



Living Without a Diagnosis: A Patient's Perspective on Diabetic Macular Ischemia

Jacqueline D. Humphreys · Sobha Sivaprasad

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ABSTRACT

Diabetic macular ischemia (DMI) is a common complication of diabetic retinopathy (DR) that can result in progressive and irreversible vision loss. DMI is associated with damage in the vessels that supply blood to the retina and the enlargement of the foveal avascular zone. Currently, there are no approved treatments specifically for DMI. Furthermore, there is limited published information about the prognosis, prevalence or outcomes of DMI, and there is no consensus regarding diagnostic criteria. It is vital to ensure that there is sufficient, accessible and accurate information available to support patients, caregivers and physicians. To lay the foundation for more research into DMI and its impact on patients, we (a patient with DMI and an expert ophthalmologist) have worked together to interweave our personal perspectives and clinical experiences with a review of currently available literature on DMI. The development of a set of

confirmed diagnostic criteria for DMI would assist both patients and physicians, allowing patients to access validated information about their condition and supporting the development of clinical trials for treatments of DMI. Training for physicians must continue to emphasise the importance of treating a patient holistically, rather than only treating their symptoms. Most importantly, developing trust and a healthy rapport between a patient and their physician is important in managing health anxiety and ensuring adherence to beneficial treatments or lifestyle adjustments; physicians must cultivate an open and flexible management approach with their patients. Finally, holistic educational programmes for patients, physicians and the general public around DMI and how it can affect daily functioning would facilitate general understanding and disease awareness.

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J. D. Humphreys
Patient Author, Swansea, UK

S. Sivaprasad (✉)
NIHR Moorfields Biomedical Research Centre,
Moorfields Eye Hospital, 162 City Rd, London EC1V
2PD, UK
e-mail: Sobha.sivaprasad@nhs.net

PLAIN LANGUAGE SUMMARY

Diabetic macular ischemia (DMI) is a common problem for patients with diabetic retinopathy that can lead to sight loss. There is very little information available about DMI, particularly from a patient's point of view. To address the lack of information about DMI, we (a person with DMI and her eye doctor) have worked together to examine what it is like to live with DMI. It is

important to provide clear and accessible information about diseases to patients and carers. The lack of information about DMI may be upsetting for some people, and should be addressed with more research. Developing of a set of confirmed signs and symptoms for the diagnosis of DMI would allow people to be more confident in the information that they receive about their disease, and support the development of treatments for DMI. The support of others is central to the well-being of people with vision loss. Although people with vision loss may also lose independence, care from loved ones can help to improve quality of life. Most importantly, developing trust between a patient and their doctor is central to managing people's fears about their eyesight, and making sure that they follow helpful advice. Doctors must use an open and flexible approach with their patients, providing information in an honest and understandable way.

Keywords: Diabetes; Diabetic macular ischemia; Diabetic retinopathy; Patient perspective; Qualitative; Quality of life; Retina

Key Summary Points

Diabetic macular ischemia (DMI) is a common complication of diabetic retinopathy (DR) that can result in progressive and irreversible vision loss.

To address the lack of available information about DMI, we (a patient with DMI and an expert ophthalmologist) have worked together to interweave our personal perspectives and clinical experiences.

Physicians must cultivate an open and flexible management approach with their patients, providing information in a digestible manner.

Development of a set of confirmed diagnostic criteria for DMI would allow patients to access validated information about their condition and support clinical trials for treatments of DMI.

DIGITAL FEATURES

This article is published with digital features, including audioslides, to facilitate understanding of the article. To view digital features for this article go to <https://doi.org/10.6084/m9.figshare.20122640>.

INTRODUCTION

Diabetic retinopathy (DR) is a vision-threatening condition that can arise in patients with type 1 or 2 diabetes, and is the leading cause of blindness among people of working age in developed countries [1–3]. Diabetic macular ischemia (DMI) is a common complication of DR that can result in progressive and irreversible vision loss [4–7]. Although DR is well studied, with several treatment options available depending on disease stage and severity [8–12], there is limited published information on the prognosis, prevalence or outcomes of DMI and no consensus regarding diagnostic criteria. As a result, although comparisons can be made with existing research into related conditions, such as DR and other diseases that cause vision loss, accessible information specifically on DMI is scarce in comparison to information on other retinal conditions. Furthermore, there are currently no approved treatments specifically for DMI [6]; instead, guidelines tend to focus on the management of risk factors that lead to the development of DR (e.g. optimising glycaemic and blood pressure control) [12]. This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

What is Diabetic Macular Ischemia?

