

# Caregiver Burden Among Patients Receiving Anti-VEGF Intravitreal Injections for AMD and DR: A Cross-Sectional Study in Guangzhou

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**Purpose:** To evaluate the caregiver burden and its associated factors among patients receiving anti-VEGF intravitreal injections for age-related macular degeneration (AMD) and diabetic retinopathy (DR) in a tertiary hospital in Guangzhou, China.

**Methods:** This cross-sectional study recruited 88 patients who received intravitreal anti-VEGF injections and their primary caregivers. Patients completed the Activities of Daily Living (ADL) scale, while caregivers completed the Zarit Burden Interview (ZBI) and the Connor-Davidson Resilience Scale (CD-RISC). One-way ANOVA and Pearson correlation analysis were conducted to assess the associations between patient function, caregiver burden, and related sociodemographic factors.

**Results:** The mean ADL score of patients was  $18.99 \pm 8.34$ , while the mean caregiver burden score was  $18.22 \pm 18.04$ . A significant positive correlation was found between the patient's ADL score and caregiver burden ( $r = 0.405$ ,  $p < 0.01$ ). Caregivers who were employed part-time or not cohabiting with patients reported significantly higher burden scores ( $p = 0.034$  and  $p = 0.03$ , respectively). Additionally, the caregiver burden among DR patients was higher than among AMD patients ( $p = 0.026$ ).

**Conclusion:** Significant caregiver burden exists among those assisting patients receiving intravitreal injections, especially for DR patients and those with reduced ADL function. Caregiver availability and living arrangements should be considered in the design of follow-up schedules to improve treatment adherence and outcomes.

**Keywords:** intravitreal injection, caregiver burden, anti-VEGF, age-related macular degeneration, diabetic retinopathy, ophthalmic care

## Introduction

Age-related macular degeneration (AMD) is the leading cause of irreversible severe visual impairment among individuals over 50 years of age in developed countries.<sup>1</sup> The global prevalence of early AMD is approximately 8.01%, with an estimated 196 million affected individuals in 2020 and projections reaching 288 million by 2040.<sup>2</sup> Diabetic retinopathy (DR), a common complication of diabetes, also leads to progressive vision loss and affects an increasing number of patients worldwide.<sup>3</sup> Between 1990 and 2010, visual impairment and blindness due to DR increased by 64% and 27%, respectively.<sup>4</sup>

Intravitreal injection of anti-vascular endothelial growth factor (anti-VEGF) agents has become the mainstay treatment for both AMD and DR. In the United States, as many as 5.9 million patients received intraocular injections in 2016.<sup>5</sup> While effective in preserving vision and macular function,<sup>1</sup> these injections require repeated administration and long-term follow-up, placing substantial demands on patients and their caregivers.<sup>6</sup> So, AMD patients need to go to the hospital for eye examinations and intraocular injections for a long time. AMD patients often need to be accompanied by a caregiver to complete medical activities, especially when they have severe late vision loss.<sup>1,6</sup> Many patients with impaired vision rely on caregivers for assistance with transportation, medical visits, and daily activities.

Caregivers play a vital role in supporting patients with chronic eye diseases. The caregiving burden of caregivers is a problem that cannot be ignored in patients with intraocular injections, and we need to pay close attention to it. The current research on the burden of caregivers focuses on caring for the elderly with disabilities<sup>7</sup> and dementia.<sup>8</sup> Faced with

the elderly with disabilities or dementia, caregivers need to take care of the daily life of the elderly, including feeding, bathing, urinating and medication, etc.<sup>9</sup> all of which cost the caregivers a lot of time and energy.<sup>10</sup> People who take care of disabled elderly people often show a great care burden, hoping that someone can help them with their work and reduce their burden.<sup>11</sup> There are many factors influencing the caregiver burden of caregivers, such as the self-care ability of the caregiver, economic status and emotional state of the caregiver, etc.<sup>12,13</sup> Studies have shown that AMD and DR are mainly the elderly, and the work burden of caregivers will increase. Therefore, AMD and DR patients bring more time burden to their caregivers,<sup>14</sup> economic burden<sup>15</sup> and psychological burden.<sup>16</sup> Research focusing on caregivers of ophthalmology patients, particularly those undergoing intravitreal injections, remains limited.

