

Patients with Advanced Diabetic Retinopathy's Understanding of Diabetes Mellitus and Their Diabetic Eye Disease: A Survey of 100 Patients Currently Undergoing Treatment for Diabetic Retinopathy in a Large Retinal Practice

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Abstract

Objective: To better understand what patients with advanced diabetic retinopathy understand about their DED and treatment, control of their diabetes, and risk factors for disease progression, and to assess which areas clinicians may want to target for education to increase patient understanding.

Methods: 100 consecutive patients with at least 5 previous visits to a retinal clinic were surveyed to better understand patients' understanding of diabetes mellitus (DM), diabetic eye disease (DED), and the treatments they were receiving for DM and their DED. Demographic information (age, gender, educational status, ethnicity, language, duration and treatments for DM) was collected, along with information about treatments and understanding of risk and modifiable factors about DM. Data was verified against the chart.

Results: 100 surveys were completed; 97% of patients said they "understand DM". 61% of patients were 60 years or older, and half of the patients had done some post-secondary educational training. The ethnic breakdown included 27% Caucasian and 38% Hispanic. Fasting blood glucose (FBG) was known in 89% of patients and when asked the range of FBG: 6% did not know; 17% had FBG as >160 mg/dl; and 35% had a FBG of <130 mg/dl. Regarding controlling their DM, 74% of patients did not identify exercise and 33% did not identify dietary habit as important in control.

95% identified blood pressure (BP) as important to monitor. 39% were unable to identify their current BP range, 31% identified their systolic BP as ≥ 130 mmHg, and 7% described it as usually >150mmHg. Patients were asked to identify DM related ocular complications: 23% said bleeding; 7% said diabetic macular edema; and 73% said blindness or visual loss. As patient age increased, the ability to correctly identifying current treatments, and knowledge of hemoglobin A1C (HbA1C), decreased. Ability to correctly identify HbA1C increased with increasing education.

Conclusions: This survey shows patient misunderstanding in how DM is treated, risk factors for DM, and how monitoring should be done. Emphasis is likely needed in diet modification and exercise for control of DM. Patients may be at risk for poor understanding of DM care/treatment (particularly those with lower educational achievement, or more elderly). Additional resources may need to be developed for sub-sets of patients.

Keywords: Diabetic retinopathy; Diabetic eye disease; Patient understanding; Hemoglobin A1C; Diabetes mellitus; Risk factors

Introduction and Review of Literature

Diabetes mellitus (DM) is an increasingly common metabolic disorder in the US and developed nations, and is affecting younger patients, effectively increasing the role of the ophthalmologist in the care of such patients as longer duration of diabetes increases the risk of DED [1]. According to the WHO there are more than 346 million persons worldwide who are living with DM-over 90% of which have type 2 diabetes mellitus (DM2) [2]. Diabetic retinopathy (DR) and diabetic macular edema (DME) are responsible for considerable morbidity in patients with DM and are currently serious public health

problems as DM increases [3-5]. Diabetes education is a key component in management of DM and its many complications (a PubMed search for "patient education" and diabetes' yielded almost 9000 unique titles) yet many patients still do not understand their disease, its management, complications, or treatments, despite current clinical patient education paradigms. The American Academy of Ophthalmology and the American Diabetes Association, among many medical associations, highly advocate patient education through educational handouts, webpages, teaching, etc. and many of these resources are invaluable to patients.

Much has been written on education of patients with DM in general, but what is the outcome of education on patients with established disease? The medical literature has a plethora of

information on the effects of DM and the treatment of diabetic eye disease (DED), as well as a paucity of information on the outcomes of all that education [5-10]. This leads to a gap in knowing what areas of patient education need more attention, and particularly which patients are at risk of complications from DM due to lack of understanding of their disease.

Despite all the education, many patients do not seem to understand their disease or treatment regime. Patients being treated for retinopathy are an excellent cohort to examine as their diabetes must have been established long enough and with poor enough control to exhibit the end organ damage. They are patients living with chronic disease, being treated in an ongoing care setting. The purpose of this study was to review patients at a large retinal practice in Los Angeles, using three separate sites and patients from 8 retinal surgeons, on their understanding of DM and their treatment regime. Issues examined included basic demographic information, understanding of DM, understanding of risk factors, awareness of one's own disease and the treatments currently undertaken at the retinal clinic.

