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ORIGINAL RESEARCH

Improving Clinical Management of Diabetic Macular Edema: Insights from a Global Survey of Patients, Healthcare Providers, and Clinic Staff

Focke Ziemssen · Michelle Sylvanowicz · Winfried M. Amoaku · Tariq Aslam · Bora Eldem · Robert P. Finger · Richard P. Gale · Laurent Kodjikian · Jean-François Korobelnik · Xiaofeng Lin · Anat Loewenstein · Paul Mitchell · Moira Murphy · David R. Owens · Nick Parker · Ian Pearce · Francisco J. Rodríguez · Jude Stern · S. James Talks · David T. Wong · Tien Yin Wong · Jane Barratt

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ABSTRACT

Introduction: In contrast with patients receiving therapy for retinal disease during clinical trials, those treated in routine clinical practice experience various challenges (including administrative, clinic, social, and patient-related factors) that can often result in high patient and clinic burden, and contribute to suboptimal visual outcomes. The objective of this study was to understand the challenges associated with clinical management of diabetic macular edema from the perspectives of patients, healthcare providers, and clinic staff, and identify opportunities to improve eye care for people with diabetes.

Methods: We conducted a survey of patients with diabetic macular edema, providers, and clinic staff in 78 clinics across 24 countries on six continents, representing a diverse range of individuals, healthcare systems, settings, and reimbursement models. Surveys comprised a series of single- and multiple-response questions completed anonymously. Data gathered included patient personal characteristics, challenges with appointment attendance, treatment experiences, and opportunities to improve support. Provider and clinic staff surveys asked

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F. Ziemssen (✉)
University Eye Clinic, Department of Ophthalmology, University Hospital Leipzig, University of Leipzig, Leipzig, Germany
e-mail: focke.ziemssen@medizin.uni-leipzig.de

F. Ziemssen
Centre for Ophthalmology, Eberhard Karl University of Tübingen, Tübingen, Germany

M. Sylvanowicz
Bayer Consumer Care AG, Basel, Switzerland

W. M. Amoaku
Queen's Medical Centre, Nottingham, UK

T. Aslam
Manchester Royal Eye Hospital, NHS Central Manchester University Hospitals and University of Manchester, Manchester, UK

B. Eldem
Department of Ophthalmology, Hacettepe University, Ankara, Turkey

R. P. Finger
Department of Ophthalmology, University Medical Centre Mannheim, University of Heidelberg, Mannheim, Germany

similar questions about their perspectives; and clinic characteristics were also captured.

***Results*:** Overall, 5681 surveys were gathered: 3752 from patients with diabetic macular edema, 680 from providers, and 1249 from clinic staff. Too many appointments, too short treatment intervals, difficulties in traveling to the clinic or arranging adequate support to travel, out-of-pocket costs, office/parking fees, and long waiting times were noted by all as contributing to increase the burden on the patient and caregiver. Patients generally desired more in-depth discussions with their provider, which would help with information exchange and better expectation-setting.

***Conclusions*:** The wealth of systematic data generated by this global survey highlights the breadth and scale of challenges associated with the clinical management of patients with diabetic macular edema. Addressing the opportunities for improvement raised by patients, providers, and clinic staff could increase patient adherence to treatment, reduce appointment burden, and improve clinic capacity.

Keywords: Diabetes; Macular edema; Patient experience; Visual outcomes

R. P. Gale
York and Scarborough Teaching Hospital NHS Foundation Trust, York, UK

L. Kodjikian
Service d'Ophtalmologie, Hôpital Universitaire de La Croix-Rousse, Hospices Civils de Lyon, Lyon, France

L. Kodjikian
Laboratoire UMR-CNRS 5510 MATEIS, INSA, Université Lyon 1, Villeurbanne, France

J.-F. Korobelnik
Service d'Ophtalmologie, CHU Bordeaux, Bordeaux, France

J.-F. Korobelnik
Universitaire Bordeaux, INSERM, BPH, UMR1219, 33000 Bordeaux, France

X. Lin
Guangdong Provincial Key Laboratory of Ophthalmology and Visual Science, Zhongshan Ophthalmic Center, Sun Yat-sen University, Guangzhou, China

A. Loewenstein
Department of Ophthalmology, Faculty of Medicine, Tel Aviv Medical Center, Tel Aviv University, Tel Aviv, Israel

