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Patient at High Risk of Loss to Follow-Up, Part of the Focused Sight Initiative: Quality Improvement Interventions in Retinal Disease

Announcer:

Welcome to CE on ReachMD. This case discussion, part of the Focused Sight Initiative: Quality Improvement Interventions in Retinal Diseases, titled "Patient at Risk of Loss to Follow Up" is provided by Evolve Medical Education.

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Dr. Sambhara:

Hi, my name is Deepak Sambhara. I'm a retina specialist and partner, as well as the medical director of research at the Eye Clinic of Wisconsin. I want to thank you for joining me as we'll talk about a very interesting case of a patient I saw in my practice, and we're going to hammer home some very important points as it pertains to how to introduce the topic of retinal disease to a patient to ensure a culture of compliance and timely follow-up that is necessary to ensure good patient outcomes.

This is a 63-year-old white male actively working a blue-collar job, who's noticing worsening vision in both eyes over the past year, not improved with the new prescription. So the patient shows up to my clinic and he says he can't see any of the knobs at work for his job, and he just wants to be able to run the machines as he works on second shift.

And he feels truly in his heart that all he needs is a new pair of glasses. His past medical history is significant for diabetes mellitus type 2 that was diagnosed recently, a year ago, and he is only on oral agents, metformin 500 mg a day, but when pressed on it, the patient does endorse noncompliance.

He also doesn't know his most recent HbA1c number, which, again, is a good indicator of how compliant the patient might be with his underlying disease. He doesn't have a significant past ocular history, but to be fair, he does volunteer that this is his first eye exam in 10 years.

So this is his baseline imaging. What we're looking at is both OCT as well as the near infrared reflectance image of this patient's left eye. And this is badness. What we see is evidence of chronicity. You can see on the NIR image, the darker areas corresponding to intraretinal hemorrhages. You can also see if we rewind this video on the cross-sectional OCT, there are hyper-reflective foci, intraretinal hyper-reflective material, and diffuse thickening of the retina, which is reflected in intraretinal as well as subretinal fluid. Surprisingly, the patient has 20/100 vision, and the CST is swollen as ever at 770 microns thick. You know, diabetics are oftentimes surprising in how much reserve they have as far as visual acuity goes and perhaps sometimes the visual acuity might actually be surprising in how well they can see relative to how bad or advanced the OCT and anatomy may appear. That being said, when you see an OCT like this, you know that this is somebody with very severe disease that needs a very prompt and very frequent follow-up and therapy.

And so that's exactly what the MO and the strategy was for me when I saw this patient. I diagnosed him with severe non-proliferative diabetic retinopathy, along with macular edema. And as we all know, the standard of care in the modern era for diabetic macular edema requires anti-VEGF, vascular endothelial growth factor inhibitors, in order to try and de-turgesc the retina and reach a steady and

anatomical state. Now, the standard of care also involves injections of medicine in the eye to deliver that anti-VEGF therapy, and oftentimes that can be quite scary or disturbing to somebody who isn't very familiar with eye injections, retina care, or in general who doesn't interface much with the healthcare system at baseline. And so when I was discussing this patient's diagnosis, he obviously was shocked and surprised at the nature of how severe his eyes were, and he initially exhibited some element of distrust, like, I don't believe you. How could my diabetes be severe? I was just diagnosed a year ago. I don't believe that glasses can't fix this. I mean, these were sayings and kind of rationale that the patient had when talking to me, and it was very difficult to try and tackle that and combat that because it can sometimes quickly turn into a game of he said, she said, and you should take my word for it because of my education or my background, when really this is a collaborative approach and experience. And what I've learned to do over time is really lean into a patient's fear, apprehension, anxieties, and get a better understanding of what they're actually worried about and try and build together as a team to let them know I'm actually on their side, I'm trying to help improve their vision so they can do the things they want to do, like in this case, work second shift without having to worry too much about their vision.

