Strategies to Improve Prevention and Management in Diabetic Retinopathy: Qualitative Insights From a Mixed-Methods Study

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■ ABSTRACT

Nonproliferative and proliferative diabetic retinopathy (DR) are common, progressive complications of diabetes with a rising incidence. Over time, patients with nonproliferative DR may progress to more advanced stages of DR, with an increased risk of vision-threatening conditions such as diabetic macular edema (DME). DME is the most frequent cause of vision loss in patients with diabetes and eventually can lead to blindness. Early-stage DR is asymptomatic; therefore, a coordinated management strategy is crucial to prevent or limit the progression of DR. Such a strategy includes regular screening for DR risk factors, glycemic control, and prompt diagnosis of DR. Preventive care should include a comprehensive dilated eye exam, ancillary tests, and patient education involving a multidisciplinary team composed of ophthalmologists, retina specialists, and primary diabetes care providers, including primary care providers and endocrinologists/diabetologists. However, although guideline recommendations for regular screening and patient education are well disseminated, many people with diabetes are not receiving ophthalmological care that could prevent visual impairment and blindness. We designed a mixed-methods study to explore the impact of patient-focused education on patient knowledge and self-efficacy in relation to DR prevention and management and to assess how online education can help to change patient knowledge, competence, and practice. Analysis of in-depth, qualitative data involving people with diabetes with or without DR collected 5–16 weeks after education participation shows that online patient education is an effective tool in building patient knowledge and awareness about DR and in motivating action in DR self-care.

In parallel to the expanding national obesity epidemic in the United States, the incidence of diabetic retinopathy (DR) has risen steadily. Nonproliferative and proliferative DR are common, progressive complications of type 1 and type 2 diabetes that affect 28.5% of adults with diabetes who are ≥ 40 years of age (1). Over time, patients with nonproliferative DR may progress to more advanced stages of retinopathy with an increased risk of vision-threatening conditions such as diabetic macular edema (DME). DME is the most frequent cause of vision loss in patients

with diabetes and eventually can lead to blindness (2,3). Additionally, as nonproliferative DR progresses to proliferative DR, associated complications can contribute to profound visual loss, including vitreous hemorrhage and tractional retinal detachment.

DR is asymptomatic in its early stages, and patients rarely notice vision changes. As a result, they might not seek treatment in a timely manner. Therefore, a coordinated management strategy is crucial to optimally addressing the clinical challenges of DR and limiting its progression (4). Preventive strate-

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TABLE 1. DR Patient Education Programs

Live Online Date*	Program Title and Description	Learning Objectives
29 July 2015	Diabetic Retinopathy Part 1: What Is It, and Are You at Risk? An education program targeting patients who have diabetes but have not been diagnosed with DR	<ul style="list-style-type: none"> • Understand the impact of poorly controlled diabetes on the development of vision problems • Understand how high blood glucose, high blood pressure, and high cholesterol levels cause damage to the retina • Learn what you can do to prevent DR-related vision loss
14 October 2015	Diabetic Retinopathy Part 2: Preserving Your Eyesight An education program targeting patients who have diabetes and have been diagnosed with DR	<ul style="list-style-type: none"> • Understand that DR is initially a disease without symptoms and that early diagnosis is necessary to prevent vision loss • Learn about what to expect with available treatments, including the pros and cons of each • Know what to do if you experience sudden vision changes

*Programs remained available online for on-demand viewing from their live date through 14 April 2016.

gies include screening regularly for DR risk factors, promoting lifestyle modification and pharmacological intervention as needed to optimize glycemic control, and making a prompt diagnosis of DR when it has developed. To this end, quality ophthalmological care should include a comprehensive dilated eye exam, ancillary tests, and patient education involving a multidisciplinary team composed of ophthalmologists, retina specialists, and primary diabetes care providers, including primary care providers and endocrinologists/diabetologists (4). People with diabetes need to be knowledgeable about and engage in self-care to control risk factors for DR, including elevated blood glucose, blood pressure, and lipid levels. Current nonpharmacological treatment options for DR include laser surgery and vitrectomy; pharmacological treatment includes intravitreal injections of ranibizumab and aflibercept, which are inhibitors of vascular endothelial growth factor (5).

