUCTION

- Dry age-related macular degeneration (AMD), is a widespread and incurable macular disorder that is responsible for progressive vision loss<sup>1</sup>
- As a result, disease progression typically hinders patients' capability for day-to-day activities<sup>2-5</sup>, often necessitating the aid of a caregiver
- Caring for patients with dry AMD often results in fatigue, depression and overall reduction in quality of life (QoL)<sup>6</sup>
- A comprehensive understanding of the caregivers' perspectives on patient functioning and the impact of caregiving can help reveal the potential value of new treatments for dry AMD



### Objectives

- To investigate the functional impact of dry AMD on patients from the caregiver's perspective
- To evaluate the impact of caring for patients with dry AMD on caregiver work productivity and QoL

## METHODS

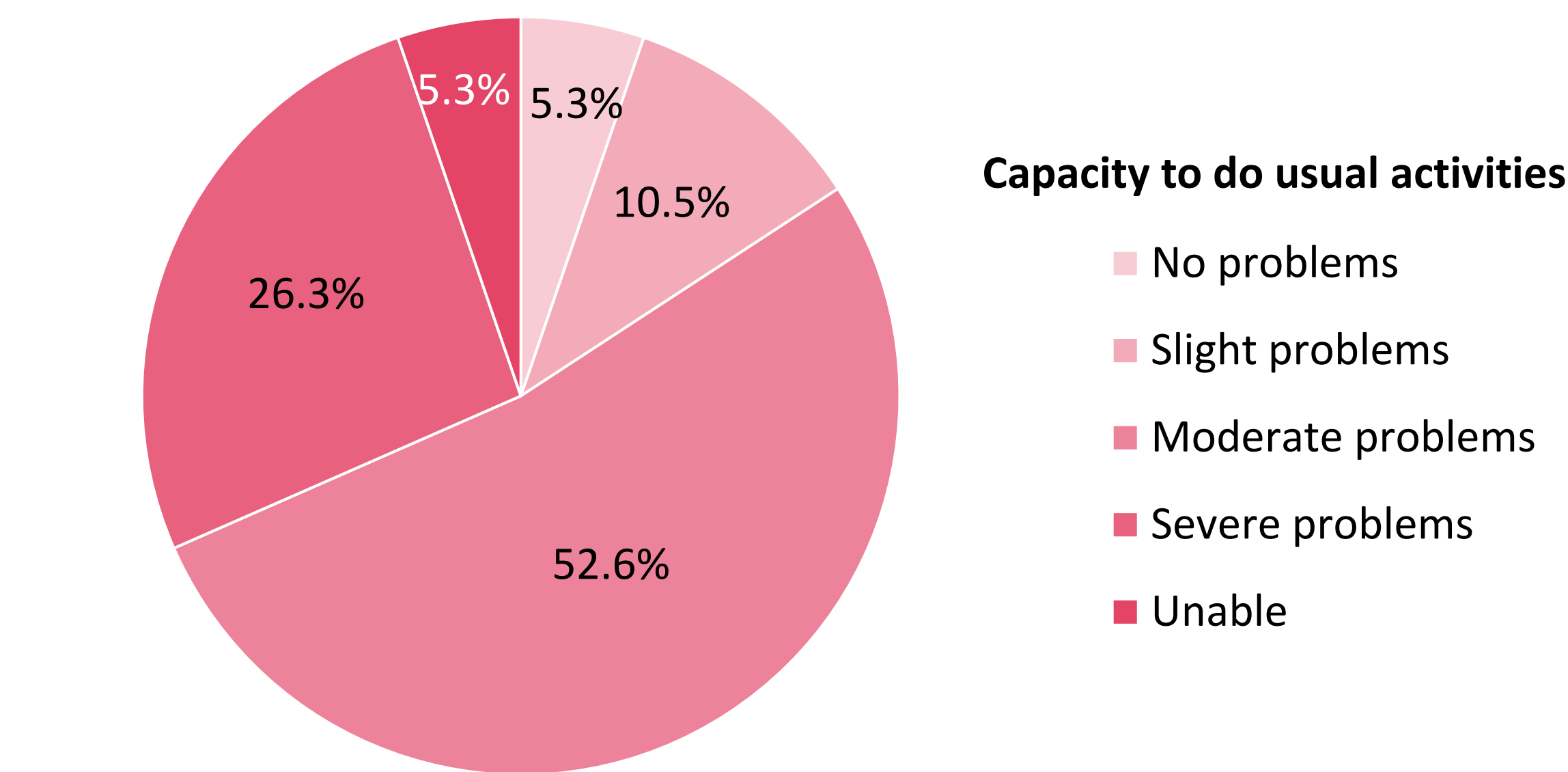
- In this cross-sectional qualitative interview study, adult caregivers (aged ≥18 years) providing unpaid care for ≥3 months within the prior year for a patient aged ≥50 years with dry AMD were included
  - Caregivers of patients with wet AMD or other age-related eye conditions (e.g., cataracts, diabetic retinopathy) were excluded
  - Caregivers were also excluded if they or their patient had diseases that severely impair functioning (e.g., Alzheimer's disease, metastatic cancer)
- Trained moderators conducted semi-structured telephone interviews with caregivers from the UK and US (March 2021–June 2023)
- Caregiver perspectives on patients' functional impairment in daily activities, and impact of dry AMD on the caregiver's own health, daily life, QoL and work productivity, were assessed
  - Patient-reported outcomes are reported separately (International Society for Pharmacoeconomics and Outcomes Research 2024, May 6; Poster presentation - PCR11)

