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 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.
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 people 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

### 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 | - 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 | - 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.
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 after completing their 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
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
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)

"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

| TABLE 3. Sample Characteristics |
|---------------------------------|
|                                | Program 1 Participants | Program 2 Participants |
| Age (years)                    | (n)                    | (n)                     |
| 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                       |
kidney disease, high cholesterol, anemia, stomach problems (gastro- 
resis), 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 con-
dition 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 re-
ally 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 reti-
nopathy 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 be-
cause of the high blood sugars for 
a while, you know, that my vi-
sion would kind of not be crystal 
clear. But I’ve never had a prob-
lem 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 ten-
dency 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 reti-
nopathy 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 retinop-
athy 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 symp-
toms. 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 par-
ticipants 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

Before education participation, interviewees in both programs identified 
routine blood glucose monitoring as 
their main diabetes self-management 
and DR prevention strategy, along-
side regular eye exams and what one 
participant called the “diabetic tri-
gle”—medications, diet, and ex-
ercise. After program participation, 
participants emphasized that the ed-
uation had reinforced for them the 
importance of continuing to pursue 
the glucose monitoring and control 
regimens, and all expressed a height-
ened awareness of the importance of 
following their monitoring and con-
trol 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 partic-
ips described having “frequent,” 
“regular,” and “routine” comprehen-
sive eye examinations, including reti-

nal exams. Indeed, all participants 
were adamant about the importance 

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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 therapeudic 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.” (Participant 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 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 online 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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