In the context of ophthalmic diseases such as AMD and DR, the burden of care experienced by caregivers can be multifaceted. In this study, “caregiver burden” is defined as the combination of logistical, emotional, and practical challenges faced by individuals providing support to patients with visual impairment. Specifically, caregiver burden encompasses two major domains: (1) the responsibility of repeatedly accompanying patients to the hospital for anti-VEGF intravitreal injections and follow-up examinations, and (2) assisting patients with daily activities that are affected by vision loss, such as mobility, personal care, medication management, and household tasks. Both the logistical demands of ongoing treatment and the continuous need to compensate for patients’ reduced functional independence due to low vision contribute to the overall caregiver burden in this population.

With the deepening of the aging of the population, the number of people suffering from AMD and DR is gradually increasing. The burden of disease caused by disease patterns is threatening socio-economic and public health stability. The burden of patients and caregivers are gradually exposed and have an impact on the results of their treatment. Patients with intraocular injection will be less likely to return to the hospital for treatment, because the medical care of patients needs the cooperation of caregivers. This study aims to assess the burden of care experienced by caregivers of patients receiving anti-VEGF therapy for AMD and DR. We also seek to identify factors associated with increased caregiver burden, providing evidence to inform supportive interventions and improve patient adherence to treatment.

## Methods

This was a cross-sectional study conducted from September to December 2019 in the Ophthalmology Hospital, a tertiary care center in Guangzhou, China. A total of 88 patient–caregiver dyads were included using convenience sampling. Using convenience sampling, patients who were injected intraocular drugs needed to complete ADL, and their caregivers were asked to fill out caregivers’ burden and resilience questionnaires. This study was conducted over three months from September to December 2019, at Zhongshan Ophthalmic Center in Guangzhou. The study was reviewed and approved by the Ethics Committee of Zhongshan Ophthalmic Center, Sun Yat-sen University (No. 2020KYPJ205). Written informed consent was obtained from all participants. All patient data were de-identified to ensure confidentiality, and the study was conducted in accordance with institutional policies and the principles of the Declaration of Helsinki.

## Inclusion and Exclusion Criteria

### Inclusion Criteria

(1) Patients who had received intravitreal anti-VEGF therapy within the past month. (2) Caregivers aged  $\geq 18$  years with no cognitive or psychiatric impairments. (3) Caregivers who provided daily support free of charge and were not professional care providers.

### Exclusion Criteria

Caregivers unable or unwilling to complete the questionnaires.

## Instruments

### Sociodemographic Data

Information of the patients, such as living arrangements, chronic diseases, diagnosis, payment of medical expenses, gender and age. Additionally, living arrangements of caregivers were also gathered by the interviewer, including household chores, working, financial situation, health condition.

### Zarit Caregiver Burden Interview

The scale was compiled by Zarit in the 1980s.<sup>17</sup> It is an effective tool to follow up the burden of elderly caregivers at home.<sup>18</sup> The scale has been translated into different languages, and it has been widely used in North America, Europe, Japan and Brazil.<sup>18</sup> In 2006, scholars Wang Lie et al translated ZBI into Chinese. The Chinese version of the scale includes two dimensions: personal strain and Role strain. Each item uses a 5-level scoring method, from no to always, and scored in order of 0, 1, 2, 3, 4, with a total score of 0 to 88 points. According to ZBI score, candidates are divided into high care burden group (ZBI score  $\geq$  39 points) and low care burden group (ZBI score  $<$  39 points). The Cronbach coefficient of this scale in this study was 0.947.

### Activity of Daily Living Scale

The scale was compiled in 1969 by Lawton and Brody of the United States.<sup>19</sup> It is consisted of the Physical Self-maintenance Scale (PSMS) and the Instrumental Activities of Daily Living Scale (IADL). There are 14 items on the ADL scale. It is scored with 4 grades, which are fully capable of doing (1 point), somewhat difficult (2 points), need assistance (3 points) and unable to do (4 points). Both of them have shown good reliability and validity in years of applied research. The Cronbach coefficient of this scale in this study was 0.950.