## RESULTS

### Caregiver perspectives

- Of the 20 caregivers interviewed, 19 (95.0%) were spouses/family members of the patient
- Overall, the mean (standard deviation [SD]) age for caregivers was 49.0 (13.0) years, with a mean (SD) duration of care of 2.8 (2.4) years
  - Caregivers reported a mean age (SD) for all patients of 67.3 (8.9) years; 70.0% and 10.0% of patients were reported by caregivers to have mild and at least moderate visual impairment, respectively
  - Three (15.0%) patients also had GA diagnosis as reported by caregivers
- Most caregivers (16/19 who responded to the question, 84.2%) reported that patients experienced at least moderate problems with usual activities over the last month (**Figure 1**)
  - One patient was reported to be unable to conduct any usual activities
  - In the past month, caregivers reported a mean (SD) of 5.9 (1.3) patient activities were affected by dry AMD, of which reading, driving, and shopping were the three activities caregivers reported to be most difficult for the patient

**Figure 1. Ability of patients with dry AMD to do usual activities in the last month from caregivers' perspective**



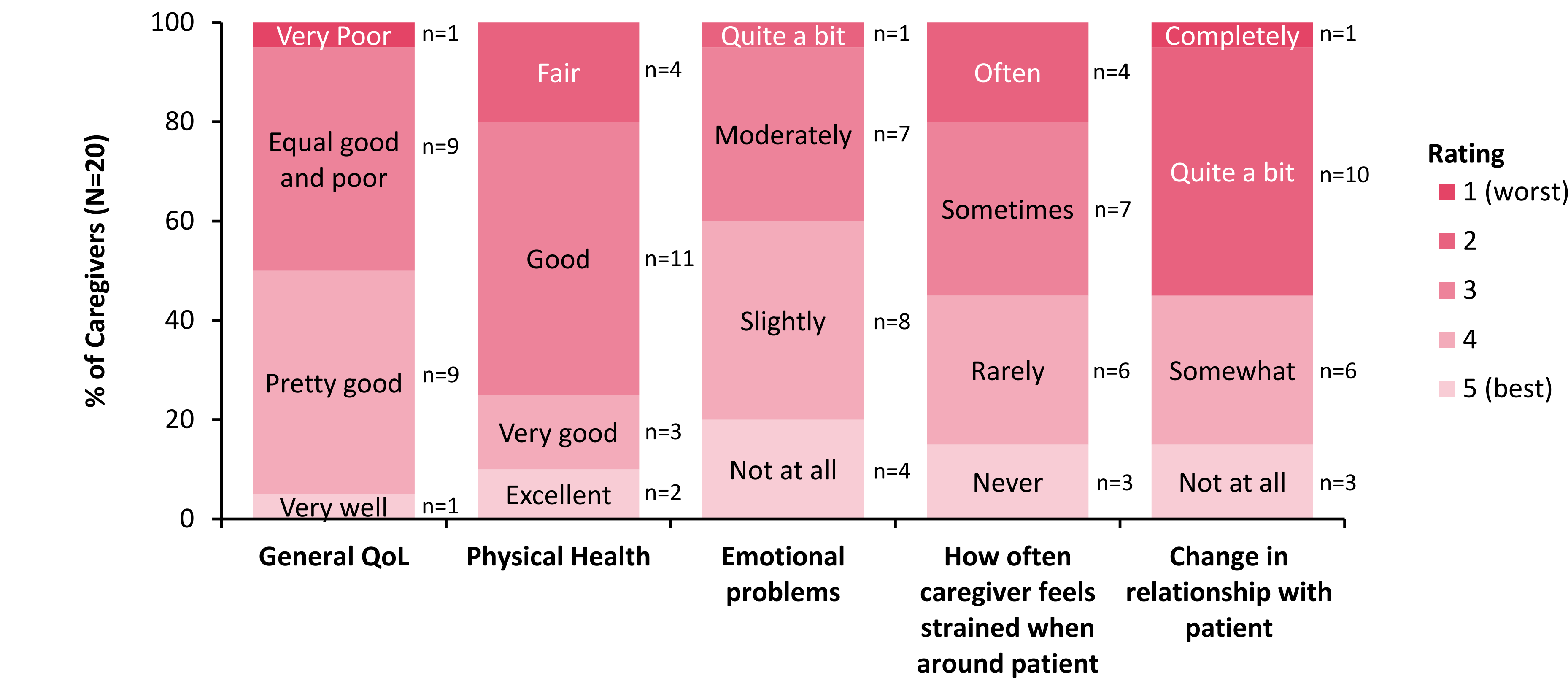
Percentages were calculated from caregivers with responses (n=19) and correspond to the proportion of caregivers reporting on each level of capacity for patients to do usual activities. AMD; age-related macular degeneration