This prospective study had obtained an IRB approval through Quorum IRB.

Methods

Standard clinical practice in this setting has all patients receiving a handout from the physician from the AAO on diabetes and diabetic eye disease (DED), and it is routine at each visit to inquire about fasting blood sugars, blood pressure, and hemoglobin A1C, which is transcribed into the patient's chart for documentation. Patients are counseled by the physician on glucose and blood pressure control, and correspondence is sent back to the primary care physician regarding the diagnosis and treatments undertaken after the visit.

Consecutive patients who had at least 5 previous visits to the retinal clinic (to establish a history of care in the practice), and have a diagnosis of DR were asked to participate in a 15 question survey, administered by ophthalmic technical staff in the office. Patients were instructed that the survey was entirely optional and they were free to withdraw at any time should they agree to participate. The ophthalmic staffs were instructed to read the survey questions in either English or Spanish to the patient, and not to prompt the patient. Answers requiring verification were verified against the information contained in the patient's chart by the technician at the time of the questionnaire completion. At times where patients were asked to provide a list of symptoms/signs (eg what complications can diabetes cause to your eyes?) if the technician felt the answer was close (eg. Diabetic Macular Edema, or swelling of the retina) the answer was scored as correct; if unsure the technician was to record the answer verbatim, and the answers were reviewed by the author for appropriate scoring. The technician and physician were looking for an approximate understanding from the patient, not exact medical terminology.

Patients were informed that their treating physicians were not aware of who was taking the survey and were free to decline or withdraw at any point. A selected technical staff at each office participating (three in total) were assigned to collect the data during normal clinic screening time, and only that technician conducted and filled out the survey at each site to ensure consistency. An ethics approval from Quorum Review IRB was obtained prior to starting the study.

Results

100 surveys were conducted at three different sites, with approximately equal distribution of surveyed patients taken from each site. When asked if "you feel you understand diabetes", 97% of patients answered "yes".

Demographics

61% of patients were 61 years of age or older and half of the patients had done some post-secondary educational training. Twenty-seven percent were of Caucasian descent, and 38% were of Hispanic origin (Table 1).

Demographics
Age
21 to 30: 1%
31 to 40: 0%
41 to 50: 13%
51 to 60: 25%
61 to 70: 30%
>70: 31%
Ethnicity
White: 27%
Asian: 10%
African American: 17%
Hispanic: 38%
Middle Eastern: 6%
Mixed: 2%
Highest educational achievement
8th grade or lower: 15%
High school: 33%
College: 33%
Professional School: 12%
Masters: 7%

Table 1: Patient Demographics.

Forty-five percent of patients have had DM for over 20 years, with 8% having had it for more than 40 years (Table 2).

How long have you had diabetes?
Less than 5 years: 7%
5 to 10 years: 16%
11 to 15 years: 11%
16 to 20 years: 21%

21 to 25 years: 15%
26 to 30 years: 13%
31 to 35 years: 6%
36 to 40 years: 3%
More than 40 years: 8%

Table 2: Duration of DM.

Knowledge of DM and Treatment

Regarding knowledge of their DM, 80% identified as having type 2 DM, and 10% as having type 1 DM, 10% were unsure as to which type they had. 83% were correct in their identification of which type they had, and 14% (including the 10% of all patients who did not know) were incorrect. For 3% of patients it was not determinable by the chart which type of DM they had. When asked how their DM is controlled, 64% identified oral medication, 54% identified insulin, 40% identified diet control, and 12% identified exercise. However when asked for ways to control DM, only 67% indicated diet and 26% identified exercise as helpful (Tables 3 and 4).

95% of patients correctly identified that blood pressure control is important to monitor. However 39% were unable to identify what their blood pressure readings usually are, and 31% identified their systolic blood pressure as being over 130mmHg regularly (7% described it as usually great than 150 mmHg).