Although guideline recommendations for regular screening and patient education are well disseminated, a recent cross-sectional analysis of National Health and Nutrition Examination Survey data suggests that approximately one-third of peo-

ple with diabetes in the United States are not receiving ophthalmological care that could prevent visual impairment and blindness (6). There are many potential reasons for this gap in care; however, gaps are specifically evident in effective communication, coordination of care between health care providers (HCPs) and patients, and patient education and may lead to missed opportunities to prevent disease progression (7–9).

In light of these gaps, we designed a study to explore the impact of patient-focused education on patient knowledge and self-efficacy in relation to DR prevention and management. Patient-directed education is an essential element of diabetes self-management to build the knowledge and skills patients need to modify their behaviors, make informed decisions about their care, and more effectively interact with HCPs (10). Additionally, patient-directed education is emerging as a cornerstone of patient engagement in the context of health care reform and as a crucial tool in improving patient outcomes (11,12). However, there is little published research on the potential for such education to stimulate qualitative changes in knowledge and

self-efficacy as a potential precursor to behavior change.

Design and Methods

We designed two online patient education activities that could be viewed live and on demand (Table 1). The education goal was to empower patients to be their own advocates for optimal ophthalmological care. The study goal was to assess how the education initiative helped to change patient knowledge, competence, and practice.

Because the environments in which patients navigate health and health care are complex, we adopted a mixed-methods approach to data collection and analysis, using both quantitative data, which allows for statistical interpretation and generalization, and qualitative data, which supports depth of understanding and the acknowledgment of how context shapes behavior change. We collected and analyzed data across three phases of program delivery: 1) baseline data via an online pre-test survey concerning patients' knowledge and beliefs, 2) survey data after patient exposure to education content to measure the immediate impact of education, and 3) follow-up data 5–16 weeks after activity completion via both an online

survey and in-depth qualitative interviews with participants. Here, we report solely on the qualitative component of the study.

Recruitment for Qualitative Interviews

We used a combination of social media channels (YouTube, Facebook, and Twitter) and traditional email-based announcements to invite community-dwelling people with diabetes, with or without DR, to participate in an online patient-focused education activity. Recruitment efforts were partially channeled through partnerships, including the online communities of DLife, The Diabetes Hands Foundation, and the Joslin Diabetes Center of Harvard Medical School in Boston, Mass. Recruitment included a combination of tweets on Twitter, posts on Facebook, and YouTube promotions for users with expressed interests in diabetes; email messages to patient databases of partner organizations; and announcements on the websites of the partners listed above. Total reach was difficult to estimate because of the social media elements; however, it is conservatively estimated that >300,000 individuals with expressed interests in diabetes (e.g., patients, patient advocates, and caregivers) were exposed to recruitment messages.

Program 1, titled *Diabetic Retinopathy Part 1: What Is It, and Are You at Risk?*, targeted people with diabetes and no DR diagnosis. Program 2, titled *Diabetic Retinopathy Part 2: Preserving Your Eyesight*, targeted people with diabetes and a diagnosis of DR. Participants completed knowledge test questions before and immediately after activity completion to gauge knowledge acquisition.

Approximately 1 month after completing either program, participants were invited via email to complete a screening survey to determine their eligibility to be interviewed. At the time we began screening program participants as potential interviewees, there were 160 participants for

program 1 (August 2015) and 183 for Program 2 (November 2015). Participants were eligible to participate in interviews if they had a confirmed diagnosis of type 1 or type 2 diabetes, and, for Program 2, had been diagnosed with DR.

People who met these eligibility criteria were subsequently invited via email to participate in telephone interviews. Of 64 Program 1 participants who responded to interview invitations, 20 were eligible, 9 did not respond to scheduling information, and 11 were interviewed. Of 64 Program 2 participants who responded to interview invitations, 18 were eligible, 8 did not respond to scheduling information, and 10 were interviewed.

The Western Institutional Review Board provided ethical approval for this study, and we obtained informed consent from all participants before conducting interviews. Participants received a small honorarium after completing their interviews. We conducted telephone interviews that lasted ~30–45 minutes per participant, 5–16 weeks after the educational activity in which interviewees took part. All interviews were semi-structured in format.