P. Mitchell
University of Sydney (Westmead Institute for Medical Research), Sydney, NSW, Australia

M. Murphy
Exploristics Ltd, Belfast, Northern Ireland, UK

D. R. Owens
Swansea University Medical School, Swansea, Wales, UK

N. Parker
The International Agency for the Prevention of Blindness, London, UK

I. Pearce
Royal Liverpool University Hospital, Liverpool, UK

F. J. Rodríguez
Fundación Oftalmologia Nacional, Escuela de Medicina y Ciencias de la Salud, Universidad del Rosario, Bogotá, Colombia

J. Stern
The International Agency for the Prevention of Blindness, Sydney, Australia

S. J. Talks
The Newcastle Upon Tyne Hospitals NHS Foundation, Newcastle Upon Tyne, UK

D. T. Wong
Department of Ophthalmology and Vision Sciences, St. Michael's Hospital, University of Toronto and Unity Health Toronto, Toronto, ON, Canada

T. Y. Wong
Tsinghua Medicine, School of Clinical Medicine, Beijing, China and Singapore Eye Research Institute, Singapore National Eye Center, Singapore, Singapore

J. Barratt
International Federation on Ageing, Toronto, ON, Canada

Key Summary Points

Patients receiving therapy for retinal disease in routine clinical practice experience various challenges that can often result in high patient and clinic burden, and contribute to suboptimal visual outcomes.

This study aimed to understand the challenges associated with clinical management of diabetic macular edema from the perspectives of patients, healthcare providers, and clinic staff.

Systematic data generated through this global survey revealed challenges (including disease and appointment burden, comprehension of disease, and expectation-setting) and opportunities (including improving patient-doctor conversations and access to appropriate education materials for patients, facilitating better appointment coordination, and increasing the role of the caregiver).

Quantifying the scale of these barriers and opportunities could help to provide practical and meaningful interventions to reduce patient burden, and to improve treatment adherence and clinic capacity.

INTRODUCTION

Approximately 8.4% of the global population is living with diabetes, which is predicted to increase to 10% by 2045 [1]. Diabetic retinopathy (DR) is a major microvascular complication that affects approximately 35% of people with diabetes; a third of these (1–13% overall) progress to develop serious DR, including diabetic macular edema (DME) [2, 3]. Thus, DR and DME are leading causes of blindness and vision impairment [4, 5], with prevalence projected to increase alongside a rapidly aging global population.

The current gold standard treatment to prevent vision loss with DME is regular intravitreal anti-vascular endothelial growth factor (VEGF) injections [6]. Over the past 15 years, various treatments have been trialed and licensed for treating DME, including ranibizumab [7], aflibercept (2 mg and 8 mg) [8, 9], brolucizumab [10], and faricimab [11]. While clinical trials have demonstrated that regular and proactive treatment can result in the maintenance and improvement of vision [12, 13], life-long and regular treatment is often required to maintain vision in the long term. As such, a considerable burden on patients and their families, as well as on physicians and the healthcare system, is associated with this treatment. In real-world settings, various medical and non-medical factors (e.g., administrative, clinic, and patient-related) may lead to many patients receiving fewer than the label-recommended number of injections [14, 15]. Addressing adherence to, and persistence with, treatment and follow-up is a major goal in the management of retinal diseases [16, 17].

To date, few studies have examined the factors impacting real-world treatment of DME. Here, we report the outcomes from a global survey of patients with DME, their healthcare providers (HCPs), and associated clinic staff that aimed to provide deeper insights and broader perspectives on treatment and support for DME. The primary objective of the study was to identify the challenges and opportunities associated with managing DME from the perspectives of these three groups.

METHODS

Survey Setting and Design

The global survey was designed by members of the Barometer Program, an international coalition of experts in retinal disease, vision care, and aging who work to optimize clinical practice and improve treatment outcomes by considering the perspectives of patients, caregivers, and HCPs. The survey was developed according to guidelines from the Declaration of Helsinki and the World Health Organization's International Ethical Guidelines for Biomedical Research. As a Primary Market Research Survey, ethics committee approvals are not required; however, local

requirements were assessed by individual institutions and countries. No personally identifiable information was collected, and the survey did not inform treatment decisions. Appendix 1 (electronic supplementary material) provides details. The survey was conducted with 78 participating ophthalmology clinics across six regions: North America, South America, Europe, Africa, the Middle East, and Asia–Pacific. Appendix 2 (electronic supplementary material) describes the participating clinics.

Each clinic completed an online questionnaire that covered topics such as the location of the clinic (and sector), communication between other (clinic/hospital) departments, appointment logistics, and participation in clinic audits.