And so the key points here is the patient doesn't have regular routine follow-ups, so initial mistrust in the healthcare system might be deeply rooted or have to do with a prior event that went poorly for the patient. But that's something that's beyond my control right now dealing with this patient in my exam chair. So what I have to do is basically navigate the situation in front of me based on who's in my chair and the information I have available. And so we know that this is an anxious patient at baseline, and we know that anxiety is primarily driven by the fact that he is of working age, he is concerned about maintaining his quality of life and being able to go to work, and he's looking for ideally a simple fix to a much more chronic disease. Now, knowing all of that, it's important to try and come at it from a collaborative approach. You know, I think trying to gentle parent a patient isn't the right way of treating somebody who has a chronic disease that requires frequent procedural follow-ups, like diabetic macular edema.

I think that the idea of treating a patient who has a new diagnosis of a disease that requires anti-VEGF therapies is to validate their concerns. Truly understand that, hey, I get where you're coming from as far as not having good sight, to feel like you're not able to perform your duties at a job or even at home without some strain or maybe even recent deterioration that's occurred, but we can work together to try and make that better. And in order to discuss diabetic macular edema, I oftentimes try and break things down into simple building blocks. And I oftentimes use the example of the retina being like the camera film in the camera needing to be paper thin, like camera film in order to function.

And diabetes is a disease that affects blood flow to the body, including to the teeny tiny arteries and veins that feed blood and oxygen to the retina. And I think of diabetes and sugar as having too much sugar in your blood vessels being like having acid run through your pipes. And so if you dumped a jar of acid down your kitchen sink, you'd have a leak in your house.

And similarly, after months to years of uncontrolled sugars, the pipes in your retina, those blood vessels, the inner lining of those walls wither away a little bit, and the contents inside of those blood vessels leach out into the retina. And so instead of having a paper-thin retina, you have a retina that looks like a sponge dipped in water, and you have significant swelling.

And when I try and use those types of analogies or break down complex pathophysiology into simpler terms, it makes it easier for patients to understand. The other thing that I really lean into, beyond just using similes and coming up with comparisons, is to actually show the patient their anatomy. Show them what a normal retina looks like, like the retina on the left-hand side of this image. This is a retina that is A-OK, a hundred percent normal. This is what a retina should look like when you look one up in a textbook. This is the patient's retina. And if you look at how vastly different what we see on the right hand is versus the left hand, that can certainly help to create a sense of urgency and also validate some of the concerns I'm bringing up, as well as the patient's own subjective experiences with their vision.

And I oftentimes find that leaning into multimodal imaging is one of the best ways to demonstrate pathology to a patient. Diabetes doesn't necessarily always equal diabetic macular edema. Diabetic retinopathy sometimes can be very significant before edema ever actually occurs or if it ever occurs. And sometimes you can have neovascularization in the absence of edema where patients' visual acuity are maintained, and in those cases, showing them a fundus photo or if you have leakage that you could demonstrate on a fluorescein angiogram, all of those things can work very well in demonstrating exactly the extent of pathology, especially when you have a control normal that you can look up and show them as a frame of reference.

And by setting expectations on the front end, letting the patient know what normal looked like and what his own retinas looked like, knowing what therapy is necessary, the patient had a more realistic point of view of what to expect, knowing that injections are not just walk-off home runs. This isn't Freddie Freeman in the World Series. This is going to be chipping away, you know, in a world full of jackhammers, we're working with chisels. Everyone's looking for that jackhammer fix, but DME is a cyclical condition that relapses and

remits and recurs, and oftentimes at first diagnosis takes a long time to get under control. And so understanding that, hey, I am one piece of a much larger puzzle, that I can help take care of your eyes, but really overall systemic glycemic control is what's necessary in order to prevent further worsening of your eyes, as well as other organ systems, really does a good job in highlighting the need for compliance. And so from the patient standpoint, as somebody who's looking at their eye doctor as the first point of interface for the diabetic disease, to hear that their eye disease is simply a manifestation of a much bigger problem with systemic glycemic control is a way to try and encourage the patient, to let them know: follow up with your primary doctor or your endocrinologist. Get your feet examined once a year. Get your blood work, your creatinine, your kidney levels checked. Make sure that you follow up with routinely scheduled diabetic care because it all pays dividends.