### Connor-Davidson Resilience Scale

The scale was developed by Conner and Davidson in 2003.<sup>20</sup> It has been translated into multiple languages, which has been widely used and verified in clinical practice.<sup>21</sup> The scale contains 25 items, involving 5 dimensions of ability, emotion, acceptance of change, control and mental influence. It can be used for community population, outpatient, clinical patients, anxiety patients and patients with stress disorder. The Chinese version was revised by Xiao Nan and Zhang Jianxin, including three dimensions of tenacity, self-improvement and optimism. 5-level score is adopted, from “never” (0 points) to “almost always” (4 points). The score ranges from 0 to 100 points. A high score indicates a high level of mental resilience. The Cronbach coefficient of this scale in this study was 0.931.

## Data and Statistics

Epidata3.1 software (EpiData, Association, Odense, Denmark) was used for double entry of data, and SPSS20.0 software (IBM Cooperation, New York, USA) was used for statistical analysis. Descriptive statistics were used to summarize demographic information. One-way ANOVA tested differences in caregiver burden across subgroups. Pearson correlation analysis assessed the relationship between patient ADL scores and caregiver burden. A p-value  $<$  0.05 was considered statistically significant.

## Result

3.1 Of 95 eligible patient–caregiver dyads, 7 were excluded due to incomplete or inconsistent questionnaires, yielding an effective response rate of 92.63% (n = 88). The mean age of patients was  $60.75 \pm 10.09$  years, and that of caregivers was  $40.24 \pm 12.01$  years.

3.2 Demographic information of both patients and caregivers is summarized in [Tables 1](#) and [2](#). The majority of caregivers were family members, including spouses or children. Approximately 59.1% of caregivers were employed part-time and involved in additional work-related responsibilities.

3.3 According to the Zarit Burden Interview (ZBI), 12 caregivers (13.64%) were classified as experiencing high caregiver burden (ZBI score  $\geq$  39), while 76 caregivers (86.36%) had low burden levels (ZBI score  $<$  39) ([Table 3](#)).

3.4 The mean patient ADL score was  $18.99 \pm 8.34$ . The mean caregiver burden score was  $18.22 \pm 18.04$ , and the mean resilience score was  $67.25 \pm 19.16$ . A moderate positive correlation was observed between the patient’s ADL score and the caregiver burden score ( $r = 0.405$ ,  $p < 0.01$ ), indicating that decreased patient independence was associated with greater caregiver burden ([Table 4](#)).

**Table 1** Socio-Demographic Data of the Caregivers

Items	Classifications	Frequency (n)	Percentage (%)
Gender	Male/Female	43/45	48.9/51.1
Working	Yes/No	52/36	59.1/40.9
Living arrangements (Living with patients)	Yes/No	54/34	61.4/38.6
Assisting staff	Yes/No	46/42	52.3/47.7
The financial situation of the caregiver	Pension	14	15.9
	Wage	55	62.5
	Spouse	12	13.6
	Child	2	2.3
	Investment	5	5.7
	Household income (monthly)	<10,000	51
	10,000~14,999	20	22.7
	15,000~19,999	11	12.5
	>20,000	6	6.8
Live in Guangzhou	Yes/No	41/47	46.6/53.4
Combined with high blood pressure or diabetes	Yes/No	16/72	18.2/81.8

**Table 2** Socio-Demographic Data of the Patients

Items	Classifications	Frequency (n)	Percentage (%)
Gender	Male/Female	54/34	61.4/38.6
Payment of medical expenses	Fully at your own expense	42	47.7
	Social medical insurance	42	47.7
	Public medical	4	4.5
Patient's disease	AMD/DR	41/47	46.6/53.4
Combined with high blood pressure or diabetes	Yes/No	65/23	73.9/26.1

**Abbreviations:** AMD, age-related macular degeneration; DR, diabetic retinopathy.

**Table 3** Caregiver Care Burden Group

Groups	ZBI	N (%)
High-burden group	≥39	12 (13.64)
Low-burden group	<39	76 (86.36)

**Abbreviations:** ZBI, zarit caregiver burden interview. Data are presented as n (%).

**Table 4** Pearson Correlation Analyze Between Different Questionnaires

	Patients' ADL	ZBI	Total Mental Flexibility
Patients' ADL	1	<b>0.405**</b>	-0.035
ZBI	<b>0.405**</b>	1	-0.118
Total mental flexibility	-0.035	-0.118	1

**Note:** Bold values indicate statistical significance \*\*P < 0.05.\*\*\*P is the result of Pearson correlation analyze.