Data were collected by paper-based optical mark recognition (OMR) surveys without collecting any personally identifiable information. In participating clinics, surveys were completed by patients who were currently receiving (or had previously received) anti-VEGF injection therapy for center-involved DME; HCPs (providers, hereafter) who prescribe and/or administer anti-VEGF injections for the treatment of DME, and allied clinic staff members who did not prescribe or administer anti-VEGF injections for the treatment of DME but regularly interacted with patients. Surveys were translated into the relevant language(s) and validated by an independent translational company and designated country translator for the survey sponsor. In parallel, data on patients with DR and neovascular age-related macular degeneration (nAMD), and providers and clinic staff who interacted with patients with nAMD, were collected via separate surveys designed and developed by the Barometer Program (encompassing different questions relevant for these populations), which will be reported separately given the differences in challenges between diseases. Surveys were completed by participants at the clinic or at home; support in completing the surveys was allowed. Data collection at each clinic was expected to span 3 months; however, clinics not meeting their recruitment targets were given additional time. All data were collected between June 2021 and October 2022 when countries were at various stages of risk, response, and recovery following the COVID-19 pandemic.

Survey Content

The surveys were based on a previously conducted large-scale survey on DR [18, 19]. The diabetes survey collected information on disease awareness, experience within the clinic, and access to healthcare services. Within this diabetes survey, questions covered experience with treatment, the patient's overall healthcare, access to screening, and status of DR. The diabetes survey was a qualitative study, and was not validated systematically. For more information, please see Appendix 3 (electronic supplementary material).

For this survey, two pilot studies were performed in four clinics to ensure the questions planned for this global survey were clear and appropriate. Formal criteria and item validity were evaluated, as well as practical aspects of recording (readability, content, and scope). Appendix 3 (electronic supplementary material) describes the questions included in each survey. No clinical data, such as visual acuity, morphology, or underlying disease, were collected in this survey. Data on adherence to treatment will be reported separately.

Data Analysis

All questions were summarized by the number and percentage of individuals selecting each option. Question statements that had a Likert scale rating for 'Strongly Agree' and 'Somewhat Agree' were combined as 'Agreement'; and for 'Strongly Disagree' and 'Somewhat Disagree' as 'Disagreement'. Statements asking responders to gauge the importance of a topic were combined ("Extremely important" and "Very important" as "Important"). Missing data were handled conservatively. Assumptions were made in handling inconsistent responses to ensure information deemed to be correct was collected (according to discrepancy rules).

RESULTS

Demographics and Baseline Characteristics

There were 5681 survey participants: 3752 patients with DME, 680 providers, and 1249

clinic staff (Table S1). The majority of providers were retinal specialists (44.9%) and general ophthalmologists (28.2%). The majority of clinic staff were ophthalmic nurses who did not administer anti-VEGF therapies (22.6%) and optometrists (16.2%).

Regarding the 78 clinics, 52.6% were standalone eye clinics, and 26.9% were eye clinics within a hospital. Most were in an urban setting (89.7%). A similar proportion were either public (39.7%) or private (37.2%) (Table S2).

Table 1 provides demographic information for patients. Further demographic information can be found in Appendix 4 (electronic supplementary material).

Key Challenges in Patient Care

Patients

Table 2 reports the key challenges that patients with DME face regarding their disease burden, and comprehension of the disease and treatment. When asked about their DME treatment, 6.6% of patients believed it was not a priority, and 25.9% of patients doubted whether it was necessary. Additional challenges identified by patients related to appointment burden were: traveling to the clinic (ability/distance/cost) (48.4%), long periods of waiting during the appointment (48.0%), other chronic health conditions (45.0%), and it is hard for an accompanying person to attend (40.8%). Figure 1 depicts the contribution of comorbidities to difficulties in attending eye appointments. Further patient challenges can be found in Appendix 4 (electronic supplementary material).

Providers

Providers reported other challenges that they believed made it difficult for patients to manage their DR/DME (Fig. 2); primarily, comorbidities outside the eye. Poor patient adherence within the first year of treatment is perceived as a challenge in 78.2% of providers' clinics. Further challenges reported by providers can be found in Appendix 4 (electronic supplementary material).

Clinic Staff

Clinic staff were generally in agreement with providers on the perceived challenges for patients in managing their DR/DME: chronic health conditions, personal costs, and being a burden to family and friends (Appendix 4).

Key Opportunities to Improve Patient Care

Key opportunities to provide better support included appointment reminders, financial assistance with all aspects of appointment visits and treatment costs, better informational material, more holistic care within the clinic (additional time with providers to discuss disease and treatment, and additional diabetes/DME services within their clinics), less frequent appointments and longer time between appointments without losing vision, and an information pack for employers to explain DME and the need for regular treatment (Table 3 and Table S3).