Qualitative Data Analysis

Interviews were audio-recorded and transcribed verbatim. We removed identifying information and typographical errors from all transcripts, which we imported into NVivo 11 Mac software (QSR International, Australia). We used grounded theory and a process of constant comparison to analyze participant responses both across and within interviews (13–15). In grounded theory, the data, rather than a pre-set hypothesis, guide the direction of analysis, which involves generation of themes and hypotheses as an ongoing, iterative process. Analysis included three steps: 1) data immersion and familiarization, 2) data coding according to

broad areas of interest, and 3) theme identification.

We coded transcript content into descriptive categories, then identified potential themes of relevance until we achieved thematic saturation (Table 2). Indicators of themes included words, phrases, or segments of text that were used in a similar manner by respondents across or within interviews and that pointed to an emerging idea or concept. We explored emerging themes in node matrices within and across transcripts and cross-checked all emerging themes or critical issues with participant attributes (i.e., sex, age, ethnicity, duration of diabetes, duration of DR, and time from program participation).

Results

Sample

We conducted 21 in-depth telephone interviews with patients who participated in one of the two education programs (Table 3). Program 1 included 11 patients with diabetes (10 with type 2 diabetes and 1 with type 1 diabetes) who were 45–65 years of age (mean age 59.6 years) who had not been diagnosed with DR. Participants' time from diagnosis of diabetes ranged from 3 to 38 years (mean 13.7 years). Program 2 included 10 patients with type 1 diabetes who were 40–68 years of age (mean age 56.9 years) who had an established diagnosis of DR or, in one case, pregnancy-related microaneurysms. These participants had been living with diabetes for a mean of 26.8 years and had a time from diagnosis ranging from 6 months to 15 years (mean 5.3 years).

Changes in DR Knowledge After Education Participation

Knowledge About Diabetes and DR Before Program 1

We explored participants' awareness of how diabetes can affect eyesight by asking them to describe vision problems typically associated with diabetes and what they knew about DR. Most

TABLE 2. Major Interview Themes

Themes (Definitions)	Exemplar Quotes
Communication	
HCPs unlikely to volunteer unsolicited information (participants' perspectives on the extent to which HCPs share information about DR)	<p>"Once he put in the eye drops, he told me to sit down and this and that. No, there was not really any type of communication."</p> <p>"My primary care doctor, nothing. She never, never discusses it at all."</p>
Questions I'd like to ask providers (questions patients wanted to ask after the program activity)	"Definitely now I'm just going to ask them if there's any detection of the diabetic retinopathy in my eye, and what are the symptoms and stuff like that."
Presumption that providers know what they are doing (reasons participants gave for poor provider communication)	<p>"I think it's more of an as-needed kind of coaching."</p> <p>"Doctors don't have time to talk to each other; hell, they don't even have time to talk to me."</p> <p>"My endocrinologist is really conservative with her information."</p>
Knowledge/Awareness of DR	
Low awareness of DR before the program activity (participants were unable to describe DR and identify its symptoms)	"I didn't necessarily understand diabetes retinopathy."
Imprecise recall after program activity (participants tried to recall information about DR after the activity)	"It's something to do with the blood vessels. I believe the blood vessels get clogged up, and so they create new channels in the eye."
Ignoring eye symptoms/health (viewing eye symptoms as part of aging rather than as a complication of diabetes)	<p>"I haven't really had all the symptoms that they describe it as. I always thought it was because of the high blood sugars for a while, you know that my vision would kind of not be crystal clear."</p> <p>"Well, I didn't have 'problems' with my eyes. So, I guess the answer is no, I didn't have symptoms that made me aware there was a problem."</p>
Self-Efficacy	
Reinforcement of need for monitoring (participants were reassured that they were using effective strategies to monitor blood glucose)	"Continue to take my medications. Check my blood sugars regularly. Continue to lose weight. Continue to cut carbs."
Heightened awareness of importance of eye health (participants emphasized the importance of getting regular eye exams)	"It's good to stay on top of eye exams."
Diffidence about the purpose of eye exams (participants knew that eye exams were important but were unsure of their purpose)	<p>"They did blood draw and everything, and it was like, 'What I'm seeing in your eyes right now, I'm not seeing any sorts of definitive leakage or anything like that.'"</p> <p>"I'm not sure what they meant by that [DR]. . ."</p>
Steps I can take to reduce DR risk (participants felt able to take steps to reduce DR risk)	"For me, it's a constant battle, but the first thing that you need to do is you need to know your numbers."