How DO you control your diabetes?
BY CATEGORY (SUMMARIZED):
Medication: 64%
Diet: 40%
Insulin: 54%
Exercise: 12%
Patient Answers
Medication only: 15%
Diet only: 2%
Insulin only: 15%
Medication and diet: 22%
Medication and insulin: 10%
Medication, diet and insulin: 9%
Medication, diet and exercise: 5%
Medication, insulin and exercise: 1%
Medication, diet, insulin and exercise: 2%
Diet and insulin: 15%
Diet and exercise: 2%
Diet, insulin, and exercise: 2%

Table 3: How patients control their DM.

How do you think you CAN control your diabetes?
BY CATEGORY (SUMMARIZED)
Diet: 67%
Insulin: 39%
Medication: 47%
Exercise: 26%
PATIENT ANSWERS
Diet only: 15%
Insulin only: 6%
Medication only: 7%
Exercise only: 9%
Diet and insulin: 6%
Diet and medication: 13%
Diet and exercise: 6%
Diet, insulin, and medication: 18%
Diet, insulin, medication and exercise: 3%
Diet, insulin and exercise: 1%
Diet, insulin, exercise and other: 1%
Diet, medication and exercise: 3%
Insulin and medication: 2%
Insulin and exercise: 2%
Medication and other: 1%
Diet, exercise and other: 1%
Other: 2%
Unknown/blank/none: 4%

Table 4: What patients feel they can do to control their DM.

Day of survey fasting blood glucose (FBG) reading was known in 89% of patients. Only 35% of patients had a FBG of less than 130 mg/dl. (Table 5) When asked what the range of their blood sugars usually are, 6% did not know what their FBG usually was, 17% described their FBG as greater than, or a range that included values greater than, 160 mg/dl.

Half, 50% of patients knew what a hemoglobin A1C (HbA1C) is, and of those, 56% (28/50) identified that it was an indication of long-term control of blood glucose. When asked about the current numerical value of their HbA1C, of all patients, 59% did not know, 7% had a value of less than 6, 10% had a value of 6.0-6.9, and 2% had a value of greater than 11% (Table 6).

Regarding DR status, 91% of patients did not know if they had proliferative or non-proliferative DR (of those who could identify their DR status, 3% identified non-proliferative, and 6% identified

proliferative DR). According to the patient charts, 36% of patients had non-proliferative, and 61% had proliferative DR. There was no diabetic retinopathy documented in the remaining 3% of charts.

Patients were asked to identify which treatments they had received for their diabetic eye disease. They were asked if they had received laser, injections, vitrectomy surgery, or just surveillance. 56% named all correct treatments they received, with an additional 31% getting most treatments correct but forgetting one (for example: 14% had forgotten that they had laser treatment). 13% could not identify how their diabetic eye disease was being treated (Table 7).

What is your blood sugar today?
Less than 100: 20%
100 to 110: 4%
111 to 120: 11%
121 to 130: 16%
131 to 140: 5%
141 to 150: 10%
151 to 160: 5%
161 to 170: 5%
171 to 180: 4%
181 to 190: 3%
191 to 200: 2%
More than 200: 4%
Unknown: 11%

Table 5: Current Blood Sugar Reading.

What is your hemoglobin A1C?
Less than 6: 7%
6.0 to 6.9: 10%
7 to 7.4: 9%
7.5 to 7.9: 2%
8 to 8.5: 5%
8.6 to 8.9: 5%
9.0-10.9: 0%
Greater than 11: 2%
Unknown: 59%
Left Answer Blank: 1%

Table 6: Known Hemoglobin A1C values.

How are you being treated for your diabetic eye condition?
Laser only: 13%

Vitrectomy only: 11%
Injections only: 29%
Surveillance only: 4%
Laser and vitrectomy: 6%
Laser, vitrectomy and injections: 4%
Laser and injections: 19%
Laser, injections and surveillance: 2%
Vitrectomy and injections: 4%
Injections and surveillance: 1%
Unknown: 7%
By Category (Summarized)
Laser: 44%
Vitrectomy: 25%
Injections: 59%
Surveillance: 7%

Table 7: Patient knowledge of treatment.

Knowledge of Diabetic Complications

Patients were asked about their understanding of complications from diabetes, as all were currently being treated for DED. Bleeding of the eye was identified by 23%, although swelling, or macular edema, was only identified by 7%. A large majority, 73%, did identify blindness or visual loss, as a complication (Table 8).