Additional Findings

Addressing Treatment-Related Opportunities

Patients and providers agreed that patients would accept more treatment if it allowed them to keep their vision (90.6 and 89.6%, respectively), that increasing the timeframe between treatments is important (78.4 and 81.2%, respectively), and that extra support to stay on treatment would be beneficial (68.4 and 85.6%, respectively). Clinic staff were generally in agreement with providers.

How Informed Do Patients Feel Regarding Their Disease, Treatment, and Available Support?

The level to which patients felt informed about their disease, treatment, and support options was assessed in the survey (Table S4). Significant proportions of patients reported being unsure about their disease and if their treatment was

Table 1 Demographic information for patients with DME

Question	Total number of patients with DME, *n* (%) *N* = 3752
How old are you (years)?	
18–29	57 (1.5)
30–39	151 (4.0)
40–49	474 (12.6)
50–59	1063 (28.3)
60–69	1187 (31.6)
70–79	596 (15.9)
80–89	119 (3.2)
≥ 90	4 (0.1)
No option selected	101 (2.7)
What is your gender?	
Female	1676 (44.7)
Male	1969 (52.5)
Other	5 (0.1)
No option selected	102 (2.7)
Which category best describes you?	
African	491 (13.1)
Asian	893 (23.8)
Black or African American	28 (0.7)
Hispanic, Latino, or Spanish origin	588 (15.7)
Indian	419 (11.2)
Middle Eastern	113 (3.0)
Native American	60 (1.6)
Western Pacific	9 (0.2)
Of European descent	477 (12.7)
Multiple ethnicities or origins	58 (1.5)
Other	130 (3.5)
Prefer not to answer	283 (7.5)
No option selected[a]	203 (5.4)

Table 1 continued

Question	Total number of patients with DME, *n* (%) *N* = 3752
What is the highest educational degree you have completed?	
Have not received formal education	764 (20.4)
Secondary degree	1794 (47.8)
University degree or further	1048 (27.9)
No option selected	146 (3.9)
What is your employment status?	
Employed/self-employed	1283 (34.2)
Retired	1239 (33.0)
Homemaker	649 (17.3)
Unemployed but willing to work	164 (4.4)
Unable to work due to health reasons	285 (7.6)
No option selected	132 (3.5)
Where do you live?	
Urban setting (i.e., large metropolis city)	2092 (55.8)
Suburban setting (i.e., residential area outside of a large city)	1021 (27.2)
Rural setting (i.e., countryside)	534 (14.2)
No option selected	105 (2.8)
Which type of diabetes do you have?	
Type 1	483 (12.9)
Type 2	2624 (69.9)
Gestational	29 (0.8)
I do not know	491 (13.1)
No option selected	125 (3.3)
How long do you spend attending your DME appointments?	
Less than 2 h	746 (19.9)
2 h to less than 4 h	1274 (34.0)
4 h to lessthan 6 h	886 (23.6)
6 h to less than 8 h	371 (9.9)
8 h to less than 10 h	147 (3.9)
10 h or more	192 (5.1)

Table 1 continued

Question	Total number of patients with DME, *n* (%) *N* = 3752
No option selected	136 (3.6)
For most of your DME appointments, who accompanies you?	
No one accompanies me	659 (17.6)
Spouse	1274 (34.0)
Child	1037 (27.6)
Sibling/extended family member	374 (10.0)
Friend/neighbor	99 (2.6)
Regular paid caregiver/health worker	30 (0.8)
Usually a different person each time	287 (7.6)
No option selected	116 (3.1)

DME diabetic macular edema

[a]Legislature in France does not allow for the collection of information on race or ethnicity, thus these patients are included in the "No option selected" category; race or ethnicity was not collected for patients from Switzerland

working (Table 2). Patients reported that family doctors and diabetes specialists were the most useful sources to better understand their DME, but fewer patients reported using other sources.

Expectations

Figure S1 depicts the information reported to be available to patients to communicate what DME is and what the patient should expect over time with treatment. Many patients with DME were unsure how long treatment would be required (41.1%) and how many treatments they were likely to have in the next 12 months (41.6%). Many patients with DME expected their vision to significantly improve (45.1%) or slightly improve (38.0%) as they continued with treatment.