participants were aware that diabetes can affect eyesight and repeatedly voiced concerns about the potential for blindness as a result of diabetes. Many Program 1 participants had already experienced some vision problems since being diagnosed with diabetes or knew

someone close to them who had vision deficits; however, before program participation, approximately half of Program 1 participants were uncertain whether eye conditions such as cataracts, glaucoma, dry eye, and DR were linked to diabetes or were age-related.

Most participants had heard about DR before participating in the activity. Nonetheless, they typically described not knowing much about DR, and few participants reported that their HCPs had spoken to them specifically about DR—a theme that

TABLE 3. Sample Characteristics

	Program 1 Participants (n)	Program 2 Participants (n)
Age (years)		
45–54	3	3
55–64	8	7
Sex		
Female	6	3
Male	5	7
Ethnicity		
Caucasian	7	9
African American	1	0
Latino/Hispanic	1	1
Asian American	2	0
Region		
East Coast	4	4
West Coast	2	2
Midwest	3	1
Mountain	1	3
South	1	0
Weeks from activity		
5–7	4	5
14–16	7	5

recurred throughout interviews with participants in both programs.

“[Diabetes] just decreases your eyesight, and it’s due to . . . you need to be in control of your blood glucose. Because with the high sugars, it causes more damage to the eye itself.” (Participant 3, female, age 55, Caucasian, type 2 diabetes, Program 1)

“Diabetic retinopathy . . . side effects to diabetes—obviously—reduces and causes problems with vision. If untreated, it could severely impact your vision, if not cause blindness.” (Participant 4, male, age 48, Caucasian, type 1 diabetes, Program 1)

“I didn’t necessarily understand diabetes retinopathy.” (Participant 10, male, age 65, Caucasian, type 2 diabetes, Program 1)

Knowledge About Diabetes and DR After Program 1

It proved challenging for participants to describe DR and identify its symptoms after viewing the activity. Overall, participants used imprecise language to describe retinopathy. Nonetheless, participants worked hard in interviews to recall their new knowledge about DR, and they did appreciate some of the important points about the condition, if not the precise technical language, as evident in the following quotes:

“It’s something to do with the blood vessels. I believe the blood vessels get clogged up, and so they create new channels in the eye, and after a while, the retina can’t absorb the light or something to that effect, and the eye doesn’t work correctly.” (Participant 11, male, age 65, Caucasian, type 2 diabetes, Program 1)

“I would describe it also, you know, blurry vision, but also like they talked about blood vessels. So, I think the blood vessels, you know, are in the back, but they do become visible I think in fact when it’s in later stage, but I would say get it checked. If you’re a diabetic, get it checked every year to make sure because it could cause blindness. In the education, it showed the back of the eye, the blood vessels, you know, pop, and then, you know, blood inside. I forgot what you call that jelly thing.” (Participant 9, female, age 54, Hispanic, type 2 diabetes, Program 1)

Program 1 participants were also better able to identify risk factors for DR after program participation. The predominant risk factors that participants identified were poorly controlled blood glucose or poorly managed diabetes, followed by insufficient diet and exercise, as illustrated in the following comments:

“The main thing is high sugar level. If it’s not controlled, it could cause prolonged time to cause the degradation of the pupil.” (Participant 1, male, age 66, Asian American, type 2 diabetes, Program 1)

“If they have diabetes, to keep it in mind and stop the sugar. Sugar, sugar, just stop it.” (Participant 9, female, age 54, Hispanic, type 2 diabetes, Program 1)

“As far as risk is watching what you are eating by not eating the elevated carbohydrates and sugars and things to prevent the high blood sugar count.” (Participant 3, female, age 56, Caucasian, type 2 diabetes, Program 1)

With prompting, a small number of participants also noted weight and blood pressure, but no one mentioned

kidney disease, high cholesterol, anemia, stomach problems (gastroparesis), or pregnancy.