What complications can diabetes cause to your eyes?
Bleeding: 23%
Swelling: 7%
New blood vessels: 8%
Increased pressure: 5%
Blindness: 73%
Cataract: 11%
Change in glasses prescription: 2%
Blurry vision: 5%
Floaters: 3%
Risk of RD: 2%
Unknown: 4%

Table 8: Patient awareness of visual complications from DM.

Patients were also asked to describe systemic complications from DM. Peripheral neuropathy was identified by 45%, and 34% identified renal damage. Amputations were identified by 5%, and stroke was identified by 6%. However, 9% were unsure of other complications from diabetes that they may be experiencing (Table 9).

Have you experienced any other complications from your diabetes?
Kidney problems: 34%
Nerve problems: 30%
Amputations: 5%
Numbness in the feet: 45%
Glaucoma: 14%
Cataracts: 42%
Hearing loss: 13%
Skin infections: 10%
Sores that do not heal: 10%
Diabetic Ketoacidosis (DKA): 2%
Stroke: 6%
Leg pain/numbness: 32%
Heart attack: 7%
None: 8%
Unknown: 9%

Table 9: Additional complications identified by patients.

Understanding Based on Age of Patient

When the data was broken down based on patient age, there was not an equal distribution across ages. There was one patient younger than 30. There were no patients 31-40. Older patients were approximately equally distributed (age 41-50: 13 patients; age 51-60: 25 patients; age 61-70: 30 patients; and age >70: 31 patients). As patient age increased, the ability to correctly identifying current treatments, and knowledge of what HbA1C was, decreased (Figure 1).

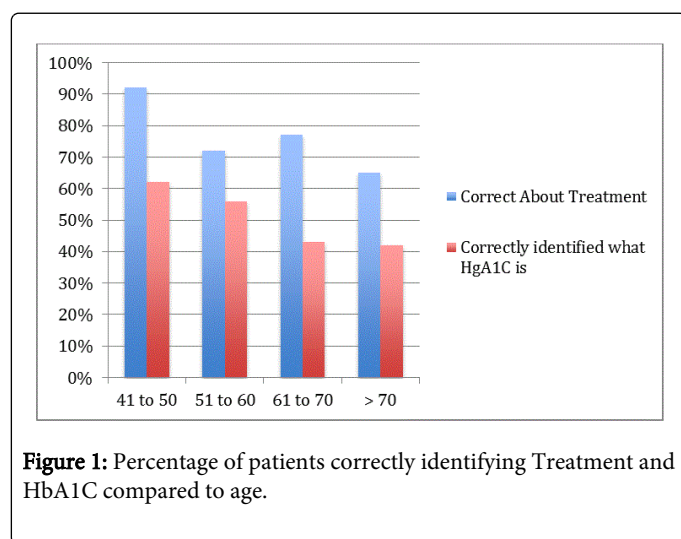


Figure 1: Percentage of patients correctly identifying Treatment and HbA1C compared to age.

Understanding Based on Educational Level of the Patient

When the data was broken down based on maximal attainment in education: 15 patients had 8th grade or less; 33 had obtained high

school; 33 had some college education; and 19 had professional/graduate school education. Across all levels, identifying which treatments they had undergone was similar. Ability to correctly identify what HbA1C is increased with increasing education. Only 2/15 patients with 8th grade or less of education knew what HbA1C was but both had a current HbA1C of less than 8% (Figure 2).

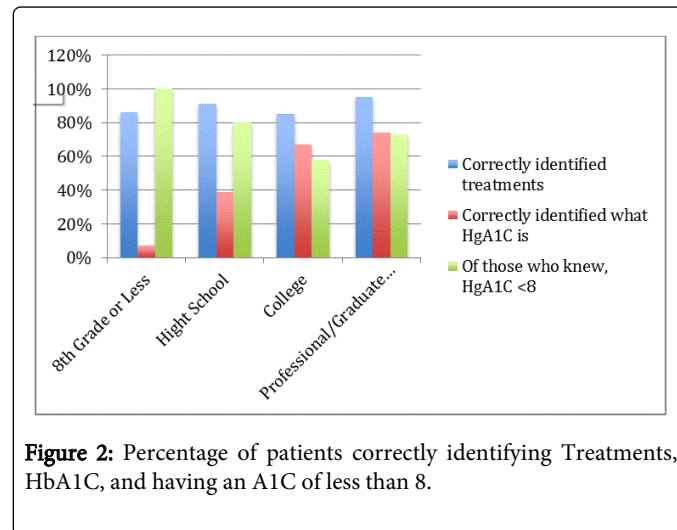


Figure 2: Percentage of patients correctly identifying Treatments, HbA1C, and having an A1C of less than 8.

