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Perspectives in Practice

## Blind Spots: Gaps in Disease Knowledge and the Role of Patient Education for Canadians With Diabetic Macular Edema

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### Key Messages

- The burden of diabetic macular edema is significant, but treatment adherence is poor.
- Low disease education may be a contributing factor, and further research is needed to understand how and when to provide information tailored to specific patients.

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### Introduction

Over a decade ago, anti vascular endothelial growth factor (anti-VEGF) injections emerged as a viable treatment for diabetic macular edema (DME), the leading cause of new blindness among working-age adults in North America (1). By targeting VEGF, the signal protein that stimulates abnormal blood vessel growth in DME, the injections offered a new approach to managing vision loss resulting from DME, largely replacing vitrectomy and laser surgery as frontline therapy (2,3). Time-release implants have been used in some cases as well, and show promise (4). However, health care is a provincial responsibility in Canada, with each jurisdiction making its own treatment funding decisions; most provincial coverage plans offer either no coverage for implants, or coverage based on a very restricted set of eligibility criteria. Anti-VEGF injections have demonstrated good effectiveness (5,6), but for optimal benefit in terms of preservation of vision, patients must undergo injections on a regular basis. Studies have demonstrated that adherence is far from optimal (7–10).

### Burden of DME Survey Results

To examine the issue of anti-VEGF adherence among Canadians with DME, Fighting Blindness Canada (FBC) conducted a national survey. A number of valuable insights were gleaned from patient responses, but perhaps most surprisingly, the key study learning came not from the findings themselves but from our challenges with recruitment. Given our small sample size, the representativeness of our results is uncertain. However, we learned that there are potential gaps in patient disease awareness and understanding that may be contributing to nonadherence to prescribed treatments.

More than two-thirds of our survey's 64 respondents reported their DME as "fairly serious" or "very serious," and 88% reported a negative impact on quality of life, supporting the results of recent patient research (11). Of all respondents, 62.5% were employed and, among this group, 92.5% indicated that DME negatively affected their ability to work. The impact of ophthalmologist appointments on patient time was significant: 50% of working respondents

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reported taking at least 4 hours off per injection appointment, with many absent for the entire day. One third of respondents who were treated with anti-VEGF injections also reported noncompliance with their injection schedule, with injection anxiety flagged as a primary reason for delaying or missing appointments. In earlier studies of patients undergoing injections for DME and wet age-related macular degeneration, 50% to 64% had expectations of discomfort worse than what they actually experienced, and the feelings of stress and anxiety evoked by the procedure were significant enough to prompt some patients to defer treatment (12,13). The prominent role played by stress in relation to adherence is supported by our own survey results.

### Low Disease Awareness

As stated, we experienced several challenges when recruiting survey participants. When collaborating with ophthalmologists to develop the survey, we noted that, in previous reports of eye diseases, recruiting a large sample of vision-impaired individuals had been an obstacle to representative research (14). This was borne out in our own recruitment efforts. Although we utilized a variety of mechanisms, including large online polling panels, our own databases and signs in physicians' offices, we found that identifying individuals with DME was far more difficult than what we had experienced with other eye conditions, even significantly rarer inherited retinal diseases.

Our study postmortem identified several reasons for this obstacle, most significantly low patient awareness related to their disease. Even when we expanded our eligibility criteria from "individuals with DME" to "individuals with diabetes and swelling in the back of one or both eyes" in the hopes of engaging those who may not remember the name of their disease, we only marginally improved recruitment numbers. We followed up on this notion in poststudy interviews with patients (identified by the health-care provider as having DME), finding that, although many are aware that they have an eye condition and know that it is related to their diabetes, they are unaware of their condition's name. This lack of awareness suggests a considerable blind spot in the patient's familiarity with their diagnosis and the nature of their disease. In hindsight, patient engagement via ophthalmologists or family physicians could have been more successful than our more passive clinic approach (through signs with the survey link), as the providers would identify those with DME even if patients could not recall the name of the condition. This is supported by a review of the literature, which reveals that recruitment methods in DME studies typically involve access through health-care providers (15,16).

Our difficulty engaging patients with DME speaks not only to the existence of gaps or blind spots in disease knowledge, but also to the importance of patient education, particularly for this group.

Existing research shows that patients with DME harbour a wide range of feelings regarding their level of disease education: Some feel that they have been sufficiently informed about the nature of their condition, whereas others want more information about DME from their health-care providers (17). In studies of eye conditions, when disease knowledge is tested—such as by questions about disease progression, possible complications and prescribed medications—a subset of patients exhibited significant blind spots or gaps in awareness (18,19). This is concerning, as being knowledgeable about one's disease status, potential progression and treatment modalities is linked to higher patient satisfaction and well-being overall (20,21). Conversely, a poor understanding of one's own condition, including long-term prognosis with and without medical intervention, is associated with suboptimal adherence to medical treatment and recommendations (22,23).

Our results support recent studies conducted in the United Kingdom and the United States showing that individuals with DME often have low awareness of their condition, that it brings them considerable concern and worry and that >25% of appointments were cancelled or not attended by the patient (17,24). The implications of such blind spots related to DME are widespread, encompassing a potentially devastating impact on sight, and an overall reduction in quality of life. It is quite possible that the physical and emotional burden of routine intravitreal injections cannot be entirely overcome by increased patient knowledge of DME. However, ensuring that patients are informed of their disease trajectory and the importance of regular treatment can only enhance their ability to meaningfully engage in decisions about their care (should that be the patient's desired outcome).