Timing and Level of Discussion Around Disease, Treatment, and Support Topics

In the first 3 months of diagnosis/treatment of DR/DME, the majority of providers reported always discussing: the risks that DR/DME could result in vision loss (59.9%), the correlation between diabetes and risk of complications (58.4%), a basic explanation of DR/DME (57.2%), and how improving diabetes control can reduce disease progression (56.2%). Less frequently discussed topics included: the frequency of treatment (41.6%), what to expect with vision change over time following treatment (40.3%), the duration of treatment (39.3%), and what to expect after completing the first year of treatment (26.5%). Fewer providers reported that they always cover topics such as how to include family or friends in the patient's care (23.7%), and how to access more information on DR/DME or support services (19.6%).

Clinic staff generally reported similar levels of discussion as providers with the patient during the first 3 months, and also said that they frequently talk about challenges that patients might face with attending appointments.

Table 2 Key challenges reported by patients with DME

n **= 3752**	**Agree, *n* (%) *N* = 3752**	**Disagree, *n* (%)**	**No option selected, *n* (%)**
Burden of disease			
I am concerned about being a burden to family/friends	1970 (52.5)	1539 (41.0)	243 (6.5)
The frequency of treatment can be too much	1939 (51.7)	1584 (42.2)	229 (6.1)
The personal costs associated with the drug itself are challenging	1847 (49.2)	1650 (44.0)	255 (6.8)
Limitations on number of treatments covered by insurance makes it difficult for me	1415 (37.7)	1985 (52.9)	352 (9.4)
I am fearful of the treatment procedure itself	1388 (37.0)	2108 (56.2)	256 (6.8)
The pain during/after the procedure is too much for me	1090 (29.1)	2397 (63.9)	265 (7.1)
I prioritize other health issues over my treatment	1078 (28.7)	2442 (65.1)	232 (6.2)
I tend to just forget about my appointments	888 (23.7)	2608 (69.5)	256 (6.8)
Disease and treatment comprehension			
I do not really understand my disease and/or treatment need	1078 (28.7)	2390 (63.7)	284 (7.6)
I am not sure if treatment is working as my vision is either not getting better or is getting worse	1046 (27.9)	2464 (65.7)	242 (6.4)
I am not sure the effort associated with treatment is worth it	1002 (26.7)	2517 (67.1)	233 (6.2)
I feel treatment was successful and I no longer need it	986 (26.3)	2515 (67.0)	251 (6.7)
Receiving treatment is just not that important to me	733 (19.5)	2772 (73.9)	247 (6.6)
I am not concerned with the risk of losing vision	774 (20.6)	2752 (73.3)	226 (6.0)

DME diabetic macular edema

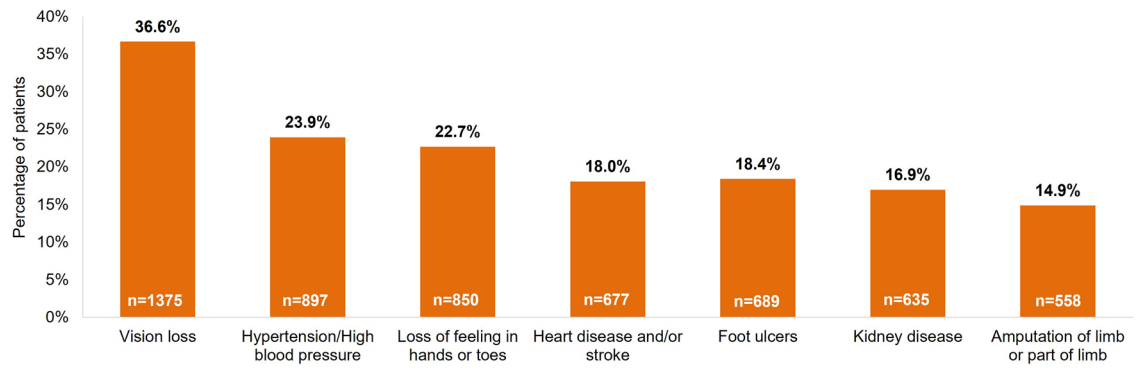

Fig. 1 Comorbidities experienced by patients with DME that make it difficult to attend eye appointments. *DME* diabetic macular edema