Knowledge About Diabetes and DR Before Program 2

Program 2 participants all had an established diagnosis of DR or microaneurysms and regularly saw an ophthalmologist for general eye care and/or a retina specialist for retinopathy care. They were generally unaware of DR as a diabetes-related eye condition before their own diagnosis and were typically surprised at their own diagnosis, which all but three participants received during a routine eye exam. Despite emphasizing their surprise, some participants also recalled experiences that are redolent of retinopathy symptoms. For example, one participant noted:

“Prior to that point, I had really no advanced warning, no deteriorated vision. I haven’t had any real problems, you know, just minor floaters over the years, just very normal type of minor floaters.” (Participant 15, male, age 54, Caucasian, type 1 diabetes, Program 2)

Similarly, another participant reflected that although before his retinopathy diagnosis he had experienced “no major vision problems,” the ophthalmologist had noted in previous visits that there was slight bleeding in his eyes and had commented to him, “As long as you keep your blood sugar in control, there should be no problem with it.” Although his eyesight was sometimes unclear when his blood glucose was high, this participant said:

“I haven’t really had all the symptoms that they describe it as. I always thought it was because of the high blood sugars for a while, you know, that my vision would kind of not be crystal clear. But I’ve never had a problem with, you know, like real limited vision or anything like that or cloudiness.” (Participant

14, male, age 61, Caucasian, type 1 diabetes, Program 2)

These comments suggest a tendency for people with diabetes—even those who are vigilant about routine eye examinations—to ignore signs or symptoms of poor eye health on the grounds that such symptoms are a normal part of diabetes. Furthermore, they suggest that before participation in the education program, not all participants fully grasped that retinopathy is initially a disease without symptoms.

Knowledge About Diabetes and DR After Program 2

After participation, when we asked Program 2 participants how they would describe retinopathy to a friend or family member, they were likely to highlight the inevitability of retinopathy for people with diabetes and the importance of blood glucose control, as shown in the following comments:

“I know, you know, that at first you don’t really notice symptoms. But if you don’t keep your blood sugars under control, that’s when it starts to get worse, and it could eventually lead to blindness. I do know that. . . . Anyone who has diabetes, whether it’s type 1 or type 2, has the possibility of developing retinopathy.” (Participant 13, female, age 61, Caucasian, type 1 diabetes, Program 2)

“You’re always thinking because they tell you it could happen any time. It can go from one eye to the other, and I’ll say, ‘Wow, you know, when is it going to happen, because it did happen suddenly.’ So I’m always thinking about it.” (Participant 20, male, age 53, Latino/Hispanic, type 1 diabetes, Program 2)

After program participation, interviewees were generally adamant about the need to be aware of risk

factors for retinopathy and to educate others about this risk.

“Sugar in the blood goes to all the vessels in the whole body, and when it goes to the eyes, the eyes are not as, you know, they’re small, and they’re more fragile.” (Participant 18, female, age 63, Caucasian, type 1 diabetes, Program 2)

These comments suggest that participants absorbed two key messages of Program 2, which were 1) that everyone with diabetes is at risk for retinopathy and 2) that good blood glucose control is essential.

Self-Efficacy Before and After Education

Glucose Control

Before education participation, interviewees in both programs identified routine blood glucose monitoring as their main diabetes self-management and DR prevention strategy, alongside regular eye exams and what one participant called the “diabetic triangle”—medications, diet, and exercise. After program participation, participants emphasized that the education had reinforced for them the importance of continuing to pursue the glucose monitoring and control regimens, and all expressed a heightened awareness of the importance of following their monitoring and control strategies more assiduously. As one interviewee noted:

“Retinopathy is just one more thing in the chain of things that can go wrong with this body if you don’t take care of your diet or of your sugar level.” (Participant 11, male, age 65, Caucasian, type 2 diabetes, Program 1)

Maintaining Healthy Eyesight

Before viewing the activity, all participants described having “frequent,” “regular,” and “routine” comprehensive eye examinations, including retinal exams. Indeed, all participants were adamant about the importance

of regular eye examinations as a key step to maintaining healthy eyesight and emphatic that others with diabetes should have their eyes routinely checked to make sure there are no changes in the retina.