### Patient-centred education for patient-centred care

Studies focused on the methods by which patients consume and accept information from their health-care providers have produced several profiles (17,25,26). For some, receiving as much information as possible at the time of diagnosis provides much needed reassurance, facilitating the planning of short-term decisions and management of long-term expectations. For others, the initial appointment with a health-care provider is so fraught with anxiety and distress that their ability to absorb and retain information, counselling and instruction is compromised. These patients are often more receptive to an incremental approach, where the acquisition of additional information from every provider interaction slowly develops a picture of their condition and optimal path forward, reducing the kinds of blind spots that can lead to poor health outcomes. Finally, there are a minority of patients who prefer minimal insight into their specific disease and the decisions required for its management. These individuals typically prefer to handle their diagnosis by placing absolute trust in their health-care provider, or by ignoring the reality of their condition in favour of maintaining a sense of pre-diagnosis normalcy. In a recent study of 810 patients with diabetic retinopathy, 17.4% preferred an ophthalmologist-dominated decision-making style and did not wish to participate in their treatment decisions (27). This approach is analogous to the car owner who leaves the details of their vehicle's repair to the mechanic, or the individual who leaves their contract's details to a lawyer; framed in this way it is perhaps unsurprising that a subgroup of patients leave health details to their health professional, and the degree to which such a position is widespread or socially normalized is worth studying on its own.

Other reasons for low disease awareness are not immediately clear. Are additional resources required to inform patients about DME in a more effective manner? Is the timing of the delivery of information an important factor that should be evaluated more closely? Should the initial "information dump" at diagnosis be spaced out? So much is being asked of specialists already. Should the initial delivery of disease information be provided by someone in a separate, specialized role, allowing ophthalmologists to focus on diagnosis and treatment? Educational materials for eye conditions are often written at a level that is too advanced for most patients (28). Could this be a factor? Are there other information delivery mechanisms not being considered, or is there a more effective way of combining existing mechanisms? In the FBC's engagements with patients, and as supported by previous research (24,26), it is clear that individuals with eye diseases often prefer to receive medical information from their physician. As a result, patients who receive limited information from their health-care providers, or who do not understand or retain what they do receive, may not supplement it with other sources. Could educational resources be utilized to provide patients with important information about their condition without increasing either their

appointment time burden or the work burden on already busy ophthalmologists? For instance, hand-held audiovisual aids in the waiting room could provide information on various topics related to DME and its management. Large monitors displaying the patient's imaging during their appointment may be helpful in bringing visual context to the ophthalmologist's words. Ancillary health professionals, such as ophthalmology-trained nurses, could reduce the burden of communication from specialists dealing with overflowing waiting rooms, by providing health-care pathway navigation to the patients onsite or over the telephone. Such initiatives should be piloted in ophthalmology practices to identify optimal modes of patient education for those who wish to be better informed about the complexities of DME.

At the FBC, we are reminded daily of the balancing act that individuals affected by blinding eye conditions must perform as they digest new and often alarming knowledge about their condition, try to minimize the life impact of their current vision impairment, and attempt to limit further progression. We recently developed an online resource called Vision Care Pathways that allows patients to self-navigate through information about their diagnosis, existing and emerging treatments, clinical trials and more, all tailored to their specific disease. The resource is supplemented by a range of individualized engagements that include telephone support, face-to-face meetings, educational sessions and specialized groups for diseases and demographics, all designed to reduce or eliminate blind spots. In combination, we have found that our online and in-person resources fill an educational gap produced by a health-care system that lays the burden of knowledge and system navigation on patients, often at the precarious time when they are processing a new diagnosis. However, there is still much that can be done to expand the ability of these and similar resources to speak to the specificity of a patient's needs. More work is clearly needed, especially to better understand what information patients want at diagnosis, what they actually receive and what their preferred format is for obtaining information over the course of their vision health journey.

### Vision for the Future

Treatment adherence is a complex, multifaceted issue. It is intertwined with a range of human factors spanning perceptions of disease, logistics, finances and other variables. The link to education implies that, although there is a minority of patients who prefer not to know more, there are likely others whose adherence could be positively affected through a reduction in disease-related blind spots—that is, with the right information, at the right time and through the appropriate format or mechanism. For those with DME, increased awareness could lead to slower disease progression and the maintenance of visual acuity. This speaks to the importance of developing resources that allow patients to learn about and manage their disease in a way that suits their individual needs. Additional research is essential to determine which services and supports may bring about more optimal treatment compliance and reduce the burden of DME.

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P.Y. has received compensation for consulting, speaking and serving on an advisory board from all companies that make treatments for diabetic macular edema (Novartis, Allergan and Bayer). J.A.P. acted in the capacity of a consultant for Fighting Blindness Canada. C.A. has no conflicts of interest to declare.

### Author Contributions

C.A. conceived the study, J.A.P. conducted analysis and all authors interpreted the data. All authors were involved in the development of the article and approved the final version submitted for publication.

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