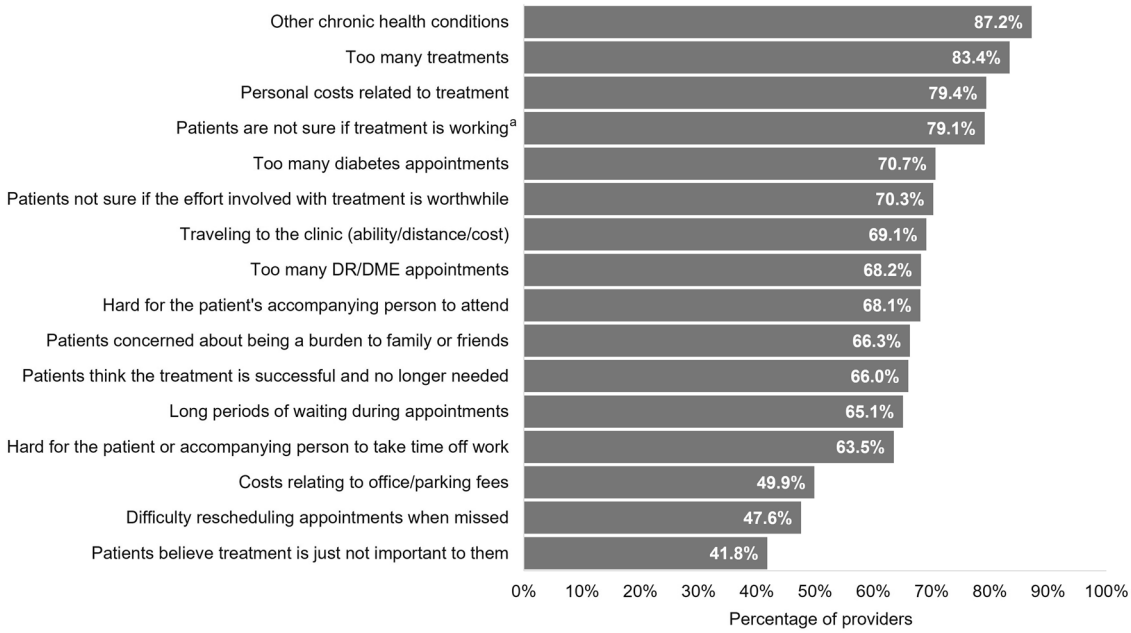

Fig. 2 Challenges that make it difficult for patients to manage their DR/DME from the provider perspective ($N = 680$). [a]Patients were unsure if their treatment was working because their vision was not improving or was declining. *DME* diabetic macular edema, *DR* diabetic retinopathy

Formal Training on Aspects of Patient Care Management

Figure S2 depicts a summary of the levels of training that providers have received regarding key aspects of care. Between 19 and 37% of providers and clinic staff indicated that they would like to receive training in each aspect of patient care.

DISCUSSION

This comprehensive systematic survey of 5681 participants from 78 clinics around the world highlighted key challenges in the management of DME, including the significant disease and appointment burden, patient comprehension of disease, and expectations with treatment. These data indicate a great opportunity for improvement in the clinical management of patients with DME by addressing modifiable factors, but also highlight a disconnect between the perceptions of patients and providers. These data highlight the breadth and scale of these challenges worldwide, and provide important insights into opportunities to tackle these issues.

Beyond optimizing patient care, patient satisfaction is intrinsically linked to their experience inside and outside the clinic [20–22]. There are various factors that contribute to a patient's difficulties or burden with appointment attendance—beyond the requirement to come to the clinic for therapy via a fully aseptic surgical procedure, patients have additional direct and indirect out-of-pocket costs (e.g., drug-related costs, and office/parking fees), and long waiting times. While data from this survey helped to confirm the importance of many challenges and barriers to patients, it was noted that almost all patients were willing to accept more treatment if they could retain their vision (an opinion shared by almost all providers). Patients generally prioritized their treatment; however, compounded appointment burden causes frustration and could result in sub-optimal adherence, and the expectation of a reduction in treatment frequency following the first year could be communicated better to patients.

Table 3 Summary of the importance of opportunities to provide better support for managing DME from the perspective of patients, providers, and clinic staff