Discussion

Complications of DM are well known in the medical literature, and much literature exists about patient education. While there are many factors involved in patient understanding of disease, it is very important to consider patient understanding for improved outcomes [3-6,11].

Our study looks at patients already diagnosed and being treated for advanced complications from DM. Five percent of participants had previously had amputations. All patients were currently being treated (and having been seen on at least 5 prior occasions) at a retinal practice for DED. Forty-five percent of patients had had DM for over 20 years. In accordance with current practice at the offices, all patients had been educated by physicians in the practice regarding their eye disease, treatments, and regarding risk factors (including hypertension, glucose controls, and HbA1C).

Despite the current educational practices employed by the practice, as well as at their primary or diabetologist offices, 74% of patients with established DM did not identify exercise as a means of controlling DM and 33% did not identify dietary habit. Four percent did not know what to do to control their DM, despite being currently treated for DM. Diet and exercise are cornerstones in DM care, and can decrease insulin and oral medication use, and yet that message does not seem to be well understood by many complicated DM patients.

Of these patients with advanced diabetic complications, 11% did not currently know their FBG, and 4% had a FBG of greater than 200 that day. Poor control, and lack of understanding of the important measures in diabetic control may contribute to why these patients were being treated for DED and had a high self-reported rate of additional complications related to DM. HbA1C was largely unknown (59%) despite patients being asked at all 5 prior appointments what their HbA1C was (as well as being instructed to communicate what the HbA1C with the office at all appointments). Of the remaining 41%, 12% had a HbA1C of greater than 8%. Again this high HbA1C

correlates with the high FBG, poor diabetic control, and high complication rate in these patients. When this was broken down based on age, the more elderly the patient, the less likely they were to know what HbA1C was (for patients over 70 years, only 42% were able to correctly identify what HbA1C was). As education levels increased, knowledge of HbA1C also increased, although in this age group, knowledge of HbA1C did not correlate with lower levels of glycosylated hemoglobin (Chart 2).

Over 85% of patients were able to correctly identify their treatments to some degree, with 56% knowing the exact treatments they had received. When this was broken down based on age, the more elderly the patient, the less likely they were to know which treatments they had received (for patients over 70 years, only 65% were able to correctly identify their treatments). It seems that across all levels of education, patients were able to identify most treatments they had received (85-95%). Patient understanding of disease treatments is especially important in the setting of multiple medical issues, for communicating between patients' different doctors, and in cases of changes to providers mid-course of therapy. Most patients seemed to have a reasonable understanding of their course of therapy, despite not having a good understanding of how to achieve, and what constitutes, good glycemic control.

This study was not powered to prove differences between any sub-groups of patients. This study was a survey method, done on consecutive patients at three different offices from a large retinal practice in Los Angeles, with the surveys being divided roughly equally between all offices. Voluntary surveys have an inherent risk of selecting persons who are willing to volunteer their ideas, and the study methods does bias towards patients who are more comfortable and confident in their answers (as the survey was done in front of a technician, and therefore not completely anonymously). This study, however, does give us a glimpse in the niche of patient education and understanding for patients with advanced DM and DED.

This survey does demonstrate some trends towards patient misunderstanding on how DM is treated, what the risk factors are, how monitoring should be done. Emphasis still needs to be made on diet modification and exercise in controlling DM and its end-organ changes. Certain patients may be at risk for not understanding DM care and treatment, based on current commonly practiced educational

methods (those with lower educational achievement, or more elderly patients). Additional resources may need to be developed for these sub-sets of patients to provide better understanding of treatments and therapies.

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