**Table 1. 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, <sup>a</sup> mean (SD)	30.9 (11.7)
Hours of work missed per week, <sup>a</sup> mean (SD)	2.8 (4.2)
Hours providing care per day, <sup>a</sup> mean (SD)	6.5 (8.2)
Impact of caregiving on work productivity <sup>b</sup> , n (%)	N=13
Never affected	4 (30.8)
Rarely affected	3 (23.1)
Sometimes affected	4 (30.8)
Often affected	2 (15.4)
Always affected	0 (0.0)

<sup>a</sup>In the past week in which the caregiver provided care. <sup>b</sup>Percentages were calculated from caregivers with responses (n=13) and correspond to the proportion of caregivers reporting on the impact of caregiving on work productivity. AMD, age-related macular degeneration; SD, standard deviation

**Figure 2. Impact of caring for patients with dry AMD on caregiver QoL**



AMD, age-related macular degeneration; QoL, quality of life. Statements for each rating equate to semi-structured responses provided by caregivers

### Impact of caring on caregiver work productivity

- In total, caregivers spent a mean (SD) of 6.5 (8.2) hours per day providing care (**Table 1**)
- Most (15/20, 75.0%) were employed, working a mean (SD) of 30.9 (11.7) hours per week
  - A total of 46.2% (6/13) reported that caregiving sometimes or often affected work productivity, and in the last week, 2.8 (4.2) work hours were missed due to caregiving (mean [SD]) (**Table 1**)

### Impact of caring on caregiver QoL

- In general, although most caregivers reported that their QoL was "pretty good" (9/20, 45.0%) or "equal good and poor" (9/20, 45.0%), most were at least "slightly" bothered by emotional problems (16/20, 80.0%) (**Figure 2**)
- When around their patient, over half of the caregivers reported feeling strained, either sometimes (7/20, 35.0%) or often (4/20, 20.0%) (**Figure 2**)
  - Almost all caregivers reported that patients either always (3/20, 15.0%), often (13/20, 65.0%) or sometimes (3/20, 15.0%) required help with usual activities; however, a third (33.3%) of patients reported that they did not seek help
- Caregivers reported that their own time spent with friends/family (7/20, 35.0%), shopping (4/20, 20.0%), self-care (2/20, 10.0%), and hobbies/housework (1/20, 5.0%) were the most impacted activities by providing care for patients
- The majority of caregivers reported that their other relationships had changed due to time spent caregiving

## CONCLUSIONS

- Caregivers observed that most patients with dry AMD struggle with daily activities and rely on caregivers for everyday tasks
- Caring for patients with dry AMD impacts caregiver work productivity, personal relationships, and QoL

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