Statement	Total number of patients with DME, *n* (%) *N* = 3752	Total number of providers *n* (%) *N* = 680	Total number of clinic staff *n* (%) *N* = 1249
Appointment reminders sent by the clinic			
Extremely important	1941 (51.7)	314 (46.2)	732 (58.6)
Very important	1077 (28.7)	292 (42.9)	377 (30.2)
Transportation assistance to attend treatment/office visits			
Extremely important	1284 (34.2)	182 (26.8)	375 (30.0)
Very important	1118 (29.8)	283 (41.6)	436 (34.9)
Financial assistance with office/parking fees			
Extremely important	1193 (31.8)	167 (24.6)	321 (25.7)
Very important	960 (25.6)	238 (35.0)	390 (31.2)
Financial assistance with DR/DME drug/prescription costs			
Extremely important	1702 (45.4)	294 (43.2)	441 (35.3)
Very important	1039 (27.7)	265 (39.0)	489 (39.2)
Ability to monitor vision accurately with a home monitoring machine			
Extremely important	1384 (36.9)	182 (26.8)	353 (28.3)
Very important	1131 (30.1)	332 (48.8)	500 (40.0)
Medical services/treatment that travel to or near the patient's home			
Extremely important	1388 (37.0)	183 (26.9)	362 (29.0)
Very important	1205 (32.1)	308 (45.3)	518 (41.5)
Dedicated nurse in the clinic to provide guidance to improve diabetes management and answer questions about DR/DME			
Extremely important	1566 (41.7)	240 (35.3)	516 (41.3)
Very important	1254 (33.4)	308 (45.3)	498 (39.9)
More time for the doctor to answer questions/concerns at each appointment			
Extremely important	1695 (45.2)	269 (39.6)	565 (45.2)
Very important	1277 (34.0)	330 (48.5)	535 (42.8)
Extra time with the doctor to plan the next 6 months of treatment			
Extremely important	1485 (39.6)	212 (31.2)	433 (34.7)
Very important	1406 (37.5)	342 (50.3)	568 (45.5)
Phone consultations to answer any questions/concerns			
Extremely important	1615 (43.0)	171 (25.1)	490 (39.2)
Very important	1295 (34.5)	281 (41.3)	489 (39.2)

Table 3 continued

Statement	Total number of patients with DME, *n* (%) *N* = 3752	Total number of providers *n* (%) *N* = 680	Total number of clinic staff *n* (%) *N* = 1249
Always having the same clinic staff and doctor treating the patient			
Extremely important	1948 (51.9)	230 (33.8)	427 (34.2)
Very important	1165 (31.1)	295 (43.4)	471 (37.7)
Proactive discussion by doctor/clinic staff about any challenges the patient may have			
Extremely important	1822 (48.6)	241 (35.4)	476 (38.1)
Very important	1319 (35.2)	346 (50.9)	582 (46.6)
If DME in both eyes, treat both eyes on the same day			
Extremely important	1390 (37.0)	207 (30.4)	439 (35.1)
Very important	935 (24.9)	185 (27.2)	429 (34.3)
Less frequent appointments without losing vision			
Extremely important	1531 (40.8)	270 (39.7)	361 (28.9)
Very important	1283 (34.2)	335 (49.3)	558 (44.7)
Longer time in between treatments without losing vision			
Extremely important	1586 (42.3)	296 (43.5)	395 (31.6)
Very important	1200 (32.0)	293 (43.1)	529 (42.4)
Lifting of reimbursement restrictions			
Extremely important	1391 (37.1)	262 (38.5)	399 (31.9)
Very important	1028 (27.4)	258 (37.9)	438 (35.1)
Regular treatment (monthly/bi-monthly) in the first year and then reduced treatment (couple of times a year) afterwards			
Extremely important	1409 (37.6)	321 (47.2)	591 (47.3)
Very important	1270 (33.8)	300 (44.1)	521 (41.7)
An information pack for a supervisor/teacher to explain DR/DME and the need for frequent eye appointments to justify missed time at work/school			
Extremely important	1064 (28.4)	218 (32.1)	524 (42.0)
Very important	1065 (28.4)	320 (47.1)	529 (42.4)
Opportunity to join a peer-to-peer support group			
Extremely important	907 (24.2)	199 (29.3)	382 (30.6)
Very important	964 (25.7)	303 (44.6)	518 (41.5)
More involvement of the person who accompanies the patient in their care			
Extremely important	1052 (28.0)	230 (33.8)	446 (35.7)
Very important	1304 (34.8)	334 (49.1)	575 (46.0)

Table 3 continued

Statement	Total number of patients with DME, *n* (%) *N* = 3752	Total number of providers *n* (%) *N* = 680	Total number of clinic staff *n* (%) *N* = 1249
Better material available to improve understanding of DR/DME			
Extremely important	1408 (37.5)	252 (37.1)	542 (43.4)
Very important	1305 (34.8)	320 (47.1)	555 (44.4)
Coordination of diabetes appointments by a professional			
Extremely important	1517 (40.4)	269 (39.6)	531 (42.5)
Very important	1291 (34.4)	313 (46.0)	532 (42.6)
Providing diabetes care services within the eye clinic			
Extremely important	1646 (43.9)	252 (37.1)	532 (42.6)
Very important	1228 (32.7)	288 (42.4)	491 (39.3)
Providing eye care services within the diabetes clinic			
Extremely important	1573 (41.9)	280 (41.2)	559 (44.8)
Very important	1185 (31.6)	293 (43.1)	464 (37.1)