I also let the patient know that they are going to require injections frequently on the front end so that we can save time, tissue, anatomy, retinal real estate, as well as vision on the back end. So in this case, the patient began receiving monthly anti-VEGF therapy and showed up for follow-up after 3 monthly initial injections with bevacizumab.

And this is their OCT 3 months later. You can see a modest improvement in CST, 500 microns. It's still really thick and swollen. You can see DRIL or disorganization of the retinal inner layers. There still is chronic edema as well as hyper-reflective foci, but generally speaking, this is certainly a better picture than before.

The patient has a modest improvement in vision from 20/100 to 20/70, so this isn't a home run, despite the fact that the patient did everything that I asked. Start getting shots. Follow up for your routine care and show up to your appointments. So you can understand why patients sometimes, despite listening to their physicians, still feel like they're stuck in the mud here and in a rut, because despite listening to their doctor—this patient is still following up despite working a full-time job on second shift and not seeing what he expects to see, which is improvements in vision. He feels like he's doing everything as asked, following up with his PCP, but he still doesn't get why he can't turn the corner with his eyes.

So I think it's really important that when you deal with patients who have chronic disease, that we highlight and emphasize all the positive building blocks that have taken place to get them to the point where they're at with follow-up. Hey, listen, I get that you feel frustrated with your vision, but 20/100 is where you started at and you're 20/70. Look at the pictures of where you started. I get it. It's not much better to you than where you're at now, but seeing is believing, and the anatomy certainly looks better. Plus, if you have your A1c checked now and you actually know what it is, listen, we didn't even know what it was 3 months ago. So the fact that you're taking ownership of your own health is only going to pay dividends. Validate the patient's frustrations about their eyesight subjectively, but again, highlight all the wins that they have with anatomy and vision. And then finally consider pivoting to other agents or adjunctive therapies to help further the process in visual rehabilitation.

So in this case, the patient was switched to an alternative agent, faricimab, and was treated monthly for the next 4 months. He notices an improved vision and now takes an interest in looking at his scans. He's locked into his treatments.

So let's look at his most recent follow-up. Here you see a retina that's now 200 microns, 250 microns thick, significantly different than the past 2 images we went through. In fact, the patient's now 20/50, and you can see that there is much more improvement in the overall anatomical structure of the retina. If you look at the NIR image, there are less of those punctate spots that correlate to intraretinal hemorrhages, so you can even get a sense that the heme is improving, the signs of chronicity on OCT, the hyper-reflected foci, intraretinal hyper-reflective material are improving, and the patient, generally speaking, is doing better. So the goal is to improve the patient's vision and anatomy and then attempt extension. And although the patient's been coming in monthly, the fact that they're locked in with their treatment is a huge win because they are looking at pictures visit-to-visit to help serve as a barometer and a bellwether to how they're responding to care.

And it took me just 9 months to stabilize the patient to the position to get them a manifest refraction, a new pair of lenses, which quite honestly, was the first thing they asked about when they walked into my clinic. And so by making the patient part of the discussion, not just parenting them and telling them what has to happen, but having them actively involved in the decision-making pathway, validating their concerns, but also providing encouragement along the way, the patient became a champion for his own health. He advocated for his own well-being, and at this point is now a mainstay fixture in my clinic.

So the take-home points for me here are always consider a collaborative approach, not just with your referring providers, but also with your patient. It takes 2 to tango. You are out for your patient's best interests, but know that they are also out for their own best interests. And sometimes you need to tackle a problem from a couple of different vantage points. And so for me, if it's a tough case to crack off the bat, I find solace in multimodal imaging.

We are in 2025. We have tons of data and information at our fingertips, so use it, throw it back at the patient, let them see what we're dealing with, and it also serves as a good way to highlight treatment progress over time.

With that being said, I want to thank you for joining me for this case today.

Announcer:

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