**Abbreviations:** ADL, activity of daily living scale; ZBI, zarit caregiver burden interview.

## Analysis of Influencing Factors

One-way ANOVA revealed that part-time caregivers experienced significantly higher burden than full-time caregivers ( $p < 0.05$ ). Caregivers who did not reside with the patient also reported higher burden levels compared to those who cohabited ( $p < 0.05$ ). Additionally, caregivers of patients with DR reported significantly higher burden scores than those caring for patients with AMD ( $p < 0.01$ ) (Table 5).

**Table 5** Influencing Factors of Care Burden of Outpatients with Drug Injection

Influencing Factors	Classifications	N	Mean ± SD	F value	P value
Caregivers	Part-time	52	21.59 ± 18.04	4.619	<b>0.034*</b>
	Full-time	36	13.36 ± 17.12		
Caregivers	Living with patient	54	14.93 ± 16.55	4.891	<b>0.03*</b>
	Not living with patient	34	23.47 ± 19.27		
Patients	With AMD	41	13.68 ± 13.61	5.102	<b>0.026*</b>
	With DR	47	22.19 ± 20.49		
Caregivers	Elementary school or below	7	24.86 ± 24.19	1.079	0.372
	Junior high school	14	13.14 ± 11.62		
	High school	21	19.57 ± 20.16		
	Junior college	25	14.60 ± 15.75		
Caregivers	College degree or above	21	22.38 ± 19.43	0.075	0.928
	Unmarried	19	16.84 ± 16.92		
	Married	64	18.55 ± 18.69		
Caregivers	Divorced	5	19.40 ± 16.56	0.134	0.715
	Have child	66	17.82 ± 17.45		
Caregivers	No child	22	19.45 ± 20.07	0.042	0.838
	Assisting staffs	Yes	46		
Assisting staffs	No	42	18.64 ± 18.50	0.66	0.621
	Caregiver's income	Pension	14		
Average monthly household income	Wage	55	19.18 ± 18.17	0.786	0.505
	Spouse	12	21.33 ± 21.47		
	Child	2	25.00 ± 2.83		
	Investment	5	15.60 ± 16.88		
	<10000	51	20.61 ± 19.67		
Patients	10,000–14,999	20	15.70 ± 17.06	1.628	0.205
	15,000–19,999	11	15.45 ± 14.58		
	Above 20000	6	11.50 ± 10.37		
	Living in Guangzhou	41	15.61 ± 13.93		
Patients	Other places	47	20.51 ± 20.86	2.027	0.158
	Caregivers	No disease	72		
Caregivers	With diseases	16	24.13 ± 20.98	2.22	0.115
	Payment of medical expenses	Fully at your own expense	42		
Payment of medical expenses	Social medical insurance	42	15.05 ± 15.31	9.50 ± 12.12	
	Public medical	4	9.50 ± 12.12		

**Note:** Data are presented as mean±SD. \*P is the result of the t test. Bold values indicate statistical significance \*P < 0.05.

## Discussion

With the increasing use of anti-VEGF intravitreal injections for retinal diseases, the demands on caregivers have grown substantially. Our study revealed that 13.64% of caregivers experienced a high level of burden, influenced by factors such as caregiver employment status, cohabitation, and patient disease type.

Caregivers who were employed part-time reported significantly greater burden than those who were full-time or unemployed. This finding is consistent with prior studies indicating that scheduling conflicts between caregiving duties and work responsibilities contribute to elevated stress levels. Among the caregivers of patients with intraocular injections, 59.1% of them needed to undertake work tasks in addition to caring for the patient. They cared for a higher level of burden than caregivers who do not need to undertake work. The main personnel accompanying the patient for medical treatment were the patient's partner or children, accounting for approximately 86.4%. Kimberly et al conducted a questionnaire survey on the caregivers of 103 AMD patients in Australia and it was found that 66% of the caregivers needed to take on work, and 87% of the caregivers were the patients' partners or children. They spent nearly 5 hours a month to accompany patients in medical activities, which was troublesome to their schedule.<sup>22</sup> Part-time

caregivers had a relatively large care burden, mainly due to the conflict between their working hours and the patient's medical time. Disturbance in scheduling become a great trouble for caregivers.<sup>14,15,23</sup> The caregivers in our study had a mean age of  $40.24 \pm 12.01$  years, representing the core working-age population. As individuals who are actively engaged in their careers and also responsible for family obligations, these caregivers often face significant challenges in balancing work, family life, and the demands associated with accompanying patients for intravitreal injections.<sup>24</sup> The need to coordinate medical appointments for patients receiving anti-VEGF therapy places an additional strain on their time and daily schedules, contributing to the overall burden experienced by this group.