All questions were asked from the perspective of the respondent

DME diabetic macular edema, *DR* diabetic retinopathy

While appointment and disease burden are understood to adversely impact optimal patient outcomes [22–24], the data from this systematic survey point to specific options to address these challenges. More effective use of clinic staff to assist with information provision [23] could help providers to focus their discussions during appointments on treatment efficacy and outlook. Continuous professional education of providers and clinic staff is highly advantageous to empower meaningful conversations and collaborations to reduce patient and clinic burden [25]. Furthermore, providing additional diabetes care services within the eye clinic, and vice versa, could improve clinic capacity; however, this requires significant coordination and infrastructure.

Uncertainty around treatment expectations and having the opportunity to ask questions were key challenges faced by patients. Many patients did not receive written or digital information about their disease and its treatment, and frequently providers and clinic staff said that was unavailable. There is a clear need to improve the quality and availability of informational materials tailored to patients' needs and to allow for additional time dedicated to patient conversations, to ensure that patients have appropriate expectations of treatment. Addressing factors that would improve clinic capacity could allow providers to spend additional time with patients to ensure alignment on disease and treatment information, and appropriate expectation-setting.

The people who accompany patients to and from their appointments often remain an underappreciated resource [26]. Many caregivers struggle to take time off work to accompany patients, so support for caregivers (for example, caregiver networks), or information packs for caregivers' employers (and indeed for patient's employers) to explain why patients need to be accompanied to regular appointments would help patients to feel less of a burden to their caregivers, especially as in many cases they are direct relatives.

Longer-duration therapies represent the next innovation in improving patient care and reducing injection burden, appointment

burden, and potentially improving both patient adherence and clinic capacity. Newer therapies promise a realistic prospect of reducing burden through longer intervals (for example, 16-week intervals observed in clinical trials of faricimab for DME [27], and up to 20-week intervals in the PHOTON trial of aflibercept 8 mg for DME [9, 28]). The relationship between longer treatment intervals and how this affects adherence to, and persistence with, treatment warrants further investigation [29]. Home monitoring technologies might additionally reduce the number of in-person appointments [30].

It is important to understand these results in the context of how these data were collected. While surveys were collected consecutively at each participating center, thus being of representative character, factors affecting participation, such as a lack of motivation, severe mental limitations, time constraints, and the inability to overcome or insufficient means of overcoming of communication limitations will have influenced the data collection. Furthermore, considering the potential of multiple modes of bias, conclusions from these data must be carefully evaluated. Steps were taken to reduce such bias where possible; for example, by using closed questions, independently validating the local-language translation of surveys, and maintaining a focus on current opinions to avoid recall bias. The approach to data collection was designed to maximize participation; therefore, survey participants (including the proportion of non-adherent patients) may not be representative of the population of clinics. Data were collected on patients who were non-persistent; however, due to the low number of respondents (the patient may not have visited the clinic during the data collection period), no meaningful conclusions were drawn. Data should be understood in the context of collection during the COVID-19 pandemic. While this survey generated by Barometer Program members was not systematically validated, those who developed and reviewed the survey are experts across the field of the retina, and in patient advocacy. The survey was constructed based on a prior (unvalidated) survey for patients with diabetes developed by the same group (which focused primarily on access to healthcare and screening, and DR topics), and learnings from this development and review process were implemented in this survey understanding the impact of intravitreal injections for DME on patients, providers, and clinic staff, to ensure survey robustness.

CONCLUSION

The wealth of detailed data generated by this global survey demonstrates key areas where challenges to optimal care and management of patients with DME still exist. Prior to this research, such barriers were known. However, the differences in the reported barriers between patients and practitioners demonstrated the need to intensify evaluation—a treatment that is discontinued or not started at all can have no benefit. This survey systematically quantifies the scale of these barriers from various important perspectives, and identifies practical policy and clinical practice solutions to drive improvements in clinical management of DME. Improving conversations between provider and patient, providing appropriate educational materials and access to these for patients, facilitating better coordination of appointments, increasing uptake of therapies designed to lengthen treatment intervals, and helping caregivers to be more involved in patients' treatment all serve to optimize vision outcomes, improve adherence to treatment, reduce appointment burden, and ultimately improve clinic capacity.

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Declarations

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