However, although Program 1 participants were able to describe the process involved in eye examinations, after education participation, some participants remained diffident about its purpose, as illustrated in the following quotes.

"They put some drops in your eye, and then you go back, and they look at them, and they ask you to look at the screen again. I really don't pay much attention when they do it. I'm a victim. He knows his business; that's why I go to him. I really don't ask a lot of questions." (Participant 10, male, age 65, Caucasian, type 2 diabetes, Program 1)

"They did blood draw and everything, and it was like, 'What I'm seeing in your eyes right now, I'm not seeing any sorts of definitive leakage or anything like that.' I'm not sure what they meant by that . . ." (Participant 4, male, age 45, Caucasian, type 1 diabetes, Program 1)

"He looked at my vision to see if it's dilated. Then he had me look through these lenses, different lenses, and he checked my eyes, and he also used a little tool, like a light, and shined it in my eyes to see the blood vessels behind the eye to see if there's anything wrong behind my eyes, if they're bursting blood vessels or—I don't know—I guess he wanted to see more if they were swollen or anything going on in the back of my eyes." (Participant 6, female, age 50, African American, type 2 diabetes, Program 1)

Most Program 2 participants saw an ophthalmologist or a retinal specialist for routine eye exams. Although participants viewed a retinal eye exam as part of the steps they needed to take to monitor and control diabetes, they did not necessarily describe a retinal eye exam as a specific strategy to minimize DR, as illustrated by this quote from a participant with type 1 diabetes:

"The endocrinologist that I went to at the time was very well focused on a number of those elements, for successfully treating and living with the disease. One of those was annual eye exams, and he insisted upon those. That really set an early, what I call, course of action as related to my disease management, and I've just been continuing to do that throughout my life." (Participant 5, female, age 64, Caucasian, type 2 diabetes, Program 1)

Participants in both programs viewed eye exams as simply something they knew they should do to help manage their diabetes, but not necessarily as part of DR prevention and management. These findings suggest a residual deficit in participants' understanding of the specific purpose of retinal eye examinations for screening and monitoring DR, which potentially poses a barrier to self-efficacy in reducing risk for DR.

Awareness of Treatment Options Before and After Education

Most Program 2 participants had been, or were currently being, treated for DR, and three were under surveillance for what they described as "mild retinopathy" or pregnancy-related microaneurysms. Participants described a range of side effects that they attributed to treatment, including discomfort or pain (from both laser and injections); "pouchiness" under the eyes and dye allergy (from the laser); and infection, eye sensitivity, and redness (from injections) and were generally unequivocal about

treatment effectiveness. Although few interviewees were aware of alternative treatment options before participation, the education helped participants better understand their therapeutic options and identity questions they wished to ask their HCPs.

"I was not aware of the fact that there were different types of injections and different types of retinopathy . . . With that information, I feel confident with me having it that we should be able to control it better." (Participant 21, male, age 58, Caucasian, type 1 diabetes, Program 2)

"I'm looking forward to my next one [treatment appointment] where I tell him that I found out the injections are on a better outlook than the PRP [panretinal photocoagulation] and see what he has to say about that." (Participant 17, male, age 46, Caucasian, type 1 diabetes, Program 2)

Communication with HCPs

Before Education

Although participants in both programs felt that their HCPs would respond to any questions they had about DR, few participants identified their HCPs as sources of verbal or written information about DR. Participants typically noted that their providers "never discuss it at all," are "not very communicative," or "don't tell me anything special." When participants said their HCPs did refer to retinopathy, participants noted that the emphasis was typically on the importance of blood glucose control as a general tenet of diabetes management, rather than as a specific approach to preventing or minimizing the risk for DR. The main reason suggested for this communication deficit was lack of provider time; however, many participants also noted that unless they asked questions, HCPs were unlikely

to volunteer unsolicited information unless there was “bad news” to report.

