INTRODUCTION

Wet age-related macular degeneration (wAMD) is characterised by a progressive loss of central vision attributable to degenerative changes.1 It is estimated that there will be nearly 300 million people globally with AMD by 2040.2 Given this projection and increased life expectancy, it is important to monitor the impact of wAMD, with a view to optimising long-term treatment.

OBJECTIVES

A global survey of patients with wAMD and caregivers was conducted to evaluate the current management of wAMD and identify perceived barriers to treatment.

DESIGN

A 15-minute online survey was performed; a mix of in-person and telephone collection methods was used to enable responders with very poor vision to participate. The survey was developed in conjunction with an independent steering committee consisting of ophthalmologists. The survey was conducted in 9 countries (Australia, Brazil, Canada, France, Germany, Italy, Japan, Spain, and the UK).

PARTICIPANTS

Patients with a wAMD diagnosis who were treated by a healthcare professional (HCP) and received current or prior intravitreal injections to treat their wAMD were included. Caregivers who provided care and support to a patient diagnosed with wAMD meeting the criteria described were included.

RESULTS

Disease Overview

910 patients and 890 caregivers were surveyed (Table 1). Many caregivers were a child or grandchild of the patient (47%), or partner (23%), but only 7% were professional caregivers. 55% of patients had wAMD in 1 eye, but 19% of these also had dry AMD in the other eye. Most (75%) patients had been diagnosed and receiving anti-vascular endothelial growth factor injections (64%) for >1 year.

Symptoms

The most commonly reported symptoms were “blurring of central vision” and “difficulty seeing fine detail” (Figure 1). 77% of caregivers rated the patients’ vision as “very poor/ quite poor” compared with 58% of caregivers (Figure 2).

Diagnosis

Most patients (73%) visited an HCP within 1 month of first noticing a change in vision. 41% of patients who delayed visiting an HCP thought symptoms would resolve. wAMD was diagnosed during the first visit in 43% of patients; a further 30% were diagnosed within 1–3 weeks.

Obstacles to Treatment

Most patients (65%) and caregivers (77%) reported a number of obstacles in managing wAMD (Figure 2). Since treatment initiation, 30% of caregivers were extremely inconvenient, with 57% of patients reporting a number of obstacles in managing wAMD (Figure 2).

Burden of Disease

72% of patients reported that wAMD had a negative impact. Most reported an effect on practical daily-to-day activities; this impact was perceived as greater by caregivers (Figure 3). 26% of patients had also experienced a fall, with 43% of these having been hospitalised as a result. wAMD was also associated with a range of emotional effects; the biggest fear (60%) was permanent loss of vision.

Treatment and Follow-up

54% of patients started treatment immediately, and 37% scheduled an appointment within 1–3 weeks. 42% of patients attended appointments once every 4–6 weeks, and 56% of these received treatment at every visit (compared with 18% for those attending every 6–12 months). 52% of patients reported a temporary improvement or stabilisation in vision as a result of current treatment, and 22% reported a return to pre-diagnosis vision or that their vision was still improving.

Type of Treatment

Most (75%) patients had been diagnosed and caregivers (80%) had been treated for wAMD with anti-VEGF therapy. Most patients (65%) and caregivers (77%) reported to/affording technology.

Loss of Productivity

27% of caregivers found the patient’s treatment extremely inconvenient, with 57% of employed (non-paid) caregivers having to take time off work or miss personal obligations as a result of helping the patient (Figure 4).

Conclusions

Most patients and caregivers believe that there are a number of obstacles in managing wAMD, including finding the right treatment options. wAMD has a major impact on the lives of patients and caregivers, and may be associated with an economic burden (eg, lost productivity). There is a need to investigate further what factors are driving patient compliance.


References


Disclosures

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Figure 1: There is consistency between symptoms reported by patients (n=910) and caregivers (n=890).

Figure 2: Obstacles to wAMD treatment for patients (n=910) and caregivers (n=890).

Figure 3: Caregivers (n=890) rate negative disease consequences (for patients) as greater than patients do themselves (n=910).

Figure 4: Employed (non-paid) caregivers (n=659) who miss >15 days of employment are more likely to regard treatment as inconvenient.