Interestingly, caregivers who lived with the patient experienced lower burden compared to those who did not. While some literature on dementia care suggests cohabiting caregivers bear a heavier burden due to 24/7 care demands, our findings differ,<sup>25</sup> likely because patients with AMD or DR typically maintain basic daily functioning. Patients with impaired vision could take care of their daily life by themselves, but they required the company of caregivers to completed medical activities. The lower care burden for caregivers living with patients was mainly because they could meet patients' medical needs in a timely manner, saving time, and maintaining communication more efficiently.

Our results also indicate that caregivers of DR patients face greater burden than those of AMD patients. Diabetes is a complex systemic disease. However, AMD is only related to fundus retinopathy. The burden of caregivers of patients with DR requires not only medical activities, but also the management of chronic diabetes, such as blood sugar medication and diabetic complications. Compared with caregivers of patients with AMD, caregivers of patients with DR needed to spend more time and effort. The management of diabetes extends far beyond eye care, requiring caregivers to support patients with blood glucose monitoring, medication adherence, dietary planning, and the prevention or management of a wide range of complications, including neuropathy, nephropathy, and cardiovascular disease.<sup>26</sup> This ongoing, multifaceted care creates a cumulative burden that exceeds the requirements for managing AMD alone. Moreover, diabetes-related acute episodes, such as hypoglycemia or complications requiring hospitalization, can further disrupt daily routines, causing caregivers to be on constant alert and potentially leading to work absenteeism or loss of personal time.<sup>27</sup> The persistent uncertainty regarding potential disease progression and the need for lifelong disease management may contribute to higher levels of anxiety and psychological distress among caregivers of DR patients compared to those caring for individuals with AMD.<sup>28</sup>

We focused on evaluating the current status of caregiver burden among patients with ophthalmological diseases by employing a caregiver burden scale that is widely used in geriatric research. Our findings demonstrated that this scale exhibited good reliability and validity in assessing caregiver burden within the ophthalmology population, supporting its applicability in this specific clinical context.

## Limitations

In addition, we did not directly investigate the underlying reasons for caregiver burden, such as work disruptions, financial strain, or family impacts. Economic and social pressures are known to contribute significantly, and future studies should explore these aspects in more detail.

We also did not record the number of missed or delayed treatments due to caregiver difficulties. Although non-cohabiting caregivers reported higher burden, it is unclear if this affected patient adherence. Further research should examine how caregiver burden influences treatment compliance.

Finally, while we used validated Chinese scales, we did not adapt them specifically for caregivers of visually impaired patients. Further testing may help improve their suitability in this setting. These limitations underscore the need for larger, multicenter studies with more detailed and context-specific assessments.

## Clinical Implications

Based on our findings, it is clear that caregiver burden is a key factor influencing the treatment experience and outcomes of patients receiving intravitreal injections, especially for those with diabetic retinopathy. Caregiver burden in this context may involve time pressures, work disruptions, financial concerns, and the logistical challenges of supporting regular medical visits. As such, the burden and availability of informal caregivers can directly influence appointment compliance and the continuity of care. Part-time caregivers or those not living with the patient are more likely to experience disruptions in scheduling, potentially affecting patient outcomes.

Integrating caregiver-related considerations into clinical workflows—such as offering flexible appointment options, providing caregiver education, and facilitating psychosocial support—may help reduce care burden and enhance treatment adherence. Recognizing and addressing caregiver needs may ultimately contribute to better visual prognoses for patients undergoing long-term intravitreal therapy. To address these issues, clinical practice should incorporate strategies aimed at reducing caregiver burden. This could include flexible appointment scheduling, caregiver education about treatment and disease management, and access to psychosocial or community support resources. Further research should also focus on identifying specific sources of caregiver stress and evaluating targeted interventions that can support caregivers more effectively.

Recognizing and responding to caregiver needs in ophthalmology clinics is not only important for the well-being of caregivers themselves, but may also improve patient adherence and long-term visual outcomes.

## Disclosure

The authors report no conflicts of interest in this work.

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