“Quite honestly, they’ve got multi-patients to see, and they’re on a time crunch. And if it’s not bothering you or you don’t have the problem, they’re not going to bring it up.” (Participant 4, female, age 56, Caucasian, type 2 diabetes, Program 1)

“Once he put in the eye drops, he told me to sit down and this and that. No, there was not really any type of communication. Like I said, he told me, I said, ‘What are you checking for?’ He wants to make sure there is no diabetes in my eyes. I said, ‘Okay,’ and that was it.” (Participant 7, female, age 54, Hispanic, type 2 diabetes, Program 1)

Similarly, before education participation, despite acknowledging the importance of asking questions and of being actively engaged in the management of their own eye health, active engagement was an exception rather than a rule for most participants. Although some participants described themselves as ready and able to ask questions of their primary diabetes care providers, saying, for example, “I’m not afraid to talk to doctors,” most assumed that providers knew what they were doing and therefore did not ask questions.

At the same time, there was a perceived communication disconnect with HCPs. Although participants felt that their primary diabetes care providers “had their hands full with the rest of the endocrine system” and assumed that specialists (i.e., either their endocrinologist or their eye specialist) would educate them about DR, they also noted that specialists infrequently volunteered to share information about DR with patients.

“My primary care says nothing about retinopathy, but he tells me that my endocrinologist will take care of all my

diabetes questions. And when I see her, she tells me if I don’t keep my blood sugar down, I will go blind, and I’ll die.” (Participant 12, male, age 68, Caucasian, type 1 diabetes, Program 2)

“I’m under advisement and under the treatment of the retina specialists. Each time I see him [PCP]—I see him quarterly—he’ll ask me whether I have any problems with my eyes, whether I’m still seeing my retinologist. So that’s pretty much the discussion.” (Participant 14, male, age 61, Caucasian, type 1 diabetes, Program 2)

“The retina specialist doesn’t say anything at all.” (Participant 20, male, age 53, Hispanic, type 1 diabetes, Program 2)

After Education

After viewing the activity, all participants were able to list questions they would like to ask their primary diabetes care and eye health providers based on themes addressed in the education. For Program 1 participants, these themes concerned self-efficacy strategies.

“Definitely now I’m just going to ask them if there’s any detection of the diabetic retinopathy in my eye, and what are the symptoms and stuff like that. And how do I know if I have it? And is it hereditary? I want to know more about it.” (Participant 6, female, age 50, African American, type 2 diabetes, Program 1)

“Number one, I want to know if there’s anything wrong, that’s number one. Number two, if there’s nothing wrong, what shall I do to keep it that way?” (Participant 9, female, age 54, Hispanic, type 2 diabetes, Program 1)

“I guess the one thing would be if there are any things that one could implement as a long-term type 1 diabetic, relative to any other things that should be done that I’m not currently doing, to prevent the development of retinopathy.” (Patient 2, male, age 57, Caucasian, type 2 diabetes, Program 1)

Almost half of Program 2 participants identified questions specifically related to treatment that they said they would like to ask their eye health provider at their next visit.

“I actually did talk to them about the treatment procedures that were discussed in the program, as well as the duration of diabetes and the development of retinopathy. So, for example, I control the diabetes well, but because I’ve had it for so long, does that mean I’m ultimately just going to get retinopathy regardless of the management that I have? So that opened that conversation with the doctors.” (Participant 12, male, age 68, Caucasian, type 1 diabetes, Program 2)

“I learned enough to ask them some [questions], specifically my retina specialists some specific questions that he would answer . . . about how the medication works” (Participant 16, male, age 67, Caucasian, type 1 diabetes, Program 2)

Discussion

This qualitative study suggests that on-line education can empower patients with longstanding diabetes and established DR to more proactively engage with their primary diabetes care provider (primary care or endocrinologist) and eye health providers. Although many participants in both programs were somewhat aware of diabetes-related eye conditions and had heard of DR before the education, they knew little about the association of

DR with diabetes. After the education activity, participants had absorbed key messages about the gradual nature of change and symptoms associated with later stages of DR and expressed a heightened awareness about DR as one of the many conditions that diabetes can precipitate.