Although there is no consensus on the diagnostic features of DMI and very little clinical research in the field, a number of characteristics are associated with its onset and progression. DMI is linked to damage in the vessels that supply blood to the retina—specifically in layers

known as the superficial vascular complex, deep vascular complex and choriocapillaris [13–17]. These layers supply oxygen to the macula, which is the central part of the retina responsible for sharp, high-quality vision [18]. Reduced retinal blood flow and vessel density have been associated with photoreceptor disruption and subsequent vision loss [18–20]. In addition, DMI is characterised by the enlargement of the foveal avascular zone (FAZ), which in turn is linked to vision loss [21–23]. DMI often occurs alongside other complications of DR, most notably diabetic macular edema (DME), which is the result of excess fluid in the macula, although the relationship between DMI and DME is not clear [24, 25].

Although the global prevalence of visual impairment and blindness is generally decreasing, visual impairment specifically as a result of DR continues to increase [26]. Vision loss in patients with moderate-to-severe DMI may reach ‘20/80 vision’, which is the equivalent of seeing at 20 ft what a person with normal vision (20/20) would see at 80 ft [4]. However, vision as poor as 20/400 has been reported [27]. As a result of a lack of consensus regarding the diagnosis of DMI, it is difficult to determine exactly how many people have the disease; however, research suggests that up to 77% of patients with the most severe form of DR (proliferative DR) may have DMI [4]. In addition to progressive and irreversible vision loss [4, 6], DMI may increase the chance of developing further complications, including DME [6]. As DMI can result in permanent vision loss, there is an urgent need for effective treatment.

Two of the biggest factors limiting the study of DMI are the paucity of available data and a general lack of awareness of the condition among researchers, physicians and patients. In particular, there is no research focusing on the perspectives of patients who may have DMI, how well informed they feel about the disease, how it feels to have a condition with no treatment, or how a lack of formal diagnosis might affect their daily lives.

A PATIENT’S PERSPECTIVE ON DMI

To lay the foundation for more research into DMI and its impact on patients, we—Jacqueline Humphreys (a patient with DMI) and Sobha Sivaprasad (an expert ophthalmologist and Jacqueline’s treating physician)—have worked together to interweave our personal perspectives and clinical experiences with a review of currently available literature. Jacqueline is 61 years old, and qualified as a registered osteopath in 1984. She has been involved in osteopathic education alongside private practice for most of her career, and is currently a clinical tutor and lecturer for the Masters in Osteopathy course at Swansea University.

Jacqueline was diagnosed with DR prior to receiving a diagnosis of diabetes, and her symptoms have evolved over time. Although it is difficult to distinguish which experiences derive from DMI versus other complications of DR (as they frequently occur together), her experiences provide an invaluable and unique insight into living with DMI as part of DR, as well as the lived experience of vision loss in general.

Jacqueline’s Experience with Diagnosis of Vision Loss

“When I initially noticed problems, I thought it was just age-related eye changes”.

As we age, it is normal for our eyes to slowly deteriorate and to experience difficulty focusing on nearby objects or to need more light to see clearly [28]. Unfortunately, this means that it can be hard for an individual to distinguish the difference between natural age-related changes in vision and the onset of a disease.

“The optician was frankly not very straightforward. She kept sucking her teeth and making a funny face, and I asked, ‘What are you seeing in my eyes?’ She just didn’t say anything. Then I started listing everything I knew within my eye that might be causing a problem. I got to

haemorrhages, and her face just kind of cracked, so she was clearly seeing them. She said, ‘Well, I’m going to write a note for your doctor, and they’re going to take it forward’.

“Bedside manner” is typically considered an important aspect of care but has received little attention in published literature [29]. However, existing research indicates that healthcare professionals (HCPs) tend to underestimate how much information a patient wants to receive [30]. Patients under the age of 60 years or educated to at least a college level are significantly ($p = 0.02$ and $p = 0.00007$, respectively) more likely than others to want detailed information about their condition [30]. This is especially relevant for diseases such as DR, because patients may be diagnosed as early as 20 years of age. Furthermore, DR typically develops in nearly all patients with early-onset type 1 diabetes within 20 years of diagnosis [31].

“I had no other signs of diabetes than my vision. I just wonder, if I hadn’t gone to the optician, whether I would have ended up in some sort of diabetic crisis within a few weeks”.

Jacqueline was diagnosed with DR prior to realising that she had diabetes. Many countries have robust screening programmes for diseases such as DR, and patients are typically automatically enrolled upon diagnosis with diabetes [32]; however, up to 21% of patients with type 2 diabetes already have DR at the time of diagnosis with diabetes [31]. As such, permanent vision damage may already have occurred by the time of their diagnosis [33].

“GP surgeries are really busy; they didn’t have space for me”.

Delaying monitoring and treatment of DR can result in irreversible damage. One recent real-world example of this is the COVID-19 pandemic, which resulted in the delayed treatment of patients with DR [34]. Across a number of treatment centres, delays in treatment ranging from approximately 5 to 20 weeks resulted in reduced visual acuity and an increased risk of complications [35–37].

“When I arrived at my GP surgery with my note, they said, ‘Oh, nobody’s got any time to see you today... go away’”.

It is imperative to effectively triage patients who are at risk of permanent vision loss. Although to date there are no specific publications describing the impact of DMI on quality of life, the consequences of vision loss in general and DR, specifically on quality of life, are significant and increase with disease severity ($p < 0.0001$) [38–40].

Accessibility of Information About DMI

“Some people are unaware of why they are receiving injections at all”.

“When I used to go for my injections, there was also a waiting room of elderly people waiting for their age-related macular degeneration treatment. Most of them would say that they didn’t know why they were there. It’s important for me personally to understand what is happening, why it’s happening and what, if anything, we can do about it”.

Although there is limited research on the extent to which elderly patients feel informed about their care, one study found that the most common barrier to healthcare access is a perceived lack of concern and responsiveness from an HCP [41]. Fortunately, there is increasing interest from HCPs in the role that patients play in their own healthcare decisions, particularly within ophthalmology [42, 43].

“I don’t know whether information is not offered or whether it’s not offered in an easily understandable way. I had to speak to someone at consultant level to get honest answers. The juniors in the department seemed almost afraid to tell me what they saw—or wouldn’t or couldn’t explain the scans to me. It’s very difficult to trust somebody who seems a bit reticent, but then says, ‘OK, so shall we go and put an injection in your eye now?’ It’s like, ‘No, I don’t think we will!’”

Building trust between HCPs and patients is important for successful care; new patients are at particular risk of missing follow-up visits or dropping out of care entirely [44]. Being transparent with test results, encouraging questions and facilitating open discussion of a patient's treatment preferences are effective ways to build HCP–patient trust [44]. It is clear that both the initial steps towards diagnosis of a person with vision loss and decisions about subsequent care must be handled carefully to ensure the best care outcomes for patients. Providing opticians with specific training around speaking with patients who require further specialist care may help to ease the diagnosis journey of those with DR. This is especially true considering that, for a sizeable group of people, their first encounter with a diagnosis of diabetes and DR may happen at a standard eye care appointment.

“I went on the internet. When I first started looking at it, there were maybe two or three things that might have been useful. Even in the last 3 months or so, the amount of information on DMI is actually increasing”.

Relative to other complications of DR, there is little information available on DMI. A PubMed search conducted on the term “diabetic macular ischemia” on 8 October 2021 yielded only 35 results, with the majority of papers published in 2019 or later. For comparison, there were almost 4000 results for DME and close to 40,000 for DR. With so little peer-reviewed information on DMI available for physicians, it is no surprise that information that is accessible to patients is even more limited. Furthermore, information sourced online by patients may not be accurate: one study indicated that, although using Google to research eye problems significantly improves the ability to answer disease-related questions correctly ($p = 0.003$), the information found online was incomplete and unreliable in terms of treatment options [45]. It is clear that more published research on DMI is required to provide factual and reliable information to both patients and physicians.

Jacqueline's Experience of Living with DMI

“Normally, in life, it's not an effort to see—but it became an effort”.

Because patients with DR are likely to have additional complications, there is very little information about what it is like to live with DMI specifically [4, 24, 25]. Here Jacqueline, a person with DMI, describes the visual experience of how she sees in day-to-day life.

“It's like looking through a wet plastic bag. My brain does a lot of making up for things—sometimes I see words that aren't there. I have to scan four to five times to get the meaning of a sentence, which means my eyes have to do a huge amount. Within half an hour, I've got significant eye strain. Because I have damage to my macula, I have to use other parts of my retina in order to pick up images, and that is definitely not as accurate. Some bits are relatively clear, and other bits are cloudy and fuzzy. The letters move around a bit. When it's foggy and dark, it's a nightmare because I don't have clarity at all. I need a certain amount of the right light, but as soon as it changes it makes it difficult—whether too bright or dim. Judging distances and depths is a problem, even in good lighting”.

“People don't make allowances for my vision loss”.

“All of my teaching team know that I have substantial vision loss. But, when it came to getting a computer that worked for me, it took me a year and a half”.

In the UK, local services for people with vision impairment are inconsistent in terms of their availability, support content and provision of services [46, 47]. This can make it challenging for patients to gain access to technology that might help them to continue their jobs and hobbies and to carry out daily tasks.

“If you met me, you wouldn't necessarily know I was visually impaired. When my colleagues hold meetings, some of them remember to do large print for me, but

most of them forget. I have to remind my students, ‘I’m sorry I can’t read that; you’re going to have to read it out to me.’ They just don’t remember”.

Although there are ways to produce visually inclusive materials for the workplace (such as using large print, sans serif fonts and high-contrast colours), many people simply are not aware of how to accommodate people with visual impairment. It is important to create workplace environments in which all people feel welcome and are able to thrive. This could be achieved by properly educating people about the impact of vision loss, including when it is not obvious, through workplace and educational orientation programmes.

“The white stick makes me feel vulnerable”.

“A woman from the visual impairment department of the council came around, gave me a load of information and a collapsible white stick, and that was that. I didn’t get any information on how to use it”.

Research suggests that there are few, if any, well-described protocols or studies focussing on how to train and orientate visually impaired people in the use of a white cane. In one systematic review, only six documents were identified that provided information on orientation or mobility training with a white cane, and the information was incomplete and of low quality [48]. Developing suitable guidelines on how to introduce canes to patients (for physicians and local authorities) and on how to use canes for identification, orientation and mobility (for people with visual impairment) may be one way to restore confidence and independence for people with vision loss.

“Generally speaking, walking around the place, it makes you very vulnerable when you have the white stick. It’s like saying, ‘I can’t see you, so come and get me!’”

The white stick or cane is a well-recognised mobility aid and means of identification used by people with poor vision [49, 50]. However, the white cane also highlights a person’s impairment, which may cause the user to feel

vulnerable, self-conscious and embarrassed [50–52]. In some cases, the use of a white cane can result in family members becoming anxious and overprotective, hindering the user’s ability to learn how to travel independently [52].

“It’s useful for judging depth, certainly. So I have used it in that way, in unfamiliar places. But for day-to-day walking around, I don’t use a stick.”

Recently, there has been interest in developing or adapting technologies to improve the safety of visually impaired people when navigating the world [49, 53–55]. One study used augmented-reality technology to translate three-dimensional visual information into audio feedback via a mobile telephone [54]; although participants rapidly learnt to navigate using this system, it did not provide significant advantages over using a white cane with 10 h of training. Other researchers are developing a technology based on haptic feedback, such as a Wearable Virtual Cane Network that uses vibration at the wrists and ankles to signal how close an object is to the wearer [55]. When using the Wearable Virtual Cane Network, walking speed increased by an average of 23%. Furthermore, when used in combination with a white cane, navigation was significantly improved ($p < 0.05$) [55]. Finally, the EyeCane is a cane augmentation technology that provides haptic and auditory feedback about obstacles while retaining the lightweight, low-cost benefits of a standard white cane [56]. The EyeCane has been shown to improve a person’s ability to detect, identify and avoid large and high obstacles while walking [57] and requires only a few minutes of training [56]. Investing in navigational technologies may improve the safety and personal autonomy of people with low vision.

“It is difficult to have no creative outlet”.

“I used to do a lot of crafting, I used to make cards and so on—and I really can’t do that now. I’m a potter, but I don’t have my own equipment and going to night classes now is more difficult for me. I’m doing less and less, and I feel that.”

Vision loss is highly correlated with a reduced capacity to perform functional daily

activities [58]. In addition, leisure activities such as reading, social interaction, hobbies and watching television are negatively affected [59]. Unfortunately, there is little evidence that the currently available rehabilitation interventions for people with poor vision are effective: a review of 44 studies found that interventions (ranging from psychological therapies to rehabilitation programmes and assistive technologies) ultimately had little effect on quality of life, although it was acknowledged that the available data were limited by short follow-up periods [60]. One study in 2020 showed that smartphone apps were effective, practical and useable reading aids for people with visual impairments [61]. Rehabilitation programmes that are based on the perspectives of patients could be more effective at improving aspects of daily life that are important to people with vision loss.

“Losing independence is hard to accept”.

“The first major loss of independence was not being able to drive. Not choosing where I went, when I went”.

DMI is linked to loss of vision in the central macula, which is a region responsible for sharp, high-quality vision [4]. It has been found that people with simulated central vision impairment equivalent to that caused by DMI (20/80 vision) do not adjust their driving speed and therefore drive less safely [62]. Increased difficulty with driving relates to two of the commonly cited concerns for patients with DR: loss of independence and loss of mobility [63–65]. Moreover, the inability to drive also intensifies social isolation [63] and increases the likelihood of depression, even when controlling for age, sex, education and health status [66]. Furthermore, being unable to drive as a result of visual impairment makes it difficult to go shopping and therefore difficult to prepare and cook meals [67]; consequently, even basic living tasks require active support from others.

“I’m very fortunate that my partner is both able and willing to support me. We’ve got a very cooperative relationship; we negotiate things together.”

Although some patients with vision loss have partners and/or friends who are prepared to support them through vision loss, this is not always the case. Social isolation after vision loss is common, and DR can negatively impact interpersonal relationships; one study showed that 50% of patients separated from their partner a mean of 1.6 years after the onset of vision impairment [68]. Feelings of loneliness are common in people with vision loss, despite the fact that they often have to rely on the support of others to conduct their daily lives [69].

“We have got friends who are supportive, but I think that my partner is one of these extremely resourceful people who could theoretically do just about anything. I’m incredibly grateful. But I do know that it’s not without its cost.”

Around 40% of all people with vision loss require “informal” care that is provided by a friend or family member [70]. It has been estimated that informal carers spend approximately 9 h per week caring for people with vision loss, increasing to 94.1 h per week as vision deteriorates [70]. The impact of caring for parents on the reported mental health of middle-aged carers (aged 50–58 years) is known to be substantial [71], but for some people, caring for a partner has greater adverse effects on their mental health than caring for a parent, regardless of age or socio-economic status [72]. Informal care is critical to the wellbeing of people with vision loss. Therefore, it is important to safeguard the health of those who perform this vital role.

FUTURE PERSPECTIVES

“My response to finding out I was diabetic was to do something about it—but what I couldn’t change was the loss that I already had.”

Patients are increasingly able to source their own information about diagnoses; therefore, it is vital to ensure that there is sufficient, accessible and accurate information available. For complications such as DMI, for which there is little published research but a growing interest,

it is critical to consider and integrate patient perspectives into the development of educational programmes, treatments and research in general.

“It would be a huge step forward for clinicians if they had a set of criteria to work with.”

Currently, there are no standardised diagnostic criteria for DMI. In addition to the lack of available treatment, this can mean that physicians are reluctant to diagnose a patient with DMI. Developing a consensus set of criteria would be an important development for patients who have DMI and for their treating physicians; these criteria would help to support clinical trials for treatments of DMI as well as allow patients to access validated information about their own health status more readily.

“Be honest with your patients”.

“I think keeping patients well informed is the most important thing—and being honest. I certainly appreciate that. I think there are ways of being honest, in the light of sensitivity and tact”.

Building trust and a healthy rapport between the physician and patient is important in managing health anxiety and ensuring adherence to beneficial treatments or lifestyle adjustments [44]. It is vital that the training physicians receive continues to emphasise the importance of treating a patient holistically, rather than only treating their symptoms.

“I can understand that people with a different level of understanding to me might feel angry or disappointed. For me personally, I already knew the information. I knew about the underlying pathophysiology.”

Every patient is unique, with their own level of scientific knowledge and understanding. By establishing a patient’s preferences for communication and level of information, and adapting accordingly, the best outcome for a patient can be achieved.

CONCLUSIONS

There is little information available to patients and their physicians about DMI; however, as with other diseases that cause vision loss, DMI has a substantial impact on patients’ daily lives. Establishing a consensus diagnosis for DMI will help to standardise research into the subject, as well as to ensure that patients have access to validated information. In addition, a formal diagnostic criterion would support the much-needed development of a treatment for DMI. It is critical that physicians cultivate an open and flexible management approach with their patients, providing information in a digestible manner. In addition, holistic educational programmes for patients, physicians and the general public around DMI and how it can affect daily functioning would facilitate general understanding and disease awareness.

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Compliance with Ethics Guidelines. This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

Availability of Data and Materials. Data sharing is not applicable to this article as no datasets were generated or analysed during the current study.

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