Before the education, participants across both groups were aware of the need for strict glycemic control as a factor in reducing the long-term risk of vision loss and reported that they already engaged in blood glucose monitoring and control strategies. After education, participants emphasized poorly controlled blood glucose or diabetes as the predominant risk factor for developing or worsening DR and emphasized that the activity reinforced for them the importance of blood glucose monitoring more assiduously.

After activity participation, although some Program 2 participants remained unclear about alternative treatment options for DR, almost half of this group identified questions about therapeutic options as potential alternatives to their current treatment that they felt they could now ask their eye health providers.

Despite the importance of effective communication and care coordination between HCPs and patients, interviewees described poor communication about disease prevention and progression as the norm. Few participants identified HCPs as known or established sources of verbal or written information about DR, and participants often commented that neither their ophthalmologist nor their diabetes provider had mentioned any tools or resources to enhance their vision.

Participants also generally expressed the view that, although HCPs should be sharing information about patients with each other, few felt that providers did this in practice. Participants felt that their primary diabetes care providers assumed that their eye health providers were managing DR, and the eye health

providers assumed that the primary diabetes care providers were managing the diabetes. This insight points to a distinct clinical division of labor that likely influences the assignment of responsibility for educating patients.

Finally, although participations acknowledged the importance of active engagement in the management of diabetes eye health before the education, active engagement was an exception rather than a rule. After education, participants were able to identify questions they would ask their primary diabetes care and eye health providers.

Limitations

Participants who chose to view this educational intervention were not randomly selected. Rather, they had self-selected to seek further information about diabetes and DR. Accordingly, our sample may have been more likely to be proactive in inquiring about medication issues when interacting with their HCPs and also may have been atypical of the general population with diabetes. Additionally, there were key retinopathy and diabetes status differences between the two groups that may contribute to response differences. Nonetheless, our analysis of qualitative responses suggests that, even among such participants, there was some passivity with respect to discussing eye disease with HCPs, likely masked by comments that providers were “busy.” If the generally proactive participants in our sample still had a passive approach to addressing DR issues, then less proactive people with diabetes are likely to be even less likely to actively address this important aspect of eye health with their diabetes care providers. Also, although useful for many, this method of education is not suitable for all patients with diabetes. In fact, elderly patients may not be comfortable with online education, and patients without Internet access could not take advantage of such a program. However, our

results do emphasize the importance of patient-provider communication as a basis from which to begin any preventive efforts.

Clinical Implications

This qualitative study demonstrates that online patient education is an effective tool in building patient knowledge and awareness about DR and in motivating action in DR self-care. Notably, such education cannot only help to reinforce self-management behaviors (e.g., glucose monitoring and control and regular eye exams), but also build confidence as a foundation for being more actively engaged in preventing and managing DR. Participants emphatically endorsed the importance of Internet-based, “free” education as part of their ongoing approach to diabetes self-management and felt this to be especially important since their HCPs rarely addressed retinopathy, which they viewed as a “hidden” dimension of diabetes. As one participant noted:

“It’s kind of an unseen or hidden facet of diabetes that I don’t think a lot of people are aware of. I have a couple of friends with diabetes, and their vision is going to hell, and they have no idea that retinopathy may be part of the problem.” (Participant 19, male, age 68, Caucasian, type 1 diabetes, Program 2)

Participants also emphasized the need for continuous messaging to people with diabetes about the importance of glucose control and eye examinations as strategies to avoid retinopathy and also felt they had some personal responsibility for telling others about strategies to prevent vision loss. The use of Internet-based content and information technology continues to grow as a vehicle for enhancing education support in diabetes (16). Given this and the perceived communication deficits among HCPs, diabetes care providers and eye care providers may wish to consider encouraging their patients to

participate in online patient-directed education about DR as a means of building patients' self-efficacy, instilling motivation, and fostering patient engagement.

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Duality of Interest

No potential conflicts of interest relevant to this article were reported.

Author Contributions

All authors researched data, contributed to the discussion, and wrote, reviewed, and edited the manuscript. A.H. is the guarantor of this